

**“LEARNING IS MY PRESCRIPTION”:  
ADULT EDUCATION AND MENTAL HEALTH  
RECOVERY**

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## ABSTRACT

Mental health recovery is a process of gaining in autonomy and of moving towards social inclusion rather than marginalisation, towards an agentic role rather than that of ‘patient’. Recovery involves an individual and internal journey, but also requires the existence of external triggers and opportunities. The provision of opportunities to participate in education can be a crucial factor in recovery for many people with mental health difficulties and is an important equality issue.

This is an emancipatory study grounded in a participatory and constructivist approach. It discusses the history and landscape of education provision for mental health service users and in particular explores the experience of learners with mental health problems in adult and further education through individual semi-structured interviews. Focus groups of mental health service users, discussions and interviews with education and mental health service staff and visits to sites of inclusive practice provide a context for findings and recommendations.

The experience of participants was found to attest to the potential of education in promotion of recovery and in counteracting marginalisation. However, while participants in full-time education programmes were found in general to have positive experiences, good practice by education staff was *ad hoc* and dependent on effective individuals rather than on operationalised policy. Meanwhile, provision of part-time education for mental health service users remains mostly in the traditional model of classes in mental health service settings, perpetuating segregation and ‘othering’ of people with mental health difficulties.

Recommendations include development of policies which promote inclusive practice, supported by staff professional development. Partnership with mental health services is also recommended in order to develop opportunities for mental health service users to participate in adult education in mainstream settings, providing bridges to recovery and social inclusion.

## ACRONYMS

<b>AEO</b>	Adult Education Officer
<b>ALO</b>	Adult Literacy Organiser
<b>BTEI</b>	Back to Education Initiative
<b>CEF</b>	Community Education Facilitator
<b>CMH</b>	Central Mental Hospital
<b>CSO</b>	Central Statistics Office
<b>DES</b>	Department of Education and Science
<b>ESRI</b>	Economic and Social Research Institute
<b>FÁS</b>	Training and Employment Authority
<b>HEA</b>	Higher Education Authority
<b>HSE</b>	Health Services Executive
<b>IPA</b>	Interpretative Phenomenological Analysis
<b>NDA</b>	National Disability Authority
<b>NESF</b>	National Economic and Social Forum
<b>VEC</b>	Vocational Education Committee
<b>VTOS</b>	Vocational Training Opportunities Scheme
<b>WHO</b>	World Health Organisation

# CONTENTS

<b>Introduction</b>		<b>1</b>
<b>Chapter One</b>	<b>HISTORICAL AND POLICY CONTEXTS</b>	<b>6</b>
1.1	Terminology	6
1.2	Perception and treatment – past and present	8
1.3	The medical model debate	9
1.4	The Irish experience	12
1.5	Education provision – historical context	16
1.6	Education provision – current context	17
1.7	Legislative context	20
1.8	Views of education staff	22
1.9	Summary	26
<b>Chapter Two</b>	<b>THEORETICAL FRAMEWORK</b>	<b>27</b>
2.1	Recovery	27
2.2	Disability studies	31
2.3	Capitals	33
2.4	Oppression	35
2.5	The influence of Foucault	38
2.6	Stigma	40
2.7	Summary	41
<b>Chapter Three</b>	<b>METHODOLOGY</b>	<b>43</b>
3.1	Research for social justice	43
3.2	Constructivist view	45
3.3	Interpretation of data	48
3.4	Ethical issues	51
3.5	Reflexivity	54
3.6	Fieldwork	56
3.7	Difficulties in accessing participants	61
3.8	Summary	63
3.9	Tables summarising fieldwork	63
<b>Chapter Four</b>	<b>SYSTEMIC GAPS IN EDUCATION PROVISION</b>	<b>65</b>
4.1	Systemic gaps: the Irish context	65
4.2	Filling the gaps: models of good practice	70
4.2.1	<i>Development of inclusive policies within a College of Further Education</i>	70

4.2.2	<i>An outreach project in collaboration with mental health services</i>	71
4.2.3	<i>Inclusive support policies in a Northern Ireland College of Further Education</i>	72
4.2.4	<i>A UK outreach initiative</i>	73
4.2.5	<i>Supported Education</i>	74
4.3	<b>Summary</b>	75
<b>Chapter Five</b>	<b>EXPERIENCES OF LEARNERS</b>	<b>77</b>
5.1	<b>Application and enrolment</b>	<b>78</b>
5.2	<b>Stigma and disclosure</b>	<b>80</b>
5.3	<b>‘Part of society’</b>	<b>88</b>
5.4	<b>The value of learning</b>	<b>93</b>
5.5	<b>Recovery</b>	<b>96</b>
5.6	<b>Support</b>	<b>102</b>
5.7	<b>Difficulties</b>	<b>107</b>
5.8	<b>Summary</b>	<b>109</b>
<b>Chapter Six</b>	<b>CONCLUSIONS AND RECOMMENDATIONS</b>	<b>110</b>
6.1	<b>Critical gaps</b>	<b>110</b>
6.2	<b>Summary of experiences of individual participants</b>	<b>111</b>
6.2.1	<i>Recovery</i>	<i>111</i>
6.2.2	<i>The value of learning</i>	<i>113</i>
6.2.3	<i>Marginalisation</i>	<i>114</i>
6.2.4	<i>Stigma and disclosure</i>	<i>116</i>
6.2.5	<i>Support from education staff</i>	<i>118</i>
6.2.6	<i>Summary</i>	<i>119</i>
6.3	<b>Recommendations</b>	<b>119</b>
6.3.1	<i>Best practice and Universal Design</i>	<i>120</i>
6.3.2	<i>Application and enrolment</i>	<i>121</i>
6.3.3	<i>Providing a supportive and inclusive environment</i>	<i>124</i>
6.3.4	<i>Staff development</i>	<i>125</i>
6.3.5	<i>Developing access and progression</i>	<i>126</i>
6.3.6	<i>Areas for further investigation</i>	<i>130</i>
6.4	<b>Summary</b>	<b>131</b>
	<b>BIBLIOGRAPHY</b>	<b>132</b>
	<b>APPENDICES</b>	
A.1	<i>Information for participants</i>	<i>146</i>
A.2	<i>Participant consent form</i>	<i>147</i>
A.3	<i>Notice seeking participants</i>	<i>148</i>
A.4	<i>County Dublin VEC draft guidelines for inclusion and support of adult learners with mental health difficulties</i>	<i>149</i>

# INTRODUCTION

## **Background**

Participation in adult education has the potential to counteract the marginalisation and segregation which people with mental health difficulties experience in our society. For many individuals, returning to education is a strategy in a recovery journey in which they are taking charge of their lives. It can be a stepping stone to re-entering mainstream life through gains in confidence and in social and cultural capital. The existence of opportunities and supports for people with mental health difficulties to participate in education is an important equality issue.

This study examines the experience of adults with mental health problems who are taking this journey and are participating in VEC (Vocational Education Committee) adult education programmes. VECs, the main providers of adult education in Ireland, operate many programmes which target disadvantaged and marginalised social groups. Mental health difficulties, which are experienced at some time in life by one in four of the general population (WHO, 2001), are more common in socially disadvantaged than in privileged groups (Whelan, 1994; Conroy, 2005; Social Exclusion Unit, 2004; National Economic and Social Forum, 2007). It can therefore be expected that a significant proportion of VEC learners will have experienced mental health difficulties, a proportion which has been perceived by adult education staff to have increased in recent years. This trend is at least partly an outcome of the movement of Irish mental health policy from long-term hospitalisation of people with mental health difficulties towards community-based services.

In general, there has been limited development of connections between mental health services and adult education services in Ireland, an outcome of a history of very high rates of institutionalisation of people with mental health difficulties well into the mid-twentieth century, with slow progress in following international trends in closing down asylums. Ireland has also made slow progress in introducing adequate community mental health services, in spite of a number of reports from the Department of Health and Children (2006), the Mental Health Commission (2005,

2008) and the National Economic and Social Forum (2007) which advocate transformation and integration of services.

VECs have been involved in provision of adult education classes for mental health service users since the 1960s, starting with hospital-based classes and now with classes mostly in community-based mental health service settings. There are also many learners in receipt of disability payments on mental health grounds attending part-time and full-time mainstream education programmes.

Little research has been carried out in investigating the experiences of adult learners with mental health difficulties in the Irish context. Furthermore, although there are Irish examples of good practice in terms of inclusion and support of adult learners with mental health difficulties, these are generally not translated into formal policy.

### **Rationale**

This study set out to explore the experience of learners with mental health difficulties who had taken part in VEC adult education programmes, with a view to developing understanding of the benefits and difficulties they encounter and also to informing the development of VEC equality, support and inclusion policies.

The concept of recovery is central to the study. The mental health recovery model means that a person with mental health problems moves from being a passive recipient of treatment towards actively taking charge of their life and managing their own coping strategies. Seen in this way, mental health difficulties are not encompassed within a medical or biophysiological frame of reference. While the person experiencing mental health difficulties may take medication, this is by no means their only tool in working towards recovery. Other activities and approaches can be equally important. Within this model, return to education could play a very significant role, in enabling a person to re-integrate socially, to accumulate social and cultural capital and to gain in self-confidence.

The transformative potential of adult education may be of particular significance for a person who has experienced mental health difficulties and the associated dangers of marginalisation and social exclusion. Surveys repeatedly show an extremely low rate

of participation in the workforce by, and a high level of negative stereotyping and exclusionary attitudes towards, people with mental health problems (National Disability Authority, 2002; National Office for Suicide Prevention, 2007). Oppression, in the forms of marginalisation and cultural imperialism (Young, 1990), renders the position in our society of people with mental health difficulties a major equality issue. Equality legislation prohibits educational establishments from discriminating on the ground of disability, including mental health difficulties, while allowing for positive action to encourage participation of marginalised groups.

### **Methodology**

The study operates within a transformative paradigm in that it aims to influence and change policy as well as to advance understanding. A participatory approach was essential in order to counteract the traditional invisibility and disempowerment of mental health service users in both research and policy development. Mental health service user groups were consulted during the design of the study, and individual participants were involved in discussion and interpretation of their initial interviews. Constructivist grounded theory influenced the course of the fieldwork and was the main approach to analysis of transcripts, along with some use of Interpretative Phenomenological Analysis.

The core fieldwork consisted of individual interviews with learners attending full-time return to learning programmes funded under the Vocational Training Opportunities Scheme (VTOS). Learners in Traveller Training Centres, the Adult Literacy Service and in HSE training provision were also interviewed individually. Focus group discussions took place with mental health service users attending HSE and FÁS training programmes. A wide range of VEC educators were interviewed, individually and in groups, as well as a number of individual HSE mental health service personnel and disability officers/project leaders/access officers from sites of good practice in a variety of settings.

### **Findings**

Adult education for people with mental health problems can be related to the concept of a continuum of mental health, ranging from those who are experiencing very good mental health to those who are experiencing serious mental distress. At one end of the

continuum are segregated programmes specifically for mental health service users in mental health service settings, and at the other the successful participation of people with mental health difficulties in mainstream adult education programmes run by the VECs. Research into the experience of the latter group provides the core of this study's findings. However, interviews with focus groups of mental health service users and research into VEC links with segregated programmes run by mental health services also yielded interesting data.

Most of the participants who were taking part in VTOS programmes demonstrated the recovery model in action. They were taking charge of their lives, having applied to return to education on their own initiative. In general they found the experience positive, valuing the gains in confidence, social networks and progression opportunities it brought, and also valuing the experience of having the opportunity and the capacity to learn. Education staff were generally experienced as supportive and encouraging.

It was found that there were few examples of people progressing from discrete programmes for mental health service users to participation in integrated programmes. There were also very few programmes for mental health service users which were run in education as opposed to health service settings. This situation raises significant questions about segregation, progression and equality of opportunity.

Implications for policy arising from the study include recommendations for support of learners in mainstream education settings, as well as the creation of links and bridges between education and mental health services.

### **Outline of the Thesis**

Chapter One places the perception and experience of mental health difficulties in historical and policy contexts. Variations in understanding and treatment of mental health problems at different periods are discussed. The Irish mental health service's record of high rates of institutionalisation with slow development of community care services is outlined. The adult education context and the implications of equality legislation are also discussed, as well as the views and concerns of VEC adult and further education staff.

Chapter Two outlines theoretical underpinnings to the study. The mental health recovery model, developed by Anthony, Deegan and others, and its fundamental importance to the study, as well as the relationship between the recovery model and the social model of disability, are explored. The influence of Foucault on perceptions of medical treatment and psychiatry is discussed. Goffman's work on stigma and information management, Young's writings on marginalisation and cultural imperialism and Bourdieu's concepts of social and cultural capital are outlined as relevant to the experience of mental health difficulties.

Chapter Three describes the study's methodology, explaining the importance of a participatory approach and describing the use of constructivist grounded theory in interpreting data. Ethical issues are also considered in this chapter. The fieldwork is described and difficulties in accessing participants are discussed.

Chapter Four outlines and discusses the study's findings from interviews with individual participants. The experience of learners is linked to access and enrolment issues, dilemmas with regard to disclosure of information, perception of support from staff, benefits and difficulties in participation and the place of return to education in the individual recovery journey.

In Chapter Five, conclusions and their implications are summarised and discussed. Examples of good practice are described. The final section summarises recommendations for policy and for further research.

# **CHAPTER ONE**

## **HISTORICAL AND POLICY CONTEXTS**

This chapter sets perception and treatment of mental health difficulties in historical context, with particular reference to the Irish experience. The emergence of the understanding of mental health problems as medical problems is discussed, along with the fact that the ensuing dominance of a medical model of treatment has not fostered the development of links between mental health services and adult education. Educational and legislative contexts and policies are also explored and the views of adult education staff are discussed. First, I will address the issue of terminology.

### **1.1 Terminology**

The terms to be used in referring to those experiencing mental health difficulties are highly contested, because they carry the history and weight of different perceptions, approaches and models. This is important because language is not simply about communication, it is also about power. “By structuring perceptions ..... of the social world, the act of naming helps to establish the structure of this world” (Bourdieu, 1991, p.105). Language influences our perceptions and attitudes and, while providing a means for communicating with other people, it can also exclude and stigmatise them.

The term ‘mental illness’ originated in the early nineteenth century to describe conditions hitherto referred to as – among other terms - madness, delirium, folly, lunacy or melancholy. In the twentieth century, Foucault, in his critique of the hegemony of the medical model, preferred to use the terms ‘insanity’ and ‘madness’, writing that we “confine insanity within mental illness” (1961, p.xiii). ‘Mental illness’ has become a contested term because of its implicit acceptance of a medical model of psychological distress, a model which many writers and mental health service user groups see as labelling, disempowering and reinforcing social exclusion. In line with this, new social movements and support groups refer to their members as ‘service users’, ‘consumers’ or (implying more fundamental criticism of the system) ‘survivors of the mental health services’ - all terms conveying more control and autonomy than that of the passive ‘patient’.

The diagnosis of a mental illness and the assignation of a label can be a relief to some people who experience mental health difficulties. For them, the diagnosis alleviates the feelings of inadequacy, failure and self-blame which had previously attached to and increased their distress. “While the medicalisation of mental distress has brought problems of its own, it absolved the distressed person from blame for his/her condition and challenged the view that mental distress was the consequence of moral degeneracy” (Coppock and Hopson, 2000, p.151). On the other hand, as Sayce points out “the biological brain disease model, while it brings the welcome relief of removing responsibility for the ‘illness’, also has the terrible drawback of removing responsibility for everything else too” (2000, p.100). The problem may lie not in the term ‘mental illness’ itself but rather in its connotations of entrapment in the role of passive recipient of long-term medical treatment. ‘Mental health challenges’ is sometimes used as an alternative term, but can be contested on the grounds that it implies individual responsibility for rising or failing to rise to a personal challenge rather than seeing the issue in a social context.

In Ireland, two recent important documents, both of which advocate a recovery model for the mental health services, still use the term ‘mental illness’, but in a more limited sense than before. The National Economic and Social Forum in its report *Mental Health and Social Inclusion* differentiates between the terms ‘mental ill-health’, “used .. to describe the full range of mental health problems that might be encountered, from psychological distress to severe and enduring mental illness” and ‘mental illness’, “referring to specific conditions such as schizophrenia, bi-polar disorder and clinical depression” (2007, p.9). The Department of Health and Children’s policy document *A Vision for Change* uses the term ‘mental health problem’ to describe “the full range of mental health difficulties that might be encountered ....” and the term ‘mental illness’ to describe “specific conditions ..” (2006, p.6).

In this paper, I propose to use, in general, generic terms such as, ‘mental health problems’, ‘mental health difficulties’ or ‘mental distress’ which “are acceptable to the majority of service users and neither presume nor rule out the presence of any biological mental illness process” (Tew, 2005, p.18).

## **1.2 Perception and treatment – past and present**

Perception and understanding of mental health problems have, throughout history, reflected the culture of the time and influenced individual and social responses to those suffering from mental distress. In pre-modern times mental disorder was sometimes seen as the result of possession by the devil or other evil spirits. The belief that madness was inflicted by a supernatural power or by an angry deity as a punishment for sin was widespread among the peoples of the ancient world. Deuteronomy 28: 15, 28 contains a warning by Moses to his people that if they “will not obey the voice of the Lord your God or be careful to do all his commandments and his statutes ...the Lord will smite you with madness and blindness and confusion of mind”. In ancient Ireland, Robins (1986, p.5) writes that druids were believed to produce madness by throwing a ‘madman’s wisp’, a ball of straw or grass, in the victim’s face.

In the pre-modern world the majority lived within subsistence economies. The physically ill who did not die or recover, the intellectually disabled and the mentally disturbed joined the considerable population of beggars that existed in these societies, benefiting from charity in times of plenty and starving at other times. It would seem that the traditional attitude towards those with mental health difficulties was one of qualified rejection. During the Middle Ages, “mad people for the most part were not treated even as a separate category or type of deviants. Rather they were assimilated into the much larger, more amorphous class of the morally disreputable, the poor and the impotent, a group which also included vagrants, minor criminals and the physically handicapped..... the overwhelming majority of the insane were still to be found at large in the community” (Scull, 1979, pp.13/14).

Porter (2002, p.90) writes that “more formal segregation began to emerge towards the end of the Middle Ages”, developing into what Foucault calls ‘the age of confinement’. Reflecting the centrality of reason and rationality in the Age of Enlightenment, “folly and madness were no longer to roam aimlessly. Order was necessary, and the mentally and emotionally deranged were to be subjected to discipline in institutions created for this purpose. .. Mental illness was to be exiled from the social scene in both thought and practice” (Rosen, 1972, p 158). The great

divide, in the 'age of reason', was no longer that between believers and heretics, but "that between the rational and the rest...The instituting of the asylum set up a 'cordon sanitaire' delineating the 'normal' from the 'mad' which underlined the Otherhood of the insane" (Porter, 2002, p.122).

This 'othering' facilitated dehumanisation, which provided justification for the inhumane treatment of those with mental health difficulties. "In seventeenth and eighteenth century practice, the madman in confinement was treated no better than a beast; for that was precisely what, according to the prevailing paradigm of insanity, he was. In becoming crazy, the lunatic had lost the essence of his humanity, his reason" (Scull, 1979, p.64). There was a belief that "animality ...inured the madman to hunger, cold, heat, pain. It was common knowledge until the end of the eighteenth century that the insane could support the miseries of existence indefinitely" (Foucault, 1961, p.70). The inmates of asylums were also commonly subjected to the abuse of being displayed to the public gaze for entertainment – Bethlem Hospital in London up to the early nineteenth century exhibited residents for a penny every Sunday.

### **1.3 The medical model debate**

Insanity was not considered to be within the remit of the medical profession until the eighteenth century, when the English medical profession, seeking to enter the profitable field of private madhouses, began to claim that the remedies offered by their profession could cure insanity (Scull, 1979). There was a strong punitive aspect to these remedies, which included purification (blood transfusions, burning, cauterising, bitters, soaps, vinegar), immersion (hot and cold water cures, showers, surprise baths) and regulation of movement (exercise, travel, spinning/rotation). During the late eighteenth century, reflecting the development of enlightenment thinking and of concepts such as the Rights of Man, there were movements towards reform. The Quaker community, led by William Tuke, a local tea and coffee merchant, established an alternative type of institution in the York Retreat, set up in 1796. The Retreat introduced 'moral treatment', "abandoning 'medical' for 'moral' means, kindness, mildness, reason and humanity, all within a family atmosphere" (Porter p.104).

A plaque of William Tuke in the lobby of the Royal College of Psychiatrists in London symbolises the grand narrative of psychiatry that ‘moral treatment’ was the beginning of humane medical intervention and treatment of the mentally ill. However, Foucault claims that “it is within the walls of confinement that ... nineteenth century psychiatry would come upon madmen; it is there – let us remember – that they would leave them, not without boasting of having ‘delivered’ them” (1961, p.36). He perceived ‘moral treatment’ as continuing the segregation and infantilisation of those with mental health problems. Scull has another interpretation: because it was lay people who developed moral treatment, it was perceived as “a threat to pre-existing medical involvement in the mad-business and ... it took a concerted effort on the part of interested medical men to put down the challenge it posed to their emerging hegemony” (Scull, 2006, p. 34). The medical profession launched an effective campaign and obtained control of public asylums by the 1830s.

Asylums proliferated in America and in Europe in the nineteenth century and grew into mammoth institutions with huge populations of inmates, rendering individual attention impossible. The ideal of moral treatment faded into a reality of ‘warehousing’ of patients. By the twentieth century “asylums had achieved a desolateness that would have made the earlier generation of reformers heartsick” (Shorter, 1997, p. 65).

During the early involvement of medicine in the treatment of insanity, the doctors involved were referred to as ‘mad-doctors’ or ‘alienists’. The term ‘psychiatry’, coined at the turn of the nineteenth century by German physician Johann Reil (Porter, 2002, p.140), “did not come into general usage in either the English-speaking or the Francophone world till the dawn of the twentieth century” (Scull, 2006, p.87). The emergence of a particular category of medical specialists who claimed the treatment of the insane as their territory was part of a broader movement through which the medical profession gained hegemonic control over many areas not previously defined as medical. What Foucault terms “the apotheosis of the *medical personage*” in the nineteenth century “would authorise ... a new relation between insanity and medical thought and ultimately command the whole modern experience of madness. .... Mental disease, with the meanings we now give it, is made possible” (Foucault, 1961, p.256).

Freud, in the late nineteenth century, introduced the idea of a ‘talking cure’ in the treatment of mental distress. Later in the twentieth century, other models of psychotherapy and counselling were developed, ranging from Carl Rogers’ client-centred counselling, which advocated a holistic view of the person, to Ellis and Beck’s cognitive behaviour therapy. “Psychological therapies have been shown to be effective treatments for people with a range of mental health problems, including those with severe and enduring mental illness.... and evidence for their effectiveness has been growing in recent years” (Expert Group on Mental Health Policy, 2006, p.246), confirmed by many studies (Byrne Lynch, 2008; Roth et al, 1996; Carr, 2006). However, there is in general a lack of integration – and to some extent there is ideological conflict - between psychological and medical interventions, with the medical model dominating mental health services. As Pilgrim and Rogers put it, “there is still a broad and unresolved tension between somatic and conversational modes of treatment” (1999, p.121).

“The second biological psychiatry” (Shorter, 1997, p. 239) has emerged from the 1970s onward. “Since 1980 ... American psychiatry has achieved worldwide hegemony, and pills have replaced talk as the dominant response to disturbances of emotion, cognition and behaviour. Pharmaceutical corporations have underwritten the revolution, and have rushed to create and exploit a burgeoning market for an ever broader array of drugs” (Scull, 2006, p.146). These developments reflect psychiatry’s history of operating mainly within a positivist framework and seeing mental distress as “a technical-medical problem which would eventually be solved with the steady application of science” (Coppock and Hopson, 2000, p.18). The belief that herein lies the cure for mental distress is strongly contested by many, within and outside psychiatry, as giving false hope. Bracken and Thomas write, in what they call a post-psychiatry critique, that “psychiatry should start a ‘decolonisation’, a phased withdrawal from the domains that it has laid claim to .... by admitting the limited nature of its knowledge” (2000, p. 20). Although there has been growth in our understanding of the human psyche and mind, this has not kept pace with developments in our understanding of the physical world, to the extent that “our understanding of mental health and mental distress at the beginning of the twenty-first

century can be characterised as an ideological muddle” (Coppock and Hopson, 2000, p.6).

#### **1.4 The Irish experience**

Until the early nineteenth century, there was hardly any public provision for the insane in Ireland. There was a small number of private madhouses, including St Patrick’s Hospital, which had been established by Jonathan Swift in 1757, and Bloomfield, modelled on the York Retreat, which was opened by the Quaker community in Dublin in 1807. “There were in addition hundreds of insane persons incarcerated in jails; ... but it is probable that the great bulk of Irish lunatics were wandering at large or confined to peasant cabins or outhouses” (Robins, 1986, p.60). The main thrust for the separation of the insane from criminals and the creation of an asylum system came from concerned liberal Whig politicians, whose efforts led to the establishment in 1810 of the Richmond Asylum (later known as St Brendan’s Hospital) “for the reception of lunatics from all parts of the kingdom” (Report of the Select Committee on the Lunatic Poor in Ireland, 1843, cited in Robins, 1986, p.62). The asylum quickly filled to capacity and it became obvious that there was a much greater demand than anticipated. The Lunacy (Ireland) Act of 1821 provided for the development and expansion of the Irish lunatic asylum system. District asylums proliferated all over the country and continued to be built even after the Famine when population was declining. In 1914, “Ireland had a public asylum residence rate of 490 per 100,000 population compared with England and Wales, 298 and Scotland, 283” (Finnane, 1981, p.224). This “excessive commitment to the mental hospital bed” (Robins, 1986, p.203) lasted to the mid-twentieth century. In 1958 the Irish mental hospital population peaked at 21,075, which, at 0.7 per cent of the population, “appeared to be the highest rate in the world” (Robins, 1986, p.201).

This rate of incarceration may have reflected Ireland’s position as the colony of a powerful state which used the asylum system to help control social unrest, “its semi-colonial status making the imposition of centralised schemes from Westminster much easier than elsewhere in the British Isles” (Scull, 2006, p.24). Other influential factors may have been the absence of a Poor Law in Ireland until 1838 and the fact that “private madhouses on the English model were rare” (Finnane, 1981, p.21). “The great majority of [asylum] inmates were committed involuntarily; systematic review

of the confined person's status was not a statutory requirement" (Finnane, 1981, p.15). Many of those admitted to asylums were segregated from family and community for life and never discharged. A personal record is that of Hannah Greally, who, in *Bird's Nest Soup* (1971), describes her experience of spending eighteen years in an asylum after being committed and abandoned by her family. Only with the Mental Treatment Act of 1945 were formal procedures for voluntary and involuntary admissions introduced.

Running parallel to the asylums was the workhouse system, established by the Poor Law of 1838, "into which the worst problems could be put, out of sight behind its high workhouse walls.... It grew from its narrow workhouse base to become the major source of Ireland's statutory social services in the nineteenth century" (Burke, 1987, p.283). More than one hundred workhouses were built to a design allowing for "distinct wards for vagrants... rooms for the old and infirm... and wards for idiots, epileptics and lunatics" (Burke, 1987, p. 49). While the workhouses were repositories for all kinds of human misery, the asylums catered specifically for those with what were seen as mental problems. The asylums, however, could not cope with demand, and policy during the late nineteenth century was "based on expanding the district lunatic asylum system while at the same time using the workhouses to provide some relief" (Robins, 1986, p 76). The rules issued in 1843 for the operation of the asylums, that "idiots as well as lunatics, properly so-called, are to be admissible to every asylum" (cited in Robins, 1986, p.158), demonstrated awareness of the distinction between mental health problems and intellectual disabilities, but also the assumption that the asylums would confine both within their walls.

Resulting from the newly independent government's aim of "abolishing the present odious, degrading and foreign poor law system" (Dáil Eireann, 1919), the workhouses established by the Poor Law were closed down in the 1920s. Most were converted into County Hospitals or County Homes, from which, Ryan (1999) writes, the mentally handicapped became excluded. In the absence of state provision of services for people with intellectual disability, asylums were commonly used for institutional placement of adults and even children with intellectual disabilities. In Ireland, "in practice the care of the mentally ill and the mentally handicapped continued to be treated as a single problem for the next fifty years" (Robins, 1986, p.170). In spite of

developments in other countries, there were no significant developments regarding the setting up of separate services specifically for people with intellectual disabilities until the 1950s, with, even then, a “policy of total delegation of responsibility for the mentally handicapped to certain voluntary agencies” (Ryan, 1989, p.40). In spite of improvements in the 1960s and 1970s in services for people with intellectual disabilities, a 1980 Department of Health report on Services for the Mentally Handicapped found that there were 2,500 mentally handicapped people in psychiatric institutions. In 2009, there are still some 308 people with intellectual disabilities resident in Irish psychiatric hospital settings (Health Research Board, 2009).

While Ireland had introduced asylums early in comparison to other countries during the nineteenth century, it was late in closing them down during the twentieth. “At a time when mental hospitals in other countries were becoming more open, Irish mental hospitals remained closed institutions, the patients confined behind high walls and locked doors” (Reynolds, 1992, p.277). The disgraceful conditions and “worst of all, the dreary boredom of life in these hospitals” are described by Ryan (1999, p.26). Things did begin to improve in the 1950s. The Health Act 1953 removed the long-time pauper associations of the psychiatric hospitals by placing them on the same basis as the other hospitals. The late twentieth century saw a move towards decarceration, enabled partly by the development of tranquillisers and other psychotropic drugs. The numbers of psychiatric in-patients declined dramatically from 21,000 in 1958 to 4,000 in 2001. However, the process of de-institutionalisation in Ireland has been described by Amnesty Ireland as “unco-ordinated, piecemeal and *ad-hoc*” (Amnesty International Irish Section, 2003, p.19).

Medical hegemony in the Irish asylum system was established by the late nineteenth century. “The early asylums, inspired as they were by the ideology of moral treatment, were managed not by medical men but by laymen. The ‘superior resident officer’ of the district asylum in the 1820s and 1830s was the ‘Moral Governor’” (Finnane, 1981, p.39). However, the medical profession lobbied forcefully and by 1862 asylum superintendents were required to be physicians. A medical model, which places the medical profession in positions of dominance and privileges physical/biological explanations and treatments for mental distress, still dominates our mental health system. “Overall our statutory mental health services continue to

operate largely in a traditional hierarchical way with health professionals firmly in charge of the planning, organisation and dispensing of services” (Mental Health Commission, 2005, pp 32-3). While some services try to function in an open multi-disciplinary manner, the culture and hierarchical structures of the system militate against a pluralist model. In general, medical treatment is not integrated with psychological therapy, counselling support or social interventions.

The 1984 Department of Health policy document, *The Psychiatric Services: Planning for the Future*, recommended the development of a comprehensive community-oriented psychiatric service, multi-disciplinary and integrated within the community. However, as admitted over 20 years later in the report of the Expert Group on Mental Health Policy, *A Vision for Change*, “structures in mental health services changed but how services were managed and organised and thinking around how to treat people did not change substantially” (2006, p.56). *A Vision for Change* again recommended integrated community-based services, but had moved forward in advocating “the need to adopt a recovery perspective... and the need for service-users to be regarded as active participants in their own recovery rather than passive recipients of ‘expert’ care” (2006, p.13). It promoted a ‘biopsychosocial’ model, acknowledging that “the formal separation of biological from psychological and social factors has been a formidable obstacle to a true understanding of mental health” (2006, p. 18). Although strongly maintaining the dominance of psychiatrists in delivery of services, the report was viewed as positive and progressive.

Unfortunately, implementation of the recommendations made in *A Vision for Change* has been limited. Amnesty International Irish Section launched a campaign in June 2009 to promote their implementation, condemning the over-reliance of the mental health services on in-patient treatment and the lack of progress in developing alternative interventions or establishing multi-disciplinary teams. “Ireland’s mental health services ..... for the most part have not yet taken on the challenge of incorporating the recovery philosophy into the organisation and delivery of services” (Mental Health Commission, 2005, p.33). Public health service users, although they may ultimately be under the supervision of a consultant, are dealt with in face-to-face appointments by a registrar, who is changed in rotation every six months. This tends to lead to reactive treatment focused on medication rather than a holistic approach to

the person. More continuity of care and one-to-one time with a counsellor are in general available only on a private basis. In the two-tier system operating in Ireland, this means that those who can afford it may access this support, while it is generally unavailable to those without financial means.

### **1.5 Education provision – historical context**

The story of education provision within the Irish mental health services began in the mid-twentieth century, with the exception of one venture a hundred years earlier. Educational opportunity was not usually a feature of care in nineteenth century madhouses or asylums. The Commission of Enquiry into the Erection of Lunatic Asylums in Ireland in 1855 “disclosed a picture of asylum life which .... was unenlivened by any stimulus” (Reynolds, 1992 p.114). The exception was the establishment, during the mid-nineteenth century, of a school in the Richmond Asylum (later known as St Brendan’s Hospital Grangegorm). Dr Joseph Lalor, manager of the asylum at the time, believed in the value of education for patients and set up a school in 1852. “In 1862 the National Board of Education recognised the classes as national schools, subjecting them to inspection and requiring use of prescribed texts” (Reynolds, 1992, p.141). The curriculum included reading, writing, arithmetic, geometry, algebra, drawing, needlework and arts and crafts. The years 1877-85 witnessed the schools’ peak activity, and over half of the approximately 1,000 patients under treatment attended the classes. “After Lalor’s retirement in 1886 the schools gradually declined. The proportion of school pupils to patients .... declined steadily each year to 29% in 1893, the last year for which figures were published” (Reynolds, 1992, p.143). The schools gradually faded out of existence, the two schoolmistresses being eventually given the task of superintending the patients’ clothing while the schoolmaster was assigned to clerical duties in the office.

The next educational initiatives for patients in the psychiatric services seem to have taken place in the 1960s, when efforts were made in some hospitals to provide some activities and classes for the residents. This led to links with Vocational Education Committees (VECs). VECs, which are now the main providers of adult education in Ireland, were set up as a result of the Vocational Education Act 1930, initially to run schools known as ‘continuation schools’, which later became known as vocational schools. Their purpose was to provide “general and practical training in preparation

for employment in trades, manufactures, agriculture, commerce, and other industrial pursuits” (Government of Ireland, 1930, I, 3).

In the early days the adult education offered by VECs took the form of evening ‘hobby’ classes. However, there were some outreach connections with other agencies, and County Dublin VEC began providing classes in the newly established St Loman’s Psychiatric Hospital in West Dublin in the mid-1960s: “Vocational education classes..... were introduced, the subjects being domestic economy, arts and crafts, physical culture and dancing” (Reynolds, 1992, p. 295). There is little documentary evidence of this provision, which has been described by an older member of VEC staff who remembers the classes as “occupational therapy rather than education”. A tutor who was involved in teaching literacy classes in St Loman’s Hospital in the 1990s described the lack of continuity of patients attending her class from week to week, with little support from nursing staff in encouraging ongoing participation. “Possibly because they were heavily medicated, perhaps the nurses thought they couldn’t benefit from the class. It also depended what nurses were on duty”. An AEO (Adult Education Officer) who instigated classes in the Central Mental Hospital in the 1980s also found little enthusiasm among health board staff for education provision. He described the adult education service as “pushing against closed doors all the time” and being “treated like second-class citizens” with classes held in the basement. However, due to his efforts and the commitment of a key member of hospital staff who provided “trojan support”, an education service in the hospital was set up and still continues. County Dublin VEC also has longstanding links with St Ita’s Hospital in Portrane.

## **1.6 Education provision – current context**

Due to changes in mental health policies, the majority of people with long-term mental health problems are no longer in residence in psychiatric hospitals, but live in the community, whether in hostel, family, rented or sheltered accommodation. As the majority are not in employment, a range of community-based rehabilitation, education, training and employment activities for people with mental health difficulties has developed. Health service day care, education and training provision ranges from the more sheltered environment of day-hospital settings through day centres, rehabilitation training centres and Clubhouses. Vocational training is the

responsibility of FÁS, the national training agency, which contracts specialist training providers such as the National Learning Network or EVE (Eastern Vocational Enterprises) Ltd., both of which are subsidiaries of the HSE. FÁS also administers the Community Employment scheme, which has proved suitable for many people with mental health difficulties.

Many of these forms of provision have links, in local instances, with VEC adult education services in the form of VEC provision of teaching hours (i.e. payment of tutors) through Community Education or ‘hours of co-operation’ schemes, with, in the case of Community Education funding, some liaison and support from the VEC Community Education Facilitator. VECs now provide teaching hours in HSE day centres, in FÁS-run vocational training programmes, in Clubhouses or even in HSE-run hostels. These classes are in subjects such as drama, art or computers and do not usually lead to accreditation. This education is viewed, in the words of a member of mental health service staff, as “improving quality of life, not about qualifications, progression or moving on into mainstream education or employment”. These classes are a continuation of the practice of providing classes in hospital settings, replicating practice in the mental health services, where “people were moved from an institution to a residence in the community but the treatment they received and their daily lives did not change substantially” (Expert Group on Mental Health Policy, 2006, p.56).

The vocational education sector does not have an institutional culture of outreach to encourage participation of people with mental health difficulties in mainstream programmes. VEC involvement in education for people with mental health difficulties originally emanated, being of its time, from a charity rather than a human rights model. A charity approach “often stems from a sense of pity for those perceived to be less fortunate. ... However, it serves to deny people’s human dignity, to deny them a ‘voice’ in decisions and to perpetuate dependency and lack of status on the part of those being ‘helped’” (Gannon, 2007, p.2). Development in understanding of equal rights combined with the impact of equality legislation has positively influenced the attitudes of education staff towards inclusion of marginalised groups. However, this is slow to happen with regard to inclusion of learners with mental health difficulties, as witnessed by a joke made by a staff member on hearing of my research: “Do we really *want* more students with mental health problems?”

As well as VEC involvement through the payment of tutors teaching in the centres, there is a limited amount of traffic in the opposite direction. Some full-time mental health service users attend part-time VEC courses in mainstream settings, mainly with the Adult Literacy Service. These are people with long-term mental health problems who could not cope in a full-time mainstream programme. Because people in this position lack the confidence to be proactive, their engagement in education is unlikely to happen without intervention in initiating, organising and giving ongoing support for participation. As a result, such participation seems to happen only occasionally, being arranged through the intervention and support of a particularly encouraging member of HSE or VEC personnel rather than through systemic links between health and education services. Through historic VEC links with St Loman's and St Ita's hospitals, there is a higher incidence of such participation in West Dublin and Fingal Adult Education Services. Similarly, the South Dublin Adult Education Service has had connections for twenty-five years with the Central Mental Hospital (CMH). Apart from classes run in the CMH for groups of patients, in a few instances a patient due for discharge has travelled by bus from the hospital to the adult education centre for tuition, as part of their programme of preparation for discharge. The loss of this potential for engagement with local adult education services has been among the many disadvantages cited by those who opposed the proposed relocation of the CMH to rural north County Dublin.

The creation of more opportunities for people with mental health difficulties to access adult education can happen only with the development of more links and bridges between the education and mental health services. "There is a need to ensure that individuals are facilitated to access and participate in the educational system commensurate with their ability and potential for new learning. Such educational initiatives must take place in mainstream settings and operate optimally where there is a partnership approach between health and educational services" (Expert Group on Mental Health Policy, 2006, p. 247).

## **1.7 Legislative context**

The Education Act 1998 requires that “a school .... shall use its available resources to ensure that the educational needs of all students, including those with a disability or other special educational needs, are identified and provided for” (II.9.(a)). This implies moves towards inclusive access and support policies, which to date have had more impact at primary and post-primary levels than in adult education. Another development with potential impact on the inclusion and integration of people with mental health difficulties in education has been equality legislation. The Equal Status Acts 2000 and the Equality Act 2004 list ‘disability’ as one of the nine grounds on which providers of services including education may not discriminate. The definition of ‘disability’ in these acts and also in the 1998 Employment Equality Act includes “a condition, disease or illness which affects a person's thought processes, perception of reality, emotions or judgment or which results in disturbed behaviour” (Equal Status Act, 2000, p.6). This is very similar to the definition of mental illness in the Mental Health Act 2001: “a state of mind of a person which affects the person’s thinking, perceiving, emotion or judgment and which seriously impairs the mental function of the person to the extent that he or she requires care or other medical treatment in his or her own interest or in the interest of other persons” (Section 3.2).

These definitions, focusing on the impairment of the individual rather than the relationship between the person and her/his environment, emanate from an individualistic and medical model of disability. Although representing “a genuine attempt to ensure that specific disabilities are addressed, [they do not] engage with the disabling implications of law and policy that turn impairments into deprivations and barriers to equal citizenship” (Lodge and Lynch, 2004, p.78). They do not reflect the recommendation of the Commission on the Status of People with Disabilities, that the key principles underlying legislation should include “the recognition that disability is a social rather than a medical issue, the adoption of a civil rights perspective, and the recognition of equality as a key principle of the human rights approach” (1996, p.10). Nevertheless, the legislation provides some protection against discrimination and allows potential for positive action.

The Equal Status Acts apply to a wide range of services, including educational establishments. They specify four areas in which education providers must not

discriminate: admission, access, any other term or condition of participation and expulsion, all of which have emerged in this study as relevant to adult education. As well as prohibiting discrimination, the Acts allow for positive action, meaning that organisations may provide

preferential treatment or the taking of positive measures which are *bona fide* intended to —

(i) promote equality of opportunity for persons who are, in relation to other persons, disadvantaged or who have been or are likely to be unable to avail themselves of the same opportunities as those other persons,

or

(ii) cater for the special needs of persons, or category of persons, who, because of their circumstances, may require facilities, arrangements, services or assistance not required by persons who do not have those special needs.

(Equal Status Act, 2000, 14, b)

People who believe they have been discriminated against in employment or in receipt of services including education can make a complaint to the Equality Tribunal. While many cases of discrimination on grounds of disability have been heard by the Equality Tribunal, there have been few such cases brought on grounds of mental health issues (Equality Tribunal, 2009). “The absence of people with a mental disability from the statistics of anti-discrimination law in employment [may be explained by the fact that] too few jobholders with a mental disability are in mainstream full-time jobs” (Conroy, 2005, p.49). Another explanation could be that internalisation of stigma may prevent people from disputing or even perceiving discrimination. Furthermore, as reported by an Equality Tribunal solicitor, many cases claiming discrimination on mental health grounds have been initiated but withdrawn by the complainants before going as far as a Tribunal hearing because of the stress involved (Equality Authority, 2009). As yet, no cases brought against adult/further education establishments have been on mental health grounds. Furthermore, although the equality legislation permits “preferential treatment or positive measures”, there have been few ‘positive action’ initiatives in the sector to support inclusion and progression of learners with mental health difficulties.

## **1.8 Views of County Dublin VEC education staff**

Tutors, co-ordinators and managers in County Dublin VEC adult and further education have been, for the past few years, voicing concern about growth in the number of learners with a history of mental health problems. They have expressed fear and uncertainty regarding danger to tutors, impact on other learners, how to integrate people into groups and how best to work with learners who have mental health difficulties. The need for policy development and staff training has been raised regularly at meetings, in-service training and other fora. The perception of staff generally is that the proportion of students with mental health difficulties has increased over recent years. Different theories are put forward as to the reasons for this. One obvious explanation is that of changes in national mental health policy and the resulting discharge of people from psychiatric institutions. Some local areas are involved in organising programmes for learners who would in the past have been in-patients in psychiatric hospital but are now living in the community, usually in hostel accommodation. As regards mainstream programmes, a frequently expressed opinion during the ‘Celtic Tiger’ years was that, with almost full employment, those who were unemployed and availing of return to learning programmes tended to have more difficulties than would those accessing these programmes during times of higher unemployment. The reasoning was that during boom times people out of work were likely to be in that situation because of problems in their lives rather than economic factors or employment trends.

Reactions of staff to this perceived increase in participation by people with mental health problems include fear, anxiety and feelings of inadequacy. Some express a desire for more control and/or for more information about students; most want more training and professional development; and there is general demand for the development of policies and guidelines by the VEC. There are some fears about safety of staff and potential violence from learners. A particular concern has been expressed by Adult Literacy Organisers (ALOs) with regard to safety issues for tutors involved in one-to-one literacy tuition. Community Education Facilitators have some concerns about incidents of aggressive behaviour in students referred by mental health services. Both of these staff groups felt that they did not receive sufficient information about students from the referring agency, which raises complex issues regarding information sharing, confidentiality and the rights of the learner. There is variation

among Adult Literacy Organisers (ALOs) on policy regarding one-to-one literacy tuition for people with mental health difficulties. Some will not place mental health service users in one-to-one tuition situations on health and safety grounds. Others have “never had a problem” with it. There is need for discussion and policy development in this area.

A small but vocal minority of staff are in favour of a policy of asking applicants with mental health difficulties to give information on what medication they have been prescribed and requiring a contract with students whereby they are admitted to programmes on condition that they continue to take this medication. This suggestion was raised and discussed at a number of training sessions and meetings and was regarded by the majority of staff present on each occasion as an unacceptable infringement of rights and privacy. The suggestion reflects a desire to control people with mental health problems, with ‘risk avoidance’ as a priority. It is based on a perception of people diagnosed as mentally ill as needing to be ‘taken charge of’ for their own good. It also exemplifies attitudes which infantilise mental health service users: an interesting modern version of Foucault’s asylums where “madness is childhood... the insane are transformed into minors” (1961, p.239). Mancini, reporting on his qualitative study of the role of self-efficacy in recovery, writes that “the recovery concept as described by participants was.... nurtured by egalitarian, collaborative partnerships with professionals. In contrast, participants were in agreement with other published accounts and testimony from psychiatric consumer-survivors that have concluded that coercion and force present significant barriers to recovery” (2007, p. 60).

Staff generally were concerned about how to deal with ‘critical incidents’ and some saw this as the main purpose of discussion and policy development. A few seemed to assume that the main focus for discussion in relation to learners with mental health difficulties would be health and safety procedures, again evidencing the “popular delusion that people with a mental disorder are necessarily dangerous” (Taylor and Gunn, 1999, p.9). Many studies have evidenced association among the general public of violence with mental illness. Wolff *et al* (1996) in a community survey, found that “43 per cent viewed the mentally ill as more aggressive” (1996, p.195). Philo *et al* found that a similar percentage (40 per cent) of their media audience sample believed

that conditions such as schizophrenia were associated with violence (1993, p.112). However, Taylor and Gunn's analysis of UK criminal statistics data from 1947 to 1995 concluded that "people with mental illness account for a minute amount of risk to the general public; their contribution has been falling over the years of major service change" (1999, p.14). Statistics in fact show that "mentally ill people are more likely to be murdered than to be murderers. They are six times more likely to die by homicide than the general population" (Laurance, 2003, p.42).

Unfortunately, media representations, both fictional and in news reporting, tend to conflate mental illness with crime. Philo *et al*, in an analysis of a range of national and local media output including both factual and fictional representations, "showed that two-thirds of media references to mental health related to violence and that these negative images tended to receive 'headline' treatment, while more positive items were largely 'back page' in their profile, such as problem pages, letters or health" (1996, p.112). This study used qualitative methods to explore "the cumulative, longer-term influence of media content and the processes involved in the formation of beliefs and attitudes" (1996, p.xi). What Philo describes as one of their most interesting findings relates to the power exerted by media representations. Research on other areas of experience has found that personal experience is a much stronger influence on belief than is media content. However, Philo *et al* found "cases where this pattern was reversed .... where people had non-violent experience which was apparently 'overlaid' by media influences. These people traced their beliefs mostly to violent portrayals in fiction or to news reporting" (1996, p.104). Philo speculates that "such is the depth of anxiety in this area that ....reactions, even to fictional portrayals, can overwhelm experience" (1996, p.104). As education staff in general had not experienced violent behaviour from students, it may be speculated that the fears of some could be influenced by media representations rather than experience.

The Adult Education Guidance network has expressed concern about the support needs of the increasing proportion of learners experiencing mental distress. Their service's role is in the areas of educational and career counselling, but staff saw a need for an additional service which could provide personal counselling to adult learners. In 2008 they requested a meeting with a representative of the Psychological Support Service to discuss the issue. The conclusion reached was that, in the absence

of funding for a counselling service, it is important for the guidance service to be aware of and provide information on and referrals to other agencies which can provide support. The Psychological Support Service does not have sufficient personnel to provide individual counselling support to students but is available as a resource to advise and consult staff. On further discussion, Adult Education Guidance staff concluded that they have more potential than is currently being realised to provide educational mentoring support for learners with mental health difficulties. This possibility and the importance of the role of guidance at student entry and exit points are highlighted in the discussion on policy implications in Chapter Five.

VTOS co-ordinators, a key group in this study, emerge from the interviews with learners as generally very supportive and encouraging. They expressed, however, a range of attitudes towards mental health problems ranging from extremely positive and accepting to lacking in understanding and tolerance. The two extremes could be illustrated by two comments from co-ordinators. One co-ordinator felt that “students with mental health problems can gain so much from education. They are usually not difficult and can really gain in confidence through doing a course”. Another, when asked if there were any students in her class who might be eligible to participate in the study, said “we have had students who were on disability allowance [on mental health grounds] in the past. But there was nothing wrong with them, they were just skiving”.

Overall, staff attitudes reflect themes which were found in two studies of the attitudes of over 2000 people in the USA and England towards people with mental disorders: “*fear* that mentally ill persons are dangerous and should be excluded; *authoritarianism* based on the perception that persons with mental illness can’t make their own decisions; and *benevolence* based on the idea that people with psychiatric disabilities are like children and should be cared for” (Brockington et al 1993 and Taylor, 1980, reported in Corrigan, 2002, p.223, my emphases). The mixture of attitudes is well put in a County Dublin VEC tutor’s reflection after in-service training “that there is an odd mixture of compassion and prejudice towards people who have used psychiatric services”.

## **1.9 Summary**

The historical backdrop of Irish mental health services and policies is relevant to the low participation of mental health service users in adult education in Ireland. Segregation of people with mental health problems in dedicated institutions became the norm in Europe and the US during the nineteenth century. These institutions proliferated particularly in Ireland, which, from the late nineteenth to the mid-twentieth centuries, had a rate of psychiatric hospitalisation significantly higher than other countries. While following international moves towards ‘care in the community’ in the late twentieth century, Ireland was relatively slow to close down its asylums, being described in 2005 as still “struggling with the last stages of the de-institutionalisation process” (Mental Health Commission, 2005, p.33). At the same time, Irish mental health services are generally agreed to have been ineffective in implementing community care. “People were moved from an institution to a residence in the community but the treatment they received did not change.....many of these people remained ‘institutionalised’ and isolated from the rest of the community” (Expert Group on Mental Health Policy, 2006, p.56). This state of affairs has worked against building links with other services including education, and limits capacity to counteract social exclusion and marginalisation. Education provision for mental health service users reflects this history, still being located mainly in segregated mental health service settings, with limited participation of mental health service users in mainstream classes or centres. Developments in education and equality legislation promote inclusion, but are slower to happen for people with mental health difficulties than for many other marginalised groups. Attitudes and concerns of education staff display a mixture of goodwill, anxiety and fear, pointing to their need for professional development and opportunities to reflect on policy and practice.

## **CHAPTER TWO**

### **THEORETICAL FRAMEWORK**

This chapter will outline the thinking and theories underlying and inspiring my research. The recovery model is of central importance. Bourdieu's thinking on capitals, Young's writings on oppression and Goffman's theory of stigma have also influenced my thinking. In addition, writings in the areas of disability studies, equality studies, post-psychiatry and some of the ideas of Foucault and other writers on the 'history of madness' are very pertinent. This chapter will engage with these theories specifically with regard to their relevance to the study.

#### **2.1 Recovery**

In general usage, the term 'recovery' means "a return to a normal state of health, mind or strength" (New Oxford Dictionary of English). When people talk about 'recovery' in relation to their health and medical treatment they usually mean 'cure'. It is assumed that when a person recovers from, for example, a chest infection, they are completely cured and returned to the state they were in before the infection. However, in mental health recovery literature, the term 'recovery' does not necessarily imply 'cure'. Recovery is not synonymous with the disappearance of symptoms, nor does it necessarily mean that the person will return to the way they were before.

Rethink (Schizophrenia UK) defines recovery as "a personal process of tackling the adverse impacts of experiencing mental health problems, despite their continuing or long-term presence. It involves personal development and change, including acceptance there are problems to face, a sense of involvement and control over one's life, the cultivation of hope and using the support from others" (2005, pp 4-5). For Tew it is "about claiming/ reclaiming a socially valued lifestyle, and social empowerment, rather than becoming 'symptom-free'" (2001, p.8). Anthony, one of the most important American writers on the topic, describes recovery as "a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" (1993, p.527).

Current understandings of the idea of ‘recovery’ from serious mental health problems have developed only since the late twentieth century. This has to be seen in the context of the historical development of psychiatry during the previous hundred years. As outlined in the previous chapter, perception of mental health problems as mental illnesses and the evolution of psychiatry as a branch of medicine developed during the nineteenth century. During the 1890s Emil Kraepelin, a German psychiatrist, devised the first systematic classification of mental illnesses, and his work became the basis for virtually all subsequent diagnostic systems, such as the current DSM IV (Diagnostic and Statistical Manual of Mental Disorders). Like other clinicians of his time, Kraepelin subscribed to the then-new scientific system for classification of diseases, a system predicated on an unfolding sequence, linear in character, of cause, onset, course and outcome. This way of understanding illness reflected the belief that disorders were natural and organic in cause, and had histories (courses) that were inflexible and predictable. Thinking of this type has dominated twentieth century psychiatry. The hegemony of these attitudes, built in to the training of medical, nursing and paramedical staff, leads to assumptions that “people with mental illness do not recover, will always remain a burden on society and must be ‘taken care of’ rather than encouraged to become independent contributing members of society” (Ralph, 2002, p.6).

The assumption of chronic illness may be self-fulfilling and reinforced by diagnosis, side-effects of medication and institutionalisation. Allott and Loganathan sum this up: “The biography becomes the biology” (2002, p.8). This may go towards explaining why the concept of recovery has been slow to gain acceptance and to effect changes in mental health policies and practices, although it has significantly influenced policy in the USA and underpins the New Zealand mental health service policy, which is based on a recovery-centred ‘*Blueprint*’.

There was a reaction to traditional psychiatry in the anti-psychiatry movement of the 1960s. On the left wing, Laing (*The Divided Self*, 1960) argued that it was necessary to recognise that the symptoms of mental distress reflected an individual’s life experiences, hence that it was appropriate to focus not on symptoms but on the meaning behind them. On the right, Szasz (*The Myth of Mental Illness*, 1961) contended that mental illness was a social construction used to label socially

intolerable behaviour. Both of these critiques emanated from within psychiatry itself, the voices of practitioners and academics talking about those with mental health difficulties. The modern recovery movement, on the other hand, emerged through the voices of ‘service users’ themselves.

In the 1970s, following the civil rights movement and greater awareness of the rights of oppressed groups, including those with disabilities, people who had been diagnosed and treated as psychiatric patients and had experienced this as oppressive began to speak out. Much of the early writing on recovery was in the form of individual narratives, sometimes referred to as ‘consumer writing’: people’s personal stories of their own experience of mental distress, psychiatric treatment and recovery, e.g. Chamberlin (1978), Deegan (1988), Leete (1989). Deegan was the first consumer to use the term ‘recovery’, in 1988. Describing recovery as “a journey of the heart”, she writes about how, at the age of 18, her “already fragile hopes and dreams and aspirations” were crushed by a psychiatrist telling her that “my life, by virtue of being labelled with schizophrenia, was already a closed book... the best I could hope for was to take my medications, avoid stress and cope” (1996, p.3). Her “angry indignation” fuelled her decision to “get a powerful degree and have enough credentials to run a healing place myself.... Starting with one course in English Composition at the local community college I slowly made my way” to a PhD. in clinical psychology (1996, p.7). She co-founded the National Empowerment Center Inc, a federally funded national training and resource centre run by consumer/survivors and is a respected speaker on recovery at national and international level.

There is a wide range of experience of recovery and of ways of articulating the experience. Descriptions by consumer writers include “an ongoing process of growth, discovery and change” (Stocks, 1995, p.89); “a way of life, an attitude, a way of approaching the day’s challenges” (Deegan, 1998, p.15); “the regaining of belief in oneself” (Chamberlin, 1997, p.9) and “having some hope” (Leete, 1988, p.52). There is certainly a case to be made for using a term other than ‘recovery’, with its connotation of cure, to name the process. Cohan and Caras suggest ‘transformation’ as a substitute. “Recovery and rehabilitation imply that something was once broken

and then was fixed. Transformation implies the proverbial making of lemonade after life hands you lemons” (1998, unpublished, cited in Ralph, 2000, p.6).

In recent years there has been some qualitative research on the process of recovery and what it involves (Sullivan, 1994; Young and Ensing, 1999; Ridgway, 2001; Deegan, 2003; Schiff, 2004; Bradshaw et al, 2007; Mancini, 2007). In a review of the recovery literature, Allott and Loganathan write that “at its simplest, recovery can be defined as a subjective experience of regaining control over one’s life” (2002, p.2). This echoes Deegan’s statement: “To me recovery means I try to stay in the driver’s seat of my life. I don’t let my illness run me” (1993, p.10). The person moves from being “a passive, co-operative patient” (Lovejoy, 1982, p. 607) to assuming primary responsibility for their own recovery process. Interestingly, this has echoes of what Samuel Tuke of the York Retreat wrote in his *Description of the Retreat* (1813): “as we... profess to do little more than assist Nature, in the performance of her own cure, the term *recovered* is adopted in preference to that of *cured*” (quoted in Scull, 1979, p.143). Indeed, some writers see the recovery movement as a rediscovery of ‘moral treatment’ (Roberts and Wolfson, 2004; Johnstone, 1989).

The essential elements in recovery are generally agreed to be hope, empowerment and social connectedness. It involves “no longer viewing oneself primarily as a person with a psychiatric disorder and reclaiming a positive sense of self ... moving from alienation to a sense of meaning and purpose” (Ridgway, 2001, pp.338-9). Anthony includes among the most important elements of recovery “the presence of people who believe in and stand by the person” (1993, p.531). He also emphasises the fact that “a recovery vision is not a function of one’s theory about the causes of mental illness .... Recovery may occur whether one views the illness as biological or not” (Anthony, 1993, p.532). Some writers on recovery and some users’ groups are totally opposed to psychiatric medication of any kind. Many other writers and survivors, however, are not doctrinaire on the subject. “I still use professional services including medications, psychotherapy and hospitals. However, now I do not just take the medication or go to the hospital. I have learned to use medications and to use the hospital. This is the active stance that is the hallmark of the recovery process” (Deegan, 1996, p.8).

The concept of recovery is of central importance to this study. Participation in education could be an important way of “taking control of one’s life” (Rethink, 2005, pp 4-5), “claiming/reclaiming a socially valued lifestyle” (Tew, 2001, p.8), “developing new meaning and purpose in one’s life” (Anthony, 1993, p.527) and/ or “personal development and change” (Stocks, 1995, p.89). Anthony writes that “recovery can occur without professional intervention... what promotes recovery is not simply the array of mental health services. Also essential to recovery are non-mental health activities and organisations e.g., sports, clubs, adult education and churches” (1993, p. 531). In a psychosocial rather than biological view of the person, participation in meaningful and fulfilling activities is an important ingredient in wellbeing. The decision to return to education may demonstrate self-efficacy and agency on the learner’s part in taking a step forward in their recovery process, which, in turn, may build the capacity to take more control of one’s life and move further forward.

## **2.2 Disability studies**

The disability movement and the mental health recovery movement have much in common: they are predicated on a human rights model; both drew inspiration from the civil rights movement of the 1960s; and they are based on similar goals, such as the right to self-definition and self-determination, removing barriers to social integration, and gaining and retaining rights. Both movements operate on the principle that the problem lies not in individuals with disabling conditions, but in a system which has made them dependent on medical professionals and denied them full access to employment, housing, and other opportunities.

Disability studies evolved from the disabled people’s movements which emerged in the late 1960s, movements such as the Union of the Physically Impaired Against Segregation (UPIAS) in the UK and the Independent Living Movement in the USA. These movements reflected a growing awareness of the oppression of some groups in society and of the possibility of these groups combating their oppression. This involved asserting the validity and necessity of their voice being heard, as was happening in the areas of race and gender. In a radical move away from traditional medical, welfarist and ‘personal tragedy’ models of disability, within which ‘handicapped’ people were to be cared for in segregated settings rather than having

the right to participate in society as active citizens, the UPIAS *Fundamental Principles of Disability* stated that “it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily excluded from full participation in society” (1975, 15).

Oliver was the first to name this point of view a social model of disability, often seen in opposition to a medical model. What is important is “the distinction between illness and disability and the fact that they are not the same thing ... The problem arises when doctors try to use their knowledge and skills to treat disability rather than illness... Disability is a social state and not a medical condition” (Oliver, 1990, pp.2/3). Oliver sees the medicalisation of disability as a component of the individual model of disability, which includes what he calls the ‘personal tragedy theory’, and he rejects the individual model in favour of a social model which “does not deny the problem of disability but locates it squarely within society” (1990, p.3).

Applying this to mental health, it could be said that while medical treatment may have a particular contribution to managing the acute phases of people’s distress, it is important to see this treatment as only one aspect of the person’s management of their difficulties. Oliver, Brisenden and many others have written about the importance of people with physical impairments not being trapped within a medical model of treatment, and this is equally important for those with mental health difficulties. Critics of the medical approach to mental health problems also cite the negative side-effects of many drug treatments, along with inflated claims as to their effectiveness. Furthermore, the individualistic medical model locates problems in the individual and fails to take into account the impact of the environment and of important life events.

A focus on only the biological aspects of illness and treatment runs the risk of dealing with people in a reductionist way. A holistic view of the person sees the importance of the psychological, social, and developmental dimensions as well as the biological. This does not preclude the value of medication or medical treatment, which may be an important part of a service user’s recovery and management of their lives. The important thing is that it should not be the only factor and that a person who suffers from a mental health problem should be enabled to move beyond the medicalisation of their condition.

The involvement of disabled people in writing about disability was essential to disability studies as it emerged from the disability movement. “When I began to read some of the things that able-bodied academics, researchers and professionals had written about disability, I was staggered at how little it related to my own experience or indeed [that] of most disabled people I had come to know. It gradually began to dawn on me that if disabled people left it to others to write about disability, we would inevitably end up with inaccurate and distorted accounts of our experiences and inappropriate service provisions” (Oliver, 1994, p.2). Similarly, individual consumer or survivor narratives were essential to the development of the mental health recovery movement. These developments were all part of the postmodernist questioning of the notion of objectivity, and contested traditional advice to avoid researching an area close to one’s personal experience because one will be biased and unable to be objective.

### **2.3 ‘Capitals’**

Bourdieu’s conception of capital as an individual asset affirms the potential importance of education for people with mental health difficulties. Capital, for Bourdieu, can be social, economic or cultural, with, within these broad categories, field-specific capitals, e.g. educational capital and political capital. In our society, education is one of the main vehicles by which a person may advance their socio-economic position. It also has the potential to be an avenue leading away from marginalisation and social exclusion towards integration or re-integration into the mainstream. Education has this potential because it can bring to the individual increases in her/his capital – in cultural capital in particular, but also in social and, indirectly, in economic capital.

In both prevention of and recovery from mental health difficulties, the level of economic, cultural and social capital of the individual and their family undoubtedly has major impact on outcome. Economic capital may be important in cushioning the effects of discontinuity in employment and paying for services and support such as counselling or therapy, which, as opposed to solely pharmaceutical interventions, are less available to disadvantaged groups. “Poverty and social exclusion impact on

mental health in terms of illness levels but also in terms of access to services and recovery rates” (NESF, 2007, p.11).

Social capital (“the aggregate of the actual or potential resources which are linked to the possession of a durable network of more or less institutionalised relationships of mutual acquaintance and recognition” [Bourdieu, 1986, p.248]) may be relevant in terms of connections, networking, finding employment and knowing how to access the best services and practitioners. The term ‘social capital’ is currently fashionable, with Putnam’s *Bowling Alone* (2000) the most popular work on the topic. Putnam sees social capital as a property of communities, and it is assumed that there is a relationship between this form of social capital and the mental health of communities, although results of surveys have been inconclusive in linking the two. Bourdieu’s conception of social capital may be more relevant to adults returning to education. He sees social capital as a personal asset, as “the sum of an individual’s social relationships – .... perceived as assets that allow .. differential access to societal resources” (Whitley and McKenzie, 2005, p.72).

Cultural capital can be institutionalised in educational qualifications (educational capital) and/or embodied as dispositions in the individual. Bourdieu refers to educational capital as “guaranteed cultural capital”. Although the education system “does not have a monopoly on the production of cultural capital” (Bourdieu, 1979, p.80) because of the effect of “inherited cultural capital” transmitted through the family, it does have the power to confer cultural capital on its participants. This capital increases, both in itself and in its capacity to be converted into economic capital, the individual’s power, status and the options s/he may call on in adversity.

People who have experienced mental health difficulties and who choose to participate in adult education programmes are availing of an opportunity to gain in social, economic and cultural capital, to progress in recovery and to improve their quality of life and life chances. Adult education has the potential to play an important role in promoting equality of opportunity and outcome for this and other potentially marginalised groups.

## 2.4 Oppression

Young's writing on "the five faces of oppression" speaks to the situation of people with mental health difficulties. Oppression used to mean "the exercise of tyranny by a ruling group, but in its new usage oppression designates the disadvantage and injustice some people suffer not because a tyrannical power coerces them, but because of the everyday practices of a well-intentioned liberal society. Oppression in this sense is structural, rather than the result of a few people's choices or policies" (Young, 1990, p.41). Young suggests that oppression cannot be given one essential explanation but is manifested in one or more of five categories: exploitation, marginalisation, powerlessness, cultural imperialism and violence. Two of these – marginalisation and cultural imperialism - apply particularly to the position of people with mental health difficulties, and a third – violence – also has relevance.

Young describes marginalisation as "perhaps the most dangerous form of oppression. A whole category of people is expelled from useful participation in social life.... [deprived] of cultural, practical and institutionalized conditions for exercising capacities in a context of recognition and interaction" (1990, pp.54-5). Some writers date the marginalisation of those with mental health difficulties to the Industrial Revolution, to whose organised work schedules and practices those with mental health difficulties, and other groups such as the intellectually disabled, could not conform. "As capitalist economies grew more demanding of consistent discipline among workers, the less formalised and localised work opportunities which had been available to those who might be somewhat erratic in their labour started to disappear" (Barnes and Bowl, 2001 p.96). Foucault writes that

In the classical age for the first time madness was perceived through a condemnation of idleness and in a social immanence guaranteed by the community of labour. This community acquired an ethical power of segregation which permitted it to eject, as into another world, all forms of social uselessness. It was in this 'other world', encircled by the sacred powers of labour, that madness would assume the status we now attribute to it.

(Foucault, 1961, p.54)

During the 'Age of Confinement', which extended into the twentieth century, those judged to be insane or mentally ill were incarcerated, with the assumption that they would not re-enter society, much less the workforce. The closing down of asylums and long-term psychiatric facilities in the late twentieth century meant that people

with long-term mental health problems were no longer segregated in residential institutions. However, the ideal of their integration into the community has not been realised. “On virtually any indicator of ‘social exclusion’, people with long-term or intermittent mental health problems score highly” (Sayce, 1999, p.65). Internationally, people with a psychiatric history do badly in their rate of returning to work when compared with people with other disabilities. This rate is particularly low in Ireland, with, according to the CSO Quarterly National Household Survey, only 15% of people with longstanding mental health problems in employment (Disability Update 2004, table 5b), an extraordinarily low rate particularly in a period of almost full employment. “People with mental health problems and disorders are disproportionately outside the labour market of employment, indeed outside the labour force entirely, and condemned to the double isolation of mental illness and workforce exclusion” (Conroy, 2005, p. 43).

Young describes cultural imperialism as being ‘othered’ by a dominant group which regards its perspective and culture as the norm. “The culturally dominated undergo a paradoxical oppression, in that they are both marked out by stereotypes and at the same time rendered invisible” (Young, 1990, p.59). This definition could have been written specifically to describe the position of people with a diagnosis of mental illness. As outlined in Chapter One, society’s reactions to people with mental health difficulties have ranged over time through fear, demonisation, punishment, incarceration and medical treatment. There is some evidence that in ancient times the insane were viewed as having access to the supernatural. In general, however, there is evidence that they were viewed with “fear and contempt, mingled to a lesser extent with an element of compassion. .. became objects of ridicule, scorn or abuse, and remained public butts for the amusement of the populace” (Rosen, 1968, p.90). Post-Enlightenment, what those viewed as insane had to say became even less valued or heard. “The great divide, since the ‘age of reason’, became that between the rational and the rest, demarcated and enforced at bottom by the asylum walls” (Porter, 2002, p.122).

Today, our society still tends to regard people with mental health difficulties as not capable of having valid opinions. Psychiatrists are trained to regard the content of people’s experience, behaviour or speech as symptoms which help towards making a

diagnosis. The term of ‘lack of insight’ is frequently used, confining people to “a category of persons whose experience is devalued, status diminished and rational evidence dismissed” (Campbell, 1996, p.57). It is standard practice to view people diagnosed with schizophrenia or bipolar disorder as ‘not amenable’ to counselling or therapy. “Assumptions about the inability of patients to hold valid opinions are held by therapists of all kinds” (Pilgrim and Rogers, 1999, p.193). Similarly, research has tended to ignore the views of the people receiving or using psychiatric treatment. Pilgrim and Rogers describe how “clinical research in the area of mental health has tended either to exclude the views of mental patients or to portray them as the passive objects of study” (1999, p.193).

This silencing of the voice of people with mental health difficulties is matched by their being perceived in negatively stereotyped and stigmatised ways. Surveys repeatedly show high levels of prejudice against people with mental health difficulties. Attitudes are much more negative than those towards people with intellectual or physical disabilities (National Disability Authority, 2002; National Office for Suicide Prevention, 2007). This strong ‘othering’ among the general public, when a quarter of the population will experience serious mental health difficulties at some stage in their lifetime, may bespeak a defence against the fear of losing control, of losing one’s reason. It may “translate.... fears into the fearful, first by singling out difference, next by calling it inferior and finally by blaming ‘victims’ for their otherness.... reinforcing our fragile sense of self-identity and self-worth through the pathologisation of pariahs” (Porter, 2002, pp.62 - 63).

It is ironic that ‘othering’ involves the perception, reinforced by the media, of people with mental health problems as dangerous and violent. In fact, people with mental health difficulties are much more likely to be victims than perpetrators of violence. Young sees violence as oppression “when it is directed at members of a group simply because they are members of that group.....The oppression of violence consists not only in direct victimisation, but in the daily knowledge shared by all members of oppressed groups, that they are *liable* to violation, solely on account of their group identity” (1990, p.62). A survey carried out on behalf of MIND (Read and Barker, 1996), in which people with a psychiatric history were questioned about their experiences, found that 47% had been shouted at, threatened or physically attacked in

public and 38% had been harassed, intimidated or teased at work. A UK survey of 25 community based service users with schizophrenia found that during the previous 12 months 16 had been criminally victimised through physical or sexual assault, verbal threats or abuse, theft, humiliation or bullying (Colombo, 2007).

Young's thinking has been influential in the development of concepts of equality. Baker *et al* describe "a natural path from basic equality to the beliefs of liberal egalitarians and from those beliefs to equality of condition" (2004, p.21) and list the dimensions of equality of condition as five-fold: respect/recognition, resources, power, love/care/solidarity and working/learning. People with mental health difficulties experience inequality along all five dimensions. The cultural imperialism described above is synonymous with inequality of respect and recognition. Inequality of economic resources is a consequence of marginalisation. Mental health service users experience disempowerment in many areas of life including their psychiatric treatment. Inequality in the love/care/solidarity dimension results from the social isolation and reduction in social networks experienced by people with a diagnosis of mental illness. Inequality in working is evident in the low employment rate of people with mental health difficulties. Inequality in learning can result from the fact that serious mental health difficulties often have their onset during late teens/early twenties and can have a very disruptive effect on education.

## **2.5 The influence of Foucault**

Foucault's *Madness and Civilisation*, published in 1961, offered an alternative interpretation of psychiatry's role which contested psychiatry's own self-congratulatory version of its history. Foucault described the institutions set up to house 'unreasonable' people as operating for purposes of exclusion, segregation and social control. Within these settings, "the apotheosis of the medical personage" (1961, p.256) took place, inmates became subject to the 'gaze' of medicine and psychiatrists established a powerful role for themselves. Their powers "borrowed from science only their disguise or at most their justification. These powers, by their nature, were of a moral and social order. .... Increasingly the patient .... would alienate himself in the physician, accepting entirely and in advance all his prestige, submitting from the very first to a will he experienced as magic, and to a science he regarded as prescience and divination, thus becoming the ideal and perfect correlative of those powers he

projected upon the doctor” (1961, p.261). This description still rings true. When people are in great distress they want a solution. They may feel disempowered and project power onto someone else, often investing psychiatrists with knowledge and power greater than they actually have. This has been compounded by the claims made by the pharmaceutical industry for the efficacy of psychiatric drugs. Throughout the twentieth century new drugs have been heralded as breakthroughs and marketed extensively as such, only to turn out to be less effective and have more serious side-effects than predicted (Bentall, 2004 and 2009). The pharmaceutical industry has cultivated links with the psychiatric profession, documented by Breggin, (1993, 2007, 2009), Johnstone (1989) and others, making “massive investment in the promotion of reductionism and biopsychiatry” (Bracken and Thomas, 2005, p. 175).

Foucault writes that whereas “in the Middle Ages.. man’s dispute with madness was a dramatic debate in which he confronted the secret powers of the world.....we have confined insanity within mental illness”. Within this paradigm, “man no longer communicates with the madman....As for a common language, there is no such thing.... The language of psychiatry, which is a monologue of reason about madness, has been established only on the basis of such a silence” (1961, p.xii). This resonates with the silencing of cultural imperialism described above.

Foucault’s work has been influential from the anti-psychiatry movement of the 1960s up to ‘post-psychiatry’ today. However, much of the historical evidence on which he based the exposition of his ideas was faulty. He tended to romanticise the lives of people with mental health difficulties in mediaeval society and there is no evidence that the ‘Ships of Fools’, of which he wrote at length as a common way of dealing with ‘madmen’ in mediaeval times, ever actually existed (Scull, 2006, p.36). Foucault projected the French phenomenon of the ‘age of confinement’, which occurred in the seventeenth and eighteenth centuries, to Europe in general, whereas in other countries asylums did not proliferate until the nineteenth century. In addition, he does not seem to make a distinction between mental health problems and intellectual disabilities. However, in spite of these inaccuracies, Foucault’s de-constructing of the ‘grand narrative’ of psychiatry and questioning of ‘mental illness’ as a social construct rather than a medical condition are seminal to a post-modern questioning of positivist models of mental distress and of the hegemony of the medical approach. “*Madness*

*and Civilisation* is a work that is unlikely ever to be supplanted, however much it may be denounced” (Ingleby, 1983, p.149).

Post-psychiatry, a school of thought among radical UK psychiatrists, has been influenced by Foucauldian thinking, advocating an end to Foucault’s “monologue of reason about madness”. Bracken and Thomas describe psychiatry as a modernist enterprise, reductionist and technical in its approach to mental distress, which it sees as located within the individual and needing to be socially excluded and controlled. Post-psychiatry’s aim is to subdue the domination of the medical approach to mental distress, in order to let other approaches “which lack the organisation and funding of psychiatry” be heard and taken seriously, believing that “the insights of other approaches are equally important and valuable” (2005, p.274).

## **2.6 Stigma**

Goffman’s writings both influenced and reflected the twentieth century move towards de-institutionalisation of people with diagnoses of mental illness. His *Asylums*, in which he denounced asylums as hopelessly flawed ‘total institutions’, was published in 1961, the same year as Foucault’s *Madness and Civilisation*. A decade later, he described the asylums as “hopeless storage dumps trimmed in psychiatric paper.....[T]he price the patient has had to pay for this service has been considerable: dislocation from civil life, alienation from loved ones who arranged the commitment, mortification due to hospital regimentation and surveillance, permanent post-hospital stigmatisation. This has not merely been a bad deal; it has been a grotesque one” (1971, p.336).

It is Goffman’s writings on stigma which are particularly relevant to this study. Goffman refers to stigma as “an attribute that is deeply discrediting” (1963, p.13), through which a person “is reduced in our minds from a whole and usual person to a person who is quite thoroughly bad, or dangerous, or weak” (1963, p.12). The distinction he makes between ‘discredited’ (obvious) and ‘discreditable’ (capable of being hidden) stigma is particularly relevant to the person with mental health difficulties, who “must face unwitting acceptance of himself by individuals who are prejudiced against persons of the kind he can be revealed to be” (1963, p.58). Goffman seems to assume that because the person in question is able to ‘pass’ as

'normal' s/he will do so by "conceal[ing] information about his real social identity, receiving and accepting treatment based on false suppositions concerning himself" (1963, p.57). Contemporary movements of mental health users, such as Mad Pride, or Survivors Speak Out, eschew such 'passing', and publication of personal narratives of experience of mental health difficulties and treatment is increasingly common and is seminal to the recovery movement. However, stigma, disclosure and information management are still very pertinent for most people with mental health difficulties. How these issues were dealt with by participants in this study will be discussed in Chapter Four.

The internalisation of stigma is another process relevant to study participants. It is very easy for negative attributions and attitudes to become internalised. Goffman writes of the "socialisation process through which the stigmatised person learns and incorporates the stand-point of the normal, thereby acquiring the identity beliefs of the wider society and the general idea of what it would be like to possess a particular stigma" (1963, p.45). In experiencing lack of respect and regard, the stigmatised person "echoes this denial by finding that some of his own attributes warrant [stigmatisation]" (1963, p.19). However, later studies have shown that there is variation in the extent to which individuals internalise and assimilate stigma (Corrigan and Watson, 2006), a finding which is corroborated by attitudes of participants in this study.

## **2.7 Summary**

The mental health recovery movement and literature, which have much in common with the disability movement and disability studies, are fundamental to this study. The recovery literature emphasises empowerment in the transformation from "passive service recipient" (Chamberlin, 1990, p.330) to taking an active role in one's own mental health care. Key factors in the process of recovery are hope, personal growth, self-management, autonomy and participation in the community. This study makes the point that choosing an opportunity to engage in education and learning can be a powerful way of gaining/regaining autonomy, self-efficacy, meaning and hope for many individuals.

Foucault's writings on the history of madness and on the establishment of psychiatry have been both controversial and influential. Other theories of relevance include Bourdieu's conception of social and cultural capital as individual assets, thus potentially attainable by individuals through participation in education and Young's ideas on marginalisation and cultural imperialism, which relate very strongly to the experience of people with mental health problems. Finally, the relevance of Goffman's writings on stigma and particularly on information management has been discussed.

## **CHAPTER THREE**

### **METHODOLOGY**

This chapter starts by outlining the value base and epistemology underlying the study. Making a difference in terms of promoting equality and social justice is an intrinsic aim, placing the study within a transformative paradigm. Co-construction of knowledge with participants rather than analysing their experiences as expert interpreter is essential in order to counteract historical silencing of the voices of people with mental health difficulties. Later in the chapter, fieldwork with individual participants and groups is described, and ethical issues and difficulties in accessing participants are discussed. Tables at the end of the chapter summarise interviews, focus groups and other meetings undertaken in fieldwork.

#### **3.1 Research for social justice**

The distinguishing feature of research carried out within the transformative paradigm is that, as well as developing theoretical understanding of the issues, it attempts to ‘make a difference’ in influencing policy and to empower rather than exploit participants. Guba and Lincoln, in reviewing developments in social research, note that whereas “positivist adherents believe action to be either a form of advocacy or a form of subjectivity, either or both of which undermine the aim of objectivity”, there has been “a sharp shift... in the constructivist and participatory phenomenological models, [with] a step beyond interpretation and ... understanding, toward social action” (Guba and Lincoln, 2005, p. 201). Within this paradigm, the purpose of research is not just to describe the world, but to change it.

This piece of research can be described as transformative in purpose in that, through the exploration of individual experiences of learners with mental health difficulties and of the context of mental health and education services in which these take place, it aims to promote social justice and equality. It has “an explicit concern with ending inequality and with taking the side of oppressed and marginalised groups” (Humphries *et al*, 2000, p.3). It could also be described as research for social justice, which Griffiths defines as research with “a focus on the good of the individual and of the society of which she is a part” (Griffiths, 1998, p.92).

I describe this study as participatory rather than emancipatory. Many transformative studies can be described as emancipatory, involving collaboration with the participants from the start in all aspects of the research and “a recognition of the moral right of vulnerable, marginalised or oppressed research subjects to exercise ownership and control over the generation of knowledge produced about them and their world” (Baker et al, 2000, p. 179). However, the area covered by this inquiry does not lend itself to carrying out research which could be described as robustly emancipatory. The participants with whom I am working are dispersed and do not form a cohesive group with whom I could work from start to finish on the research. On the other hand, it could also be argued that studies such as this one are emancipatory in being concerned with an emancipatory action for an entire group/community rather than just those who participate in the research process, i.e. “linking research to wider questions of social inequality/social justice” (Humphries et al, 2000, p.13). An example of emancipatory research of this kind is that of Mertens, who carried out research into the court-room experiences of deaf and hard of hearing people as part of a project undertaken by the American Judicature Society. Her study, which she describes as “emanating from the emancipatory paradigm”, aimed to ‘listen to the voices’ of deaf and hard of hearing people in order to develop training for judges and other court personnel that would be “validly representative of the experiences of those with the least power” (2000, p.112).

Participatory approaches to research have emerged partly in reaction to the so-called ‘hit and run’ model, where oppressed people may be further oppressed by the work of ‘expert’ researchers using alienating or exploitative methods of inquiry. Participatory research is carried out *with* the participants as opposed to being done *to* them. Participants are involved in the design of the research and in the interpretation of data. The responsibilities of the researcher extend beyond writing up the findings and include consideration of responsibilities to participants and of the costs or benefits the research brings to them.

This participation is particularly important in a study involving people with mental health problems, in order not to replicate their traditional invisibility in research and their passivity in their own treatment. People regarded as ‘mad’ have not been considered as having anything worthwhile to say and their voices have not been

listened to, either in treatment or in research. “The main way in which users of psychiatric services have been portrayed is as objects of the clinical gaze of mental health professionals... [regarded] as continually irrational and so incapable of giving a valid view” (Pilgrim and Rogers, 1999, p.193). This exemplifies the cultural imperialism described by Young as one of the five faces of oppression.

The methodology used in this study attempts to counteract oppressive approaches where people with ‘mental illness’ have been talked about and further silenced rather than listened to. It was conducted using methods congruent with the alternative value base for mental health research which has been proposed by the UK Social Perspectives Network:

1. People are active participants or partners in their own recovery
2. People are experts *on* their own experience and *by* their own experience
3. The research agenda must be as much about promoting social change (attitudes, opportunities...) as it is about individual recovery
4. Service users, carers and practitioners who consent to participate in research must be fully informed about the purposes of the research and, if they wish, be given the findings of the research in a form that is accessible to them. (Tew *et al*, 2006, p.3)

I have aimed as far as possible to consult with people with mental health problems regarding the research design and to involve participants in interpretation of data. Before commencing the field work, I consulted with two groups of mental health service users who were attending dedicated courses in a FÁS-funded training centre and obtained advice from them on approaching and interviewing participants. Feedback which I sought from the first four individual interview participants on aspects of the contact, interview and follow-up process influenced my approach to later participants. A constructivist methodology, which involved second or further meetings with participants to discuss interpretation of their interviews, supported a participatory approach.

### **3.2 Constructivist view**

Social constructionism is a post-modern way of looking at the world, viewing it as socially constructed rather than a given, and seeing knowledge and knower as interdependent. “Human beings do not find or discover knowledge so much as we construct or make it. We invent concepts, models and schemes to make sense of

experience, and we continually test and modify these constructions in the light of new experience.....We do not construct our interpretations in isolation but against a backdrop of shared understandings, practices, language and so forth” (Schwandt, 2000, p.197). The ‘grand narratives’ (such as psychiatry) are also socially constructed, and are not necessarily the correct and only possible ways of seeing the world.

Constructivist research takes a social constructionist view of knowledge. It starts with the experience and asks how the person/participant constructs it, while acknowledging that the researcher, too, constructs her/his interpretation of what is being studied. “The constructivist paradigm assumes a relativist ontology (there are multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a naturalistic (in the natural world) set of procedures” (Denzin and Lincoln 2000, p. 21). Research involves co-construction of meaning between researcher and participant.

The constructivist paradigm described above implies a qualitative approach to research, an approach which is more suitable for investigation of the topic of this study than a quantitative approach would be. One reason for this is purely pragmatic in that, because of the stigma, and therefore the disclosure issues, involved, it would be difficult to access a sufficient number of learners with mental health problems to form a representative sample offering the chance of statistical significance and generalisation, even if such an outcome were possible. A second and much more fundamental reason is that quantitative methods such as questionnaires would not be capable of exploring or illuminating the areas of experience being investigated, even in the unlikely event that people who had experienced mental health difficulties were willing to be open about their experiences in a questionnaire. The complex, varied and multi-layered experiences being investigated in this study are much more likely to be articulated through interpersonal dialogue than through more impersonal research tools. Furthermore, a qualitative approach gives scope for the emergence of the underlying and possibly unexpected factors which are intrinsic to human experience. “Qualitative researchers have one great advantage.... We can add new pieces to the research puzzle or conjure entire new puzzles – *while we gather data* – and that can even occur late in the analysis” (Charmaz, 2006, p.14).

The question of the possibility of generalisation of findings from qualitative studies has been extensively discussed. Some qualitative researchers reject the possibility of generalisation. “The aim of inquiry is to develop an idiographic body of knowledge.... Generalisations are impossible since phenomena are neither time- nor context-free” (Guba and Lincoln, 1985, p.238). However, although empirical modes of generalisation are not applicable to this study, it is important that its findings have a broader relevance so that they can have implications for policy. Overall, I think it is more appropriate to conclude that findings can be *extrapolated* to other similar situations or groups rather than generalised, and agree with Alasuutari that generalisation is a word that “should be reserved for surveys only. *Extrapolation* better captures the typical procedure in qualitative research” (Alasuutari, 1995, p.157).

Semi-structured interviewing seems very suited to this study, in that it is “a relatively flexible and unstructured approach to questioning so that participants assume more power over the content of the conversation” (Mills, Bonner and Francis, 2006, p.9) and “offers researchers access to people’s ideas, thoughts and memories in their own words rather than the words of the researcher” (Reinharz, 1992, p.19). Semi-structured interviews are co-constructed by researcher and participant, and are a way of generating, as opposed to discovering, data. They “operate with the model that knowledge is constructed rather than straightforwardly excavated” (Mason, 2002, p.68). Whereas in a structured interview, the researcher pre-determines the sequence and exact wording of questions, semi-structured interviews are more fluid and responsive to directions or tangents taken by the participant. However, the researcher needs to be clear on the main topics/themes/questions to be addressed, and to guide the interview enough to encompass these. The key areas I wanted to address in interviews were the person’s life journey which had brought them to this place, including their mental health difficulties and their previous experiences of education; how/why they had undertaken the education programme in which they had engaged; what had been helpful/unhelpful in access and participation and the benefits and difficulties of participation.

While semi-structured interviews are more likely to enable participants to communicate about the relevant issues than a questionnaire or structured interview

survey, there are still some caveats. These are bound up with the relationship between interviewer and participant and encompass power issues as well as the distinction between therapeutic and research interviewing. These and other ethical issues are discussed later in this chapter.

### **3.3 Interpretation of data**

I began this study assuming that Grounded Theory would be the most suitable method for working with the data. Its use of concurrent data collection and analysis seemed to suit a study in an area which was hitherto under-investigated, particularly in the Irish context, and thus whose parameters, areas of inquiry and criteria for participation would possibly be modified as it progressed. However, Glaser and Strauss's rather positivist assumption (1967) that the researcher is an objective investigator discovering facts did not fit well with my belief that data are co-constructed with participants. Furthermore, guidelines for applying grounded theory analysis, as developed by Strauss and Corbin (1990) and others, seem mechanistic and overly technical in a way that might not lend itself to sensitivity on the researcher's part to participants' experience and the meaning they make of it. These reservations led to my investigation of Interpretative Phenomenological Analysis (IPA).

IPA, developed in the 1990s, is used mainly in health psychology research. Its central concern is to investigate how people make sense of their lived experience. IPA has been described as a synthesis of phenomenology (how things appear to us in experience) and hermeneutics (interpreting experience and making meaning). The IPA method acknowledges that there is a dual interpretive process (a 'double hermeneutic') going on: "the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith and Osborn, 2004, p.51). The aim is to access participants' experience, while acknowledging that this can never be completely realised.

IPA has much in common with grounded theory. Semi-structured interviews are most commonly used, although usually with a smaller number of participants. Themes and theme clusters are identified and illustrated by quotes from participants. Although superordinate themes do emerge and are written up, the focus in IPA is on the individual experience and on the meaning that each person makes from their

experience. Grounded theory, on the other hand, is looking for themes across groups in order to develop theory. These differences are not surprising, considering that grounded theory emerged from sociology and IPA from psychology. IPA's idiographic focus on the particular rather than the universal may possibly limit its usefulness in a study which aims to influence policy.

I used Interpretative Phenomenological Analysis to interpret the data from interviews with the first four participants. It was fruitful in highlighting themes arising from the interviews, and may have been quite adequate as a tool for analysing all the subsequent interview data. However, the method seemed to imply a fairly static and pre-planned approach to both the research design and the fieldwork. Also, as I learned in an IPA workshop which I attended in Aston University (2008), although the method accepts in principle the 'double hermeneutic', most practitioners take for granted that they will carry out interpretation of data after one interview without any revisiting of or discussion with participants.

Around this time, still seeking an approach which would suit both me and this study, I discovered constructivist grounded theory through reading the work of Kathy Charmaz. This approach seemed to bring together IPA's incorporation of participants' quest to make meaning of their experience with the fluidity and flexibility of grounded theory's theoretical sampling. Charmaz describes her approach as "reclaiming [grounded theory] tools from their positivist underpinnings to form a more open-ended practice of grounded theory that stresses its emergent, constructivist elements.... [using] grounded theory methods as flexible, heuristic strategies rather than as formulaic procedures" (2000, p.510).

I can claim only to have emulated Charmaz in this study, not to have succeeded in replicating her methods. I cannot claim to have used line-by-line coding throughout, but did apply it to more relevant sections of the transcripts. Nor have I been able to work with participants over the long timeframe which Charmaz has used. However, my application of constructivist grounded theory has seemed to 'fit' well with this piece of research and has yielded interesting insights.

Charmaz advocates the use of action codes (gerunds) in initial analysis of data in order to generate theory at a process rather than descriptive level.

Coding with gerunds helps you detect processes and stick to the data. We gain a strong sense of action and sequence with gerunds. .... Staying close to the data and, when possible, starting from the words and actions of your respondents, preserves the fluidity of their experience and gives you new ways of looking at it.  
(Charmaz, 2006, p 49)

Analysis progresses from these action codes to focused codes/categories and then through memo-writing to theory. Using this approach to analyse the initial four interviews generated new ideas and insights which had not emerged using IPA a year earlier. I had, admittedly, been at a less developed stage in my thinking at that stage, but using a more constructivist approach gave added value above and beyond that of the benefits of a year's development in my thinking. The analysis of the following extract from the first interview with one of the participants may illustrate the process:

Well like, what I'm trying to say is, that if the same people in this college, ...if they had've been walking down the inner city say this time say two year ago, and I'd have been hanging around there, you know what I'm trying to say, they wouldn't have had anything to do with me. And once you reach that kind of level in life you just kind of, it kind of sticks to you, I don't know, it kind of sticks to me anyway like. You're kind of different from...they're all more upper class than you or something.

I initially coded the above extract as 'stigma', which was one of the themes I was expecting to find. A year later, I saw this as my imposing a theoretical construct which had not "earned its way into the analysis" (Glaser, 1978, cited in Charmaz, 2000, p.511) instead of staying close to the data and to the experience of the participant. I was "filling in gaps using 'grand narrative', rather than enquiring how pieces make sense together" (Etherington, 2009). Using "a language of action rather than topics" (Charmaz, 2006, p.48), I coded this as 'being shunned', 'feeling that it sticks', and 'feeling different, inferior'. When I moved on to focused codes, these combined with other things the participant said ("I wasn't used to this environment", "You didn't know whether you belonged there or not" and "Feeling people can see you're an addict by the way you walk, by your face") to generate two focused codes: 'feeling like a fish out of water' and 'bearing stigma'..

Theoretical sampling was extremely useful in influencing the direction of fieldwork – both in terms of deciding what kind of participants to seek and in terms of avenues to explore at second or third meetings with them.

Theoretical sampling is a pivotal part of the development of formal theory. ... The necessity of engaging in theoretical sampling means that we researchers cannot produce a solid grounded theory through one-shot interviewing in a single data-collection phase. ....our categories take us back into the field to gain more insight about where, when, how and to what extent they are pertinent and useful  
(Charmaz, 2000, p. 519)

The approach worked well with the semi-structured interviews I used as my main research tool. An example was the emergence from the first few interviews of the intrinsic importance of learning as a benefit experienced by participants. This had not been something I had expected or focused on in questions initially, but after seeing its significance I was able to ask other participants questions around it and to explore it further in follow-up interviews with early participants. As Charmaz writes, “both grounded theory methods and intensive interviewing are open-ended yet directed, shaped yet emergent, and paced yet unrestricted. .... [T]he combination of flexibility and control inherent in in-depth interviewing techniques fits grounded theory strategies for increasing the analytic incisiveness of the resultant analysis” (2006, pp. 28-29).

### **3.4 Ethical issues**

Feminist thinking has developed understanding of the equality and power issues inherent in the researcher-participant relationship and in the interview process. Oakley has critiqued the traditional research interview model as “a mechanical instrument of data collection”, which characterises interviewees as “essentially passive individuals” and reduces interviewers to “a question-asking and rapport-promoting role” (2005, p.220). Both interviewer and interviewee are depersonalised in this process. Interviewees are manipulated as sources of data, and “a balance must .. be struck between the warmth required to generate ‘rapport’ and the detachment necessary to see the interviewee as an object under surveillance” (Oakley, 2005, p.218). Fontana and Frey describe this as “treating the interviewee as a ‘clockwork orange’, that is, looking for a better juicer (techniques) to squeeze the juice (answers) out of the orange (interviewee)” (2005, p.696). Duncombe and Jessop write that, by simulating

empathy and using counselling skills to “do rapport” and get the participant to open up, interviewers may be “faking friendship”. This may cause unfounded expectations in the participant of actual friendship, or may “encourage or persuade interviewees to explore and disclose experiences and emotions which – on reflection – they may have preferred to keep to themselves” (2002, p.120).

The essential issue in these analyses is the imbalance of power between interviewer and participant and perhaps the abuse of that power. The interviewer is using the interviewee as a source of data in what has been characterised as a “smash and grab” approach (Collins, 1998, p.1). The process benefits the researcher, who takes away the data and analyses it as a neutral ‘expert’. “The convention of interviewer-interviewee hierarchy is a rationalisation of inequality; what is good for interviewers is not necessarily good for interviewees” (Oakley, 2005, pp. 221-2).

If the interview is seen as a process of co-construction of knowledge which is produced by the interviewer and participant together – a process of data-generation rather than data-collection (Collins, 1998, p.1) - there is more reciprocity in the relationship between researcher and participant. Authenticity on the part of the researcher - Oakley’s “no intimacy without reciprocity” (2005, p.226) – may help to establish a less hierarchical relationship. So also will a working assumption that “participants’ comfort level has higher priority than obtaining juicy data” (Charmaz, 2006, p 30). Furthermore, a participatory approach such as is used in this study aims for more equality in the relationship between participants and researcher.

Participants may not see it this way, however, and perception on their part of the researcher as more ‘knowing’ will probably continue to operate to some extent. Power disparities still exist and in the end it will be myself and not the participants writing the research text. Edwards and Mauthner see the elimination of these disparities as “neither possible nor desirable” (2002, p.26) and call instead for “asymmetrical reciprocity”. They recommend that “rather than ignoring or blurring power positions, ethical practice needs to pay attention to them” (2002, p.27).

It is also essential to pay attention to the distinction between a research interview and a therapy session, activities which undoubtedly share some common characteristics.

Being the focus of another person's undivided attention and interest for at least a full hour with no demand for reciprocation is common to both situations and rare elsewhere in life. The basic skills of counselling are similar to those employed in a semi-structured research interview: attention-giving, active listening, empathic understanding, non-critical acceptance, paraphrasing, reflecting feelings, summarising and focusing (Inskipp, 1986). The fundamental aims of counselling, which include clarifying problem issues, developing understanding and encouraging insight (Burnard, 1992, p.8) and empowerment of the client, can also be outcomes of the research interview. King argues that "these aims may often be applicable in the research interview, even if they are a by-product. ... rather than stated as an explicit goal" (1996, p.182). And, as Etherington asks: "Why shouldn't research be a moral act, a positive engagement?" (2009).

This similarity to counselling has implications for the importance of establishing clear boundaries as to the role of the researcher and the limits of her/his relationship with the participant. A key difference is that

as a therapist my purpose is to help my clients re-search (into themselves and their lives), and in my role as researcher the positions are reversed: they are there to assist *me* in discovering something about a topic or concept that *I* am curious about. As a counsellor people seek *me* out; as a researcher I seek *them*. This inevitably influences the power dynamic, though it would be disingenuous to deny that the researcher is nonetheless in a powerful position

(Etherington, 2004, p.110)

The fact that I have counselling skills and experience of working as a counsellor may help in establishing good rapport and communication. However, both the participants and I need to be clear that I am not in a counselling role. Although I hope that participants gain (in insight, understanding, empowerment) from the experience of participating in the research, I also need to be sensitive to painful issues that may arise for them during interviews. "A researcher should not push the participant into an emotional abyss and then leave" (Charmaz, 1991, p.278). If the interview triggers upset in a participant to the extent that they need support, I have a responsibility to help them access that support. The NUI Maynooth Research Ethics policy states that "researchers have a primary responsibility to protect participants from physical and mental harm during the investigation" and "have a special responsibility for safeguarding the interests of vulnerable people" (2007, p.2). I gave participants my

mobile number in case they wanted to contact me to discuss anything further, which is congruent with college policy that “participants should be informed of the procedures for contacting the researcher within a reasonable time period following participation should stress, potential harm or related questions or concern arise” (2007, p.3).

I gave and read with/to each participant a ‘Participant Information’ summary written in plain English (the first language of all participants) and a consent form which I asked them to sign (see appendices 1 and 2, pp.142-3).

### **3.5 Reflexivity**

I view reflexivity on the part of the researcher as essential to the research process. Described by Etherington as the development of “an ability to notice and respond to the world around us, to stories, and to other people and events, and to use that knowledge to inform and direct our actions, communications and understandings” (2007, p.601), reflection helps us to be more aware of the personal biases, prejudices and preferences which may colour our perceptions, interactions, interpretations and even our research design.

The importance of reflexivity in research has been increasingly recognised, and it is a defining characteristic of narrative inquiry in particular. The level of reflexivity assumed by narrative inquirers such as Clandinin and Connelly (2000), with the development and maintenance of ‘wakefulness’ – a kind of high quality awareness - on the part of the researcher, seems to demand high commitment and rigorous effort which may not be possible for many researchers. However, Clandinin and Connelly’s recommendations for field notes and field texts could be productive for developing reflexivity in researchers using any research method. Their suggestions for journalling, autobiographical writing and richly detailed field notes are a means of developing insight, understanding and perspective. I have experienced the discipline of (trying to) faithfully write regular reflective journal entries on my experience of the research process as of huge personal benefit in terms both of my own personal growth, learning and development and, I hope, of the quality of the research. However, while I agree with Clandinin and Connolly that “we need to be prepared to write ‘I’ as we make the transition from field texts to research texts” (2000, p.122), for the moment I prefer to keep process notes and journals as private support materials

– ‘written up’ in field notes but not ‘written down’ in the final text. The explicit inclusion of the researcher’s personal history, thoughts and feelings seems to me to pose the risk of a level of exposure with which I might not be comfortable.

The difficulties which I encountered and also the learning I experienced in the course of the project gave me much food for thought as to how I might have approached the study differently. My findings and reflections led me to perceive my initial emphasis on learners in VTOS-funded programmes as a limited focus on adult education for people with mental health difficulties. The journey of learning which I travelled in doing this research meant that my perspective broadened in the process from consideration of the experience of learners in full-time programmes to the wider landscape of provision, access and inclusion. Had I had this broader focus from the beginning, I could have been more successful in exploring the experiences of learners in part-time programmes, perhaps accessing more participants through linking in earlier with adult literacy services and having had time to try negotiating with HSE staff to gain access to interviews with mental health service users in VEC-provided classes.

On the other hand, the experiences of learners who did take part were investigated and analysed in a fair amount of depth. The participatory approach and constructivist interpretative methods used, along with the limited number of participants, allowed for individual experiences to be voiced and heard. I hope that this will contribute to understanding of mental health recovery and the potential of education in that process.

Insider status in the VEC gave me access to learners and to staff. Even with this advantage, accessing participants was still a difficult process with many setbacks. Insider status may possibly have also had a negative impact, in that it could have influenced participants’ responses to questions about their experiences, particularly in relation to teaching staff. Could a suspicion on their part that negative feedback would reflect badly on staff have coloured the picture they painted? This bias is made less likely by assurances of anonymity.

My position of trust in County Dublin VEC enabled me to investigate widely both learner and staff experiences and the range of education provision for people with

mental health problems. Although I have explored and made reference to some initiatives by other providers, the study is limited in the main to the situation in County Dublin VEC and so cannot claim to be representative of provision and experience across the country. However, the study's findings about learner experiences and its investigation of equality issues with regard to progression should be relevant and of interest to other providers of adult and further education.

### **3.6 Fieldwork**

The core research activity for this study was individual semi-structured interviews with people with mental health difficulties who were currently attending or had attended VEC adult education programmes. These interviews took place between February 2008 and June 2009. The most significant sub-group consisted of seven people who had attended VTOS-funded programmes. A further two participants were attending Senior Traveller Training Centres, one was attending an Adult Literacy class and two were engaged in HSE-funded training programmes. Interviews were recorded and later transcribed in all cases save two where the participants (both members of the Traveller community) did not feel comfortable being recorded. Following the initial interview(s) I arranged to meet each participant again. At the second meeting we discussed some points arising from the first interview and explored my tentative conclusions/interpretations. In each case I also had some questions or issues to follow up, clarify or develop. In addition, I followed up two early participants by meeting them again a year later.

The initial focus of the study was on VTOS-funded learners, because of their more substantial engagement with the education programme in terms of time (twenty hours per week for two years) than adult learners in other VEC programmes. The rationale was that they should thereby have a more rounded experience of the education setting, which might enable them to critique the experience in more depth than participants in programmes with less time-commitment.

I considered various approaches to identifying and engaging with participants. One possible avenue was that of accessing participants through course co-ordinators. Another possibility was to visit classes to explain the research project and invite people to contact me if they were eligible and would like to take part. A third method

considered was that of distributing (or asking co-ordinators to distribute) fliers asking people who would be interested to make contact.

Accessing participants through co-ordinators means meeting only with students who have disclosed mental health problems and not with others who may have such problems but have chosen not to disclose them to teaching staff. However, the experiences of these participants and their implications for matters such as enrolment policy, policy on information disclosure and confidentiality and general attitudes and support should be relevant also to students who have chosen not to disclose their history. Furthermore, if a person has not disclosed their difficulty in the centre/college, they are not likely to make a phone call to disclose it to a researcher who they may see as associated with the VEC. This last point was confirmed by the very small response to notices circulated on my behalf by Schizophrenia Ireland and EVE Ltd., as described later in this chapter.

As a result of these considerations, most participants were accessed through their course co-ordinator. The criteria given to co-ordinators for possible participants were that a student was in receipt of disability payment and had disclosed to the co-ordinator that this had been awarded on mental health grounds. In most of the VTOS classes there were some students who were in receipt of disability payments. In many of these cases, the co-ordinator did not know what the disability or illness was, but in several classes one or two students had declared a mental health problem, or in a very few cases had been referred by a mental health agency. Aiming to interview one student from each of the centres which had possible participants, I requested the co-ordinator to ask the student in question if they would be willing to meet me, and supplied the co-ordinator with a copy of my 'Information for Participants' to give to the student (see appendix 1, p.142). If the student agreed, I made contact with them, in most cases on their mobile phone, and arranged an appointment for interview, usually in their education centre.

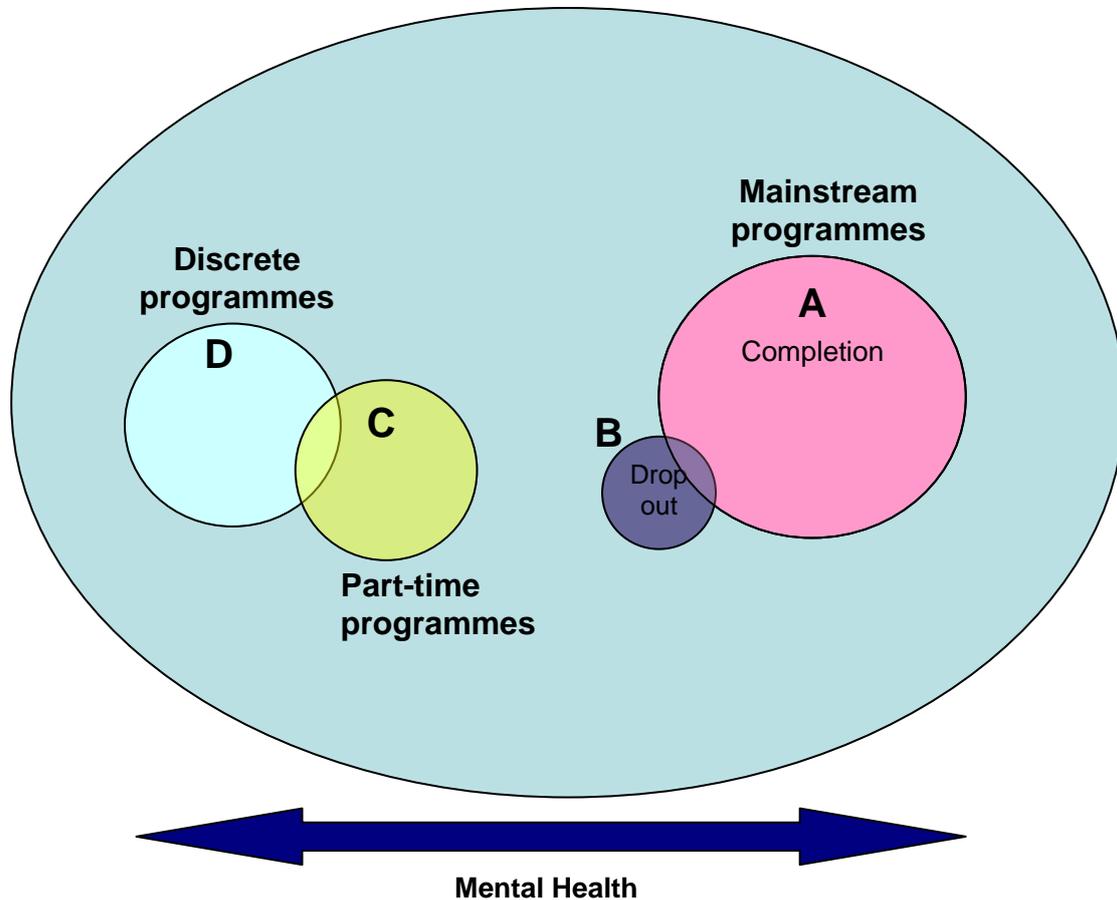
In the course of fieldwork, many of my assumptions in relation to the parameters for participation in the study had to be questioned and reviewed. In initial plans for the study I used the term 'mental health service user', as short-hand for defining participants. However, in accessing participants, I found that where co-ordinators

knew a student had a mental health problem, they often did not know the nature or history of the problem. They also did not know whether or to what extent the student had engaged with psychiatric services. Therefore the term ‘mental health service user’ became somewhat redundant, as it would have been inappropriate and in fact impossible to screen participants on this basis. In the event, it turned out that half of the participants in the study had been mental health service users. The others had been treated and recommended for disability payment on mental health grounds by their GPs, so had not engaged with the mental health services, except in being assessed by a psychiatrist on behalf of the Department of Social and Family Affairs subsequent to the GP’s recommendation. (This does not apply to the two participants from the Traveller community who by virtue of attending Senior Traveller Training Centres were in receipt of a weekly allowance regardless of health status).

Through interviews with a number of VTOS participants, it became evident that they were experiencing adult education and its benefits very positively and all spoke highly of the support received from co-ordinators and tutors. As the study progressed, I became aware that limiting the study to VTOS participants also limited it to those who were well enough to take part in a full-time education programme. Such learners are only part of the population of mental health service users who could benefit from educational opportunities. I increasingly began to wonder about the ‘other’ people – people who had started on return to education programmes and dropped out without completing them; people who had not had the confidence to apply in the first place or who had applied but been put off by some aspect of the enrolment process; and then, people who were taking part in discrete/targeted programmes without encouragement or support to progress to mainstream. I became more aware of the crucial importance of part-time education opportunities for people whose mental health problems precluded them from commitment to a full-time course.

The situation is represented by the diagram below. The intersecting circles on the right denote the participants who take part in mainstream VEC programmes – one circle (A) representing those who participated with satisfaction, and the other circle (B) those who left the programmes without completing them. Circle C represents participants in part-time VEC programmes such as Adult Literacy, Community Education or BTEI programmes. Circle D represents discrete programmes targeted

specifically at people with mental health difficulties. The ‘continuum of mental health’ underneath indicates that those participating in mainstream provision are at a better place in terms of mental well-being than those in dedicated provision, who in general are experiencing greater mental distress.



Broadening the field of study through meeting people who had left programmes early with less than satisfactory experiences (group B) was the next step, but proved to be quite a challenge. Through a meeting with a focus group in a FÁS-funded vocational training programme for mental health service users, a young woman who had started a VTOS programme five years ago and left after three months heard about my research. She was happy to take part in interviews, which proved to be illuminating as to some of the policy issues.

I tried other avenues for finding more such participants, with limited success. Both Schizophrenia Ireland (now Shine) and EVE Ltd (a HSE provider of training programmes for people with mental health difficulties) agreed to circulate a notice from me inviting people to make contact in order to take part in the research (see

appendix 3, p.144). Each of these notices yielded one reply. Neither of these respondents, though with interesting things to say about their experiences of education, fitted Category B, in that they had not attended VEC programmes but had taken part only in dedicated HSE-provided programmes. Other potential leads included clients from two different Probation Service education projects who had accessed VEC programmes and dropped out. Co-ordinators tried to get in touch with them to invite participation but in both cases the clients could not be located. Members of Category B remained elusive.

Through visiting some HSE-funded training centres (Category D) where some classes were being provided by VEC-funded tutors, I found that a small number of people from these centres were attending part-time VEC courses in mainstream settings, hence the slight intersection between circles C and D. Efforts to interview some of these learners encountered many difficulties, which are described and discussed in the next section of this chapter.

Fieldwork included many other research activities in addition to interviews with individual participants. Focus group interviews were carried out with four groups of people attending HSE/FÁS-run rehabilitation/vocational training centres for mental health service users. These discussions were not recorded, but notes were taken by myself, or in one case by a colleague who accompanied me. In the course of my work in adult and further education, I had the opportunity to discuss with tutors, co-ordinators, managers and many other VEC education staff their experiences, attitudes and reflections on learners with mental health difficulties in many conversations, interviews, meetings, training sessions and focus groups. Fieldwork also included meetings and interviews with a number of individual HSE mental health service personnel. Investigation of good practice included meetings with Disability/Access Officers from City of Dublin and Dun Laoghaire VECs, the Student Welfare Officer and the Mental Health and Inclusion Project Co-ordinator from Liberties College, and visits to Metropolitan College in Belfast and Southwark College of Further Education in London.

### **3.7 Difficulties in accessing participants**

Accessing participants for this study posed many challenges, with the final number of participants representing about one-third of the number of people with whom contact was initiated or explored. Learners with mental health difficulties are a hard-to-reach group for many reasons.

First of all, there is no doubt that many students with mental health problems do not disclose their difficulties to education staff and were therefore inaccessible to this study. Of the sixteen VTOS co-ordinators who were contacted and asked if there were learners who had declared mental health problems in their group, four did not know of any such student. This lack of visibility occurred in schools and colleges of further education more frequently than in adult education centres. In some cases, a student was in receipt of disability payment, which the co-ordinator suspected might be on mental health grounds, but the nature of the disability had not been disclosed.

While learners who had disclosed mental health problems could be invited to take part in the study, they were nevertheless hard to engage, with many barriers to their participation. Several possible participants who were asked by their course co-ordinator if they would like to take part in the study refused. In some cases this was due to their finding the idea of taking part in an interview intimidating, in spite of offers on my part for them to be accompanied at the interview by a friend or advocate. Other possible participants refused because they were not feeling well or were going through a bad patch at the time. A few people who said they would take part and would make contact with me never followed up on that. Three others had to cancel interview appointments (in one case the second interview, and in two cases the first interview) because they had been hospitalised. (One of these three interviews did take place at a rescheduled later date). Limited success in connecting with participants through the probation services and through Schizophrenia Ireland and EVE Ltd has been described above.

Last but not least in the list of barriers was the issue of mental health staff acting as gatekeepers preventing access to possible participants. The co-ordinator of a National Learning Network (HSE-funded) day centre for people with long-term mental health problems, where the VEC funds the teaching of a drama class once a week, told me

that one of the participants was attending a local VEC literacy class once a week and was, according to the centre co-ordinator, very positive about the experience. He agreed to meet me, with the co-ordinator present, for interview. However, his psychiatrist vetoed the interview, feeling it would be too stressful for him. In order to prevent such hitches with arranging other interviews, I then applied formally to the regional HSE mental health service for approval to interview participants. A psychologist contacted me to convey the information that I did not have approval, as these people would be unable to participate in interviews due to “cognitive impairment as a result of serious chronic mental illness” and medication, and their participation “would skew your results”. This experience raises the issue of the role of psychologists and psychiatrists as powerful gatekeepers who are often part of the wall of silence that surrounds those with mental health problems. Although their intervention was presented, and possibly perceived, by staff as protecting vulnerable people, it was an example of silencing the voice of those people, one of whom at least had indicated his willingness to speak. People who were capable of participating in a class were viewed as incapable of having any opinion on it. The incident illustrates the validity of what Pilgrim and Rogers have written: “Psychiatric patients [are viewed as] continually irrational and so incapable of giving a valid view... ‘Schizophrenics’ are a particular group thought inherently incapable of giving genuine informed consent (1999, p.193).

All in all, these experiences illustrate the difficulties inherent in this study’s aim of countering the invisibility of a marginalised group. The difficulties encountered illustrate the influence of lack of confidence and internalisation of stigma (in the refusal of some learners to meet and talk to a stranger about their experience); marginalisation and social exclusion (in the ‘disappearance’ of the probation service learners); and the power of cultural imperialism (in the blocking of participation and the assumption by some mental health service staff of service users’ incompetence to participate).

In spite of these difficulties, twelve learners each took part in one or more semi-structured interviews, findings from which are summarised and discussed in the next chapter.

### 3.10 Summary

The key features in the methodology of this study are its bases in a transformative paradigm and in a constructivist view of human experience. A participatory approach was central in order to act counter to traditions of discounting what people with mental health difficulties have to say. The methodology has also been influenced by the reflexivity of narrative inquiry and by feminist approaches to issues of equality and power in interviewing.

Despite many difficulties and barriers encountered in the process of accessing participants, the central fieldwork consisted of semi-structured individual interviews with learners, many of whom took part in a number of interviews. Fieldwork also included focus group discussions with mental health service users, interviews and meetings with education and mental health service staff and visits to sites of good practice.

### 3.11 Tables summarising fieldwork

#### Individual Participants

Name (pseudonym)	Programme	Interviews
1.Karen	VTOS	2 interviews 2008, 1 in 2009
2.Frank	VTOS	2 interviews 2008, 1 in 2009
3.Ultan	VTOS	2 interviews 2008
4.Nora	VTOS	2 interviews 2008
5.Denise	VTOS	2 interviews 2008/9
6.Irene	Ex-VTOS	2 interviews 2009
7.Lisa	Ex- VTOS	3 interviews 2008/9
8.Bernadette	Traveller Training Centre	4 interviews 2008/09
9.Hazel	HSE training centre	1 interview
10.Sean	Ex-PLC	1 interview
11.Louise	Adult Literacy Service	1 interview
12. Mary	Traveller Training Centre	1 interview
		Total number of interviews: 25

#### Focus groups

Centre	Number of focus group meetings
FAS-funded vocational training centre	4
HSE rehabilitation training centre	1
National Learning Network Training centre	1
BTEI class group Dun Laoghaire VEC	1

### Other meetings/interviews

Person/Role	No. of meetings
Liberties College Mental Health Inclusion Project Co-ordinator	1
Liberties College Student Welfare Officer	2
Belfast Metropolitan College Student Inclusion Officer	1
Eastern Vocational Enterprises Ltd CEO	3
National Learning Network Training Centre Co-ordinator	1
National Learning Network Training Centre Co-ordinator	1
Occupational Therapist, HSE	2
Mental Health Co-ordinator Southwark College	1
Psychiatrist, HSE	1
Clinical Psychologist, HSE	
St John of God Mental Health Services Director of Nursing	2
Disability Officer City of Dublin VEC	2
Disability Officer Dun Laoghaire VEC	1
Adult Literacy Officer County Dublin VEC	1
Adult Literacy Officer County Dublin VEC	1
Community Education Facilitator County Dublin VEC	1
County Co-ordinator County Dublin VEC	
Retired Adult Education Officer County Dublin VEC	1
Tutor Rehabilitation Training Centre	1
Development Officer Shine (Schizophrenia Ireland)	1
Manager, Clubhouse	1
Education Co-ordinator Probation Service	1
Education Co-ordinator Probation Service	1
Adult Education Service Network County Dublin VEC	2
Community Education Facilitators' Network County Dublin VEC	2
VTOS Co-ordinators' Network County Dublin VEC	2
Adult Education Officers' Network County Dublin VEC	1

### Conferences/Training

British Sociological Association, Medical Sociology Group, Symposium on Mental Health and Human Rights, Warwick University, 2007
Interpretative Phenomenological Analysis, one-day workshop, Aston University, 2008
Masterclasses in Narrative Inquiry, NUIM, Linden West and Kim Etherington, 2009
Creative Interviewing Training Workshop, DCU, Jennifer Mason, 2009

## CHAPTER FOUR

### MODELS OF EDUCATION PROVISION

This chapter first outlines the dissonance between policy and practice in **aspirationally** recovery-based mental health service provision and the resulting dearth of links between mental health and adult education services. Equality issues arising from the traditional VEC model of education provision for mental health service users are discussed. The second section describes some examples of models of good practice, both in Ireland and internationally.

#### **4.1 The landscape of education provision for Irish mental health service users**

The potential value of education for people with mental health problems is noted in a number of Irish policy documents. *A Vision for Change*, the document which outlines government policy for the mental health services, mentions adult education: “The flexible provision of adult education programmes can help address the educational needs of adults with mental health problems, especially for those who have dropped out of education early. Practical support to overcome barriers to education may be required, such as help with enrolment and travel expenses. Mentoring has also been found to be helpful” (2006, p.37). This represents a limited view of the potential benefits of educational participation. “Addressing educational needs”, the main aim of adult education, is inextricably bound up with many other potential benefits to adults with mental health problems. Participation in education can make a significant contribution to a person’s mental health and is one of the most effective ways of tackling social exclusion and marginalisation.

The National Economic and Social Forum in its report on Mental Health and Social Inclusion demonstrates greater appreciation of the potential role of education in recovery: “Access to education is central to developing positive mental health and support for those with experience of mental ill-health. One strategy is that all learning institutions should have practical and user-friendly mental health policies, along with a holistic approach towards mental health. In addition, staff in these institutions should receive training and education to raise awareness about the needs of those with

mental health problems, and confidence in working with this group” (NESF, 2007, p.67)

The aspirations expressed in both of these documents are a long way from realisation in adult education. This is largely due to lack of development of links between mental health services and education at both national and local level. At local level, failure to staff fully the proposed community mental health teams militates against proactive liaison with adult education services. At national level, “one of the central barriers to social inclusion for those with mental ill-health is a lack of responsibility by official bodies and agencies for non-health outcomes. To support recovery, responses for further social inclusion must include broader social and vocational aspects, not just health services” (NESF, 2007, p.50). There may have been some shift in thinking from a medical model towards a social model of mental health, but this has not translated into the development of integrated services with a holistic approach to promoting social inclusion. “Ireland’s mental health services have been exposed to the recovery model only in very recent years and for the most part have not yet taken on the challenge of incorporating the recovery philosophy into the organisation and delivery of services” (Mental Health Commission, 2005, p.33).

Just as the mental health services, while moving physically from long-stay hospital care to community-based provision, are slow to adopt the change of culture needed to broaden treatment and supports beyond medical treatment, so VECs still perceive their role in education for people with mental health problems to be, for the most part, the provision of classes in segregated mental health settings. Such classes vary in their level of integration with the rest of the education or training programme in each centre. Their quality seems to range from being a comfortable arrangement which suits centre administration in providing hours when trainees are occupied at no cost to the centre, to being a highly meaningful and stimulating learning experience for participants. With cutbacks in funding for Community Education and hours of co-operation, these classes will be drastically reduced from 2009/10. This crisis could be an opportunity in pushing mental health and education services to look creatively at other forms of education provision which might encourage integration and progression of people with mental health difficulties rather than reinforcing segregation.

The provision of discrete or separate classes/programmes for people with mental health problems as opposed to their integration into mainstream programmes raises many issues with regard to equality, inclusion and progression. There is no doubt that education programmes specifically for people with mental health problems may be the only type of provision in which some people will be able or willing to participate and that it may be of crucial importance in their lives. Participants in focus groups in mental health service training programmes were unanimous in their appreciation of the benefits and support they got from being in such a setting. They made comments such as “People understand you here, they’ve been through the same thing”. Most participants in the part-time programme for mental health service users described on pp. 111-2 said that they definitely would not have engaged in education if it entailed joining a mainstream class where they might “be afraid to say something to the person next to you – they might pick it up the wrong way”. Wertheimer writes that “for many learners with mental health difficulties, one of the most important aspects of discrete provision is the opportunity to be part of a group of people who have much in common” (1997, p.39).

There were some people in each discussion group who saw a mainstream course or employment as their goal, but many if not most of the people I met in these groups did not envisage themselves moving on to participation in open work or education settings. While targeted programmes can be a stepping stone from a mental health service or hospital setting for those who do not feel ready or able to join a mainstream class group, there is a danger of people becoming ‘stuck’ in such programmes through assumptions of their own or of others that they are incapable of progressing. “A narrow view of what service users are capable of can restrict their potential” (NESF, 2007, p.50). Progressing to mainstream education is a realistic aspiration for some, but they will need encouragement, information and support in order to achieve this goal.

There are equality issues with regard to segregation of marginalised groups..... While it is valid to recognise the necessity in certain instances to design and implement programmes focusing on particular groups of people for specific reasons .... specific attention needs to be paid to ensuring progression from such entry level programmes to programmes offering higher levels of qualifications and skills. Failure to do this will result in a limited contribution to addressing the

labour market inequality experienced by particular groups of people, notably members of the Traveller community, people with disabilities, and older people.  
(Ronayne, 2005, p.3)

These equality issues are particularly relevant to people with mental health problems in view of the long history of segregation and silencing of this group. There is a danger that people in segregated settings may develop what some call a “mental patient culture” of dependency and stigmatisation. “This isolation has helped develop a subculture in which many people with psychiatric disabilities accept themselves as part of a marginalized group of second-class citizens. People in this situation tend to think of themselves as ‘mental patients’, with all the emotional baggage that implies, rather than as citizens with psychiatric disabilities” (Penney and Bassman, 2007, p.6). This is an example of “symbolic violence”, where a dominated group take their position to be fair, because they assimilate the hegemonic viewpoints, thoughts and perceptions of the dominant group. “Symbolic violence is the violence which extorts submission which is not perceived as such, based on ‘collective expectations’ or socially inculcated beliefs” (Bourdieu, 1994, p.103). Bourdieu sees symbolic violence as being in some senses much more powerful than physical violence in that it imposes and supports the legitimacy of the social order.

People at different places on the mental health continuum need different levels of challenge and support. “You wouldn’t be ready for [a mainstream course] when you’ve just been diagnosed or when you’re coming out of hospital. People said to me at the time you should get a job or do a course but no way would I have been ready for it – I’d have been missing so much it would have been overwhelming”, said a participant in this study who subsequently completed successfully a mainstream programme in an adult education centre.

Most people in dedicated training centres or health service accommodation would not have the desire or the capacity to move directly on to a full-time education programme, yet some could benefit a great deal from attending a part-time class for a few hours per week with a mainstream group. This is an important equality issue because of the potential of participation in adult education to counter the marginalisation and isolation of this group. However, there seem to be few instances of organisation of access to public service education for mental health service users.

This is partly due to shortages of HSE mental health staff and the understaffing of community mental health teams. This state of affairs in itself reflects the domination of the mental health services by a medical model of provision. “In Ireland, there is no over-arching agency responsible for ensuring the full implementation of recommendations from *A Vision for Change* that fall outside the domain of health” (NESF, 2007, p.50). Frequent calls are made for the appointment of a Director of Mental Health Services, one of whose roles would be to promote linking and integration with other government departments and services (Mental Health Commission, 2008; Amnesty Ireland, 2009; Irish Mental Health Coalition, 2009).

Progress in partnership and integration would reflect practice in New Zealand, whose mental health services have been based on a recovery-centred ‘blueprint’ since the 1990s, and are “a wellspring of ideas and guidance on recovery-based practice” (Roberts and Wolfson, 2004, p.37). The New Zealand *Blueprint for Mental Health Services: How things should be* highlights the importance of links between mental health and education services:

Provision of education and employment services is not the responsibility of the health sector. However, support to access and use these services is essential to achieving better health outcomes and recovery, and leads directly to reduced levels of illness and disability. Health services need to ensure people affected by mental illness have access to employment and education services [and should] facilitate collaboration between different sectors to ensure these needs are being met at both national policy and local service levels.

(New Zealand Mental Health Commission, 1998, p.38)

Although the deficits in Irish mental health services are outside the control of educational bodies, they do not preclude the development of initiatives on the part of adult education services to promote inclusion and progression for learners with mental health difficulties. The initiation of links with mental health services to provide educational opportunities as bridges to mainstream adult education for mental health service users should be part of the VECs’ remit of providing inclusive education and promoting equality of opportunity. The development and implementation of policies for support of learners who do access adult education is also within VEC control.

## **4.2 Examples of good practice**

In the course of this study, I investigated some sites of good practice in inclusion and support of learners with mental health difficulties. In Ireland, a mental health inclusion project in a college of further education and a VEC outreach project in collaboration with mental health services were explored. I also visited a college of further education in Northern Ireland whose support and inclusion policies are highly regarded and a college in the UK with a proactive outreach policy. Finally, I discuss the idea of Supported Education.

Policies and practices which have been successful in other countries and education systems would have to be adapted in order to work in the Irish adult education setting, apart altogether from the obvious question of resources or lack thereof. However, it is worth looking at these initiatives and reflecting on how they could be adapted to a VEC setting. They also give food for thought as to the need for more resources to promote equality in educational participation for people with mental health difficulties.

### ***4.2.1 Development of inclusive policies within a College of Further Education***

The Mental Health Inclusion project, carried out in Liberties College 2004-2006, was run in collaboration with Schizophrenia Ireland (now known as Shine) and funded under the Education Equality Initiative Phase 2. It involved the participation of staff in training and in policy development, along with interviews with students with mental health difficulties who were attending the college. The Project Co-ordinator emphasised the influence of staff training and involvement in policy development in spearheading inclusion of all marginalised groups: “Good practice in relation to students with mental health problems is simply good adult education practice”.

The Student Welfare Officer who now deals with student support services sees several lasting effects of the project in the college. Teachers’ attitudes to the students with mental health difficulties have become more positive, with a diminution of fear and greater accommodation to individual student needs. The role of Student Welfare Officer has been developed to include management of a learning support team of three teachers, each of whom has some learning support hours on his/her timetable. Inclusion and support services are presented as part of general services, such as

getting a library card or student card. The services are highlighted in the college handbook and at induction, where each class does a workshop with a member of the learning support team, who clarifies what the service can and cannot do for students. The college has improved its policy for dealing with problem situations, with development of a positive ('what can we do?' and 'what can the student do?') rather than a disciplinary attitude. Guidelines have been developed for teachers dealing with a difficult or conflict situation: to bring the matter to the attention of head of department or principal; to deal with incidents immediately and supportively; and to give students the option of bringing a supportive friend/partner/family member in to discussion. The importance of carrying out training and policy development with the whole staff, including ancillary and administrative staff, was emphasised, as well as the necessity for ongoing development rather than a one-off training session.

#### ***4.2.2 An outreach project in collaboration with mental health services***

Dun Laoghaire VEC has been running a successful part-time BTEI-funded programme in liaison with St John of God mental health services for the past five years. The St John of God Director of Nursing Services links with the VEC Access Programme Coordinator and Guidance Officer in planning and publicising the programme. St John of God services advertise the programme in day centres, out-patients' department and through occupational therapists and social workers, while the VEC Access Programme Coordinator distributes information to the centres. The course takes place one evening per week in a College of Further Education, with timing and subject areas of the classes arranged in consultation with the group.

A group of participants with whom I had a discussion reported gains in confidence and valued "having a chance to catch up on what you missed out on", especially computer skills. They report the link person in St John of God services as vital in encouraging them to enrol on the course, and the approachability of the guidance counsellor and the programme coordinator, both of whom they met at initial interview, as crucial in supporting them if they have difficulties. Participants value the fact that learners can easily return to the course after a period of absence due to being unwell. They report very encouraging tutors who are able to teach effectively a group at varied levels of ability and attainment. Although participants liked the fact that the course was located in a college rather than a mental health service setting, which

means “you can say what you’re doing”, most were dubious, and some totally negative, about the idea of joining a mainstream class. For them, being in a class of mental health service users “makes it easier to focus on what you’re learning rather than worry about your illness or what people will think of you”. Some, however, did view the course as a possible stepping stone to mainstream work or education opportunities.

I met this group in October, when most had recently started the course. It is likely that after some months of participation more of the group would gain the confidence to aspire to mainstream education or employment, a progression which the course co-ordinator reports has been made by a number of participants over the five years the programme has been running. The social and personal benefits reported by both mental health service and education staff and by participants themselves may be sufficient in themselves for many learners. However, progression opportunities are vital, even if availed of by a minority of participants. The programme’s record illustrates the importance of stepping stones which enable mental health service users to progress from segregated classes in the mental health services through discrete provision in mainstream education settings towards integration into mainstream education provision or employment.

### ***4.2.3 Inclusive support policies in a Northern Ireland College of Further Education***

A visit to Metropolitan College of Further Education in Belfast, the largest FE college in Northern Ireland, with 42,000 students, and considered a particularly good model of inclusion, was illuminating. The college developed their inclusion policies during the 1990s through involvement in a number of European projects. Their Centre for Inclusive Learning-Development (CIL-D) now has £0.5m p.a. funding for disability support.

The college’s support and inclusion services are emphasised in college literature and promotional material, from inclusion in initial publicity material and brochures to a stand for the CIL-D at college open day. Posters, fliers and bookmarks advertise the service. On the initial application/inquiry form, there is a section headed Learning Support, which asks the student ‘Do you require additional learning support because

of a Disability and/or Learning Difficulty?’ Students who answer yes are contacted by the CIL-D and invited to an appointment for interview, at which the student’s needs are assessed in discussion with her/him. There is emphasis on confidentiality – information cannot be passed on without the student’s permission. However, it is pointed out that there are advantages for students in tutors’ awareness of issues such as a student being bothered by noise or having their concentration affected by medication. In such cases the tutor might be able to help by giving class notes or information in advance. If a tutor suspects/finds that a student has a mental health problem but has not declared it, the tutor can encourage the student to refer her/himself for support. The CIL-D contacts students twice a year to ask how supports are working, and at the end of the year sends a reminder to look for supports again next year. The office will also advise re accessing support in higher education.

There is a high percentage of students with mental health problems in access /return to learning courses and these students find mentoring particularly supportive. Students availing of mentoring meet once a week with a mentor (part-time employee of the college) for support in study skills, organisation, time management, etc. The college also has counselling and guidance services. All staff do a two-hour training session on equality legislation and the college’s disability policy. This is considered sufficient for most staff. Training for dealing with difficult behaviour or conflict situations would be considered a general need, not specific to mental health problems. The centre provides information for staff in the form of guidelines and documentation on various disabilities.

#### ***4.2.4 A UK outreach initiative***

I had made contact with Southwark College in London after reading about their outreach practice and had the good fortune that their open evening and display of student work were taking place on the day of my arrival on a visit to London. This enabled me to meet the Department Head, the Mental Health Co-ordinator and several students.

The college programme, *Choices*, for people who are mental health service users, was an outcome of pottery classes which were taught on behalf of the college in the local psychiatric hospital. The idea of people moving on to classes in the college rather than

in a mental health setting was developed. The college has a full-time Mental Health Co-ordinator who recruits for the *Choices* programme by giving talks in the local psychiatric in-patient units and other mental health service centres. The programme has four modules, Ceramics, IT, Fine Art and Catering, timetabled in such a way that students can attend all of them if they want to. Each subject has an hour of tutorial time run by the Mental Health Co-ordinator, who continues to mentor ex-*Choices* students who progress to mainstream courses in the college. Three of the four ex-*Choices* students who did a mainstream course in Fine Art last year passed with distinction in a course which was perceived as so difficult by students, that out of fourteen students, seven had left by the end of the year, while all ex-*Choices* students completed the course.

I met several students who spoke about their experience of *Choices*. A young woman who is going on into a full-time degree-level Fine Art course had been taught ceramics by the *Choices* tutor in psychiatric hospital, and decided to enrol at *Choices* once discharged. She built up a portfolio and progressed to a mainstream Fine Art course, which she passed with distinction. Another man spoke of how he had never considered himself to be any good at anything in particular or to have any interest in art, until joining the *Choices* programme after being in psychiatric hospital. The students all spoke of the great encouragement they got from staff in the college – affirming their work, understanding if they were anxious or needed extra time.

#### **4.2.5 Supported Education**

Supported Education for students with mental health difficulties is a relatively simple idea aimed at providing emotional and practical support, with the “fundamental purpose of helping people with severe psychiatric disabilities secure their rightful roles in the world” (Soydan, 2004, p.228). The approach involves the provision of individualized, practical support, with mentoring to enable students to set personal learning goals and to learn the skills and access the supports necessary to complete successfully a class, course, degree, or training programme. “Using the metaphor of physical disability..... students with psychiatric disabilities may require “emotional ramps” instead of concrete ones” (Soydan, 2004, p.232).

Supported Education, originating in the USA in the 1990s, was initially successful in helping people complete college courses and minimise the devastating effects of serious mental health problems which had disrupted their education in their late teens or early twenties. Since then, it has also been used with adult mental health service users in community-based, Clubhouse-based, and even some hospital settings. Numerous research studies have shown successful outcomes for Supported Education in the form of course completion, obtaining meaningful employment and improvement in self-confidence and quality of life (Mowbray *et al*, 1999; Spaniol *et al*, 2002; Unger *et al*, 2000).

A study of a Supported Education initiative in a UK adult education setting has been reported by Isinwater *et al*. The College Link Programme, a part-time course for people with long-term mental health problems in a socio-economically deprived area of London, was set up through the collaboration of a further education college and a nearby psychiatric hospital. The programme was constructed in a framework of rehabilitation for those who would not be able to manage or attend mainstream (unsupported) education. A psychology graduate, under the supervision of a psychologist, acted as a linkworker offering support to students and staff. The study found a net diminution of £8,000 per student in government spending through greatly diminished rates of day hospital and in-patient hospital care for the participants, as compared to the year prior to their participation in the programme. “This represents a considerable saving in terms of funds—not to mention the educational, vocational, psychological and emotional short and longer-term benefits of education” (Isinwater *et al*, 2002, p.49).

### **4.3 Summary**

A recovery model is espoused in national mental health policy documents but there has been little development of the integration between mental health services and other government departments which would be necessary to support a genuine recovery approach. As a result of these missing links, educational opportunities for Irish mental health service users consist mainly of classes in segregated mental health service settings, with little development of bridges and progression opportunities to mainstream adult and further education.

Some initiatives which provide examples of “positive action” to promote equality of opportunity (Equal Status Act, 2000, 14 b) have been described in this chapter. Staff development to design and implement inclusion policies in Liberties College, outreach initiatives linking with mental health services in Dun Laoghaire VEC and Southwark College, and provision of supports such as mentoring and Supported Education all promote equality of opportunity for people with mental health difficulties and offer them greater chances of inclusion and recovery. The provision of such supported opportunities has benefits for individuals in providing stepping stones towards recovery and has benefits for society in promoting inclusion and countering the widespread marginalisation of people with mental health difficulties. These opportunities and supports are just as important as the intrapersonal qualities of motivation, hope and agency which people need in their recovery journey. A member of HSE staff who has been involved in developing the recovery approach describes the importance of educational opportunities: “The chance to try something can lead to the development of mastery and confidence, and the provision of support in turn can enable a person to move forward and access their own innate supports” and to move away from marginalisation and towards social integration and inclusion.

## **CHAPTER FIVE**

### **EXPERIENCES OF LEARNERS**

#### **Introduction**

The core findings of the study, which are reported in this chapter, emerged from interviews with individual learners, particularly with seven people who were attending or had attended VTOS-funded programmes. My original intention had been to interview a greater number of VTOS participants, but in the course of the study I decided to limit the number. This was partly to allow time to interview participants in other types of education provision as I became more aware of the importance of the availability of a variety of methods of accessing education for people at different stages on the mental health continuum. More importantly, however, a smaller number of participants allowed for the voices of individual learners to come through more clearly in exposition and analysis of the findings. One of the key features of my research methodology was a participatory approach. I considered it essential that the study should act counter to the cultural imperialism of rendering people with mental health difficulties invisible through regarding them as lacking in ‘insight’ and in valid opinions. This chapter is written in a narrative style which aims to facilitate the emergence of the voice of each of the seven core participants.

The learners on VTOS-funded programmes, referred to throughout by pseudonyms, included two male (named as Frank and Ultan) and five female learners (Denise, Jane, Karen, Lisa and Nora). Frank was the only participant who had previously completed second-level education. All took part in programmes at Level 5 on the National Qualifications Framework, with the exception of Jane, who had completed a level 4 programme. Reference is also made to the experience of the five other individual participants, two of whom were attending Senior Traveller Training Centres, one the Adult Literacy Service and two people attending mental health service training centres.

Throughout this chapter, ‘participant’ refers to an individual learner who took part in one or more individual interviews. ‘Focus-group member’ refers to people who were

attending HSE- or FÁS-run rehabilitation or vocational training programmes for mental health service users and who took part in focus group discussions.

### **5.1 Application and enrolment**

VTOS participants had applied for the programmes on their own initiative and without support from the mental health services. They made the necessary moves through their own agency and choice. The decision to apply for a mainstream return to education programme had been taken with varying degrees of determination and intent. For some of the participants, readiness and opportunity seemed to combine almost by chance to trigger their application. For others, applying was part of a plan they had deliberately undertaken. What the participants had in common was that they were well enough and far enough on the path to recovery to make contact with the centre without support – something that would be too challenging for people with more serious mental health problems to undertake and which they themselves would not have been able for at an earlier and more distressed stage of their lives. They demonstrated self-efficacy, a psychological construct which is defined as “people’s belief in their capacities to mobilise personal resources to help them to exercise control over events in their life” (Corrigan *et al*, 2006, p. 879). The experiences of participants, described below, illustrate initiative and agency.

Karen<sup>1</sup>, after a marriage break-up and a nervous breakdown in her early thirties, had spent time in hospital and had been diagnosed with bipolar disorder. She had been unable to take care of her two small children for several months and could not return to her work in childcare. “I was just existing for a long, long time... it felt like the bottom had gone out of my world”. After some months, however, through a combination of the passing of time, medication, support groups, counselling and “keeping going because I thought there has to be something at the end of this”, Karen began to look outward again. “As I started to get a little bit better, I kind of knew I needed to do something, get out of the house, and kind of start my life over again and I thought, well, a course might be the way to go”. She had been talking to a friend about this possibility, when “I happened to be up in the post-office and they had a note about the [VEC] courses ... I was standing in the queue and I picked it up and I

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<sup>1</sup> Pseudonyms are used for all participants

kind of thought, it was like it was meant to be ... the kids' school is nearby, the hours would suit me. I'd be learning something, which wouldn't do me any harm.... and I thought well if I don't like it I don't have to stay."

Another participant, Nora, after leaving school early, worked happily in a sewing factory for fifteen years until after the birth of her first baby. Her withdrawal and depression – although not named as such initially – began around that time and lasted in a chronic fashion until recently. She describes herself as “just existing ... I was there in body but not in mind”. A naturally sociable and outgoing person, she cut herself off from people and described herself as “just numb, I felt nothing, I had no words, I had no meaning for me”. Anti-depressants prescribed by her GP didn't seem to help. When her second daughter started playschool, Nora found the experience traumatic and realised she “had to do something”. Around this time, when, as she says, she was “itching for something”, the VEC leaflet advertising VTOS-funded programmes was circulated. “I walked in the hall one day and the itch was there about to be scratched”.

Other participants took a more deliberate route back to education. Denise has experienced severe and recurrent mental health problems for the last ten years, has lost her job as a result and has been repeatedly hospitalised. Her GP had suggested “a little course or something like that” and then her partner gave her a gift of an aromatherapy course. “I thought no, no, I need to be doing something a bit more, you know, I thought ‘no I need a challenge. My mind needs a challenge’”. Having been awarded disability allowance, she was eligible for a VTOS-funded programme and found in a local newspaper that the local adult education service offered a Leaving Certificate programme including business subjects. “I thought ‘this is more me’”. When she applied the course was full, but then the coordinator contacted her to tell her a place had become available. “I'm not joking you, I felt like I had won the lotto. Oh my God, it was like someone had given me my dream job. I was absolutely over the moon”.

Karen, Nora and Denise, having been ‘out of commission’ for some time, were recovering and consciously or unconsciously looking for a means to pick up the pieces and “re-enter society” as Karen put it. In each case, participating in an

education programme was regarded by them as a means of furthering their recovery and re-engagement in society. They and other research participants had taken their own decision that they were 'ready'. They were able to undertake the challenge of taking part in a mainstream programme only as the next step on a journey they had already begun. They would have been unable to contemplate this undertaking while at their lowest ebb. Nora says "I was ready... I did this course because I felt a bit better towards myself".

The fact that courses were accessible locally and fitted in with their children's school hours was crucial. The courses for which all three applied were VTOS-funded and of about twenty hours duration per week so that the classes were mostly in the mornings. The courses all led to accreditation at level 5 on the National Qualifications Framework – in Karen and Nora's cases FETAC-accredited and in Denise's case Leaving Certificate.

The two male participants were at opposite ends of the spectrum from each other in terms of attitude to applying for their courses. Ultan went to great lengths and in a focused way to secure a place in a computer maintenance course in a VEC college. After an ECDL course, followed by a Saturday course in computer maintenance, he made enquiries as to how he could progress and, on hearing from his tutor about his current course, applied immediately, seeing it as an opportunity to advance his skills and employment prospects. In contrast, Frank's return to education had been somewhat reluctant. Because he had been known in his neighbourhood to have a talent for drawing, "everyone was pissing me off, like they were on my back all the time, would you not go to college." When he applied for the course, "I was more or less conniving, if I could get a grant I could just leg it then.... I gave myself a week."

## **5.2 Stigma and disclosure**

"Stigma is a term conveying a deep shameful mark or flaw related to being a member of a group that is devalued by the societal mainstream" (Hinshaw, 2007, p.xi). The World Health Organisation acknowledges that "stigmatization of people with mental disorders has persisted throughout history, manifested by stereotyping, fear, embarrassment, anger and rejection or avoidance" (2005, p.1).

Even though there may be greater public knowledge about mental health problems, they are still ranked at or near the bottom with respect to public acceptance of difference. “Stigma and discrimination are ..... [among] the greatest barriers to social inclusion. This is felt most acutely by people with mental health problems” (Expert Group on Mental Health policy, 2006, p.36). The Irish National Office for Suicide Prevention found that six out of ten people do not believe that people with mental health problems should “do important jobs such as doctor or nurse” (2007, p.5). The National Disability Authority reported in a survey on *Public Attitudes to Disability in the Republic of Ireland* that

Many results suggested elements of discomfort and stigma, particularly in relation to people with mental health difficulties. Thus people expressed reservations or negative attitudes towards living near people with mental health difficulties; a significant proportion denied the rights of people with mental health difficulties to fulfilment through relationships, parenting or sexuality; a large minority considered that people with mental health difficulties should not have the same employment opportunities as everyone else. In all cases, the figures in relation to people with physical, sensory or learning disabilities were very different.

(National Disability Authority, 2002, pp.62-63)

A large study carried out by Link *et al* in the US found that “stigma has important effects that remain even when people improve while participating in treatment programs .... and has a substantial and enduring effect on depressive symptoms” (1997, p.187). In reporting on a later study, Link writes that “stigma strongly influences the self-esteem of people who have mental illness... Although the existence of a connection between stigma and self-esteem may not be surprising... the magnitude of the association that we uncovered is startling and disturbing” (2001, p.1625). Corrigan, Watson and Barr explored this connection and found that “self-stigma is a multilevel process that begins with awareness of public stigma. Self-stigma begins when the person internalises the stigma and applies it to people with mental illness in general or to him or herself (self-concurrence)... People who endorse self-stigma are more likely to report diminished self-esteem” (2006, p.875).

The degree to which people ‘endorse self-stigma’ varies. Karen may have been able to manage her recovery in such an effective way because she does not seem to have internalised stigma to any great degree. “It’s not something that I’m ashamed of, the bi-polar thing. Because I kind of think well it’s...it just came on me sort of, and

there's nothing I can do about it, and ... I don't think of it as being something terrible". At the time of our first interview, Karen strongly advocated the benefits of disclosure: "It's always been very positive when I've said it to people. Life is easier, in every situation". It was an effective way of eliciting support when she needed it. "People just react differently to you, and not in a bad way". A year later, now working in a community employment scheme, she told me that "I tell much fewer people now. I don't want people to make allowances for me – I want to stand on my own two feet." Karen found disclosure an effective way of eliciting support when she needed it. Now it is important to her to be more independent.

Frank articulated feelings of stigma to a greater degree. At the time of his first interview for this study, he was, at the age of 40, half way through a one-year Art and Design course in a Further Education College. He was in his first year of sobriety after a chaotic life which, since the development of an alcohol addiction in his early teens, had been dominated by alcohol, with periods of time living rough, in prison and in hospital following numerous suicide attempts. Frank's ambivalence about taking on the course, as mentioned above (p.67), may have been at least partly connected with lack of confidence and some internalisation of stigma. "You didn't know whether you belonged there or not ....Coming in here it was a different environment - people who were clean - I really mean clean - and sober, looking for something else in life, looking forward..... If the same people in this college, ... if they had've been walking down the inner city say this time say two year ago, and I'd have been hanging around there... they wouldn't have had anything to do with me".

Bourdieu defines *habitus* as "ways of standing, speaking and walking and thereby of feeling and thinking ... dispositions [which], rather than regulate what one does, tell one who one is" (Bourdieu, 1998, p.81). "When *habitus* encounters a social world of which it is the product, it is like a fish in water: it does not feel the weight of the water and it takes the world about itself for granted" (Bourdieu and Wacquant, 1992, p.127). It could be said that Frank's *habitus* rendered him a 'fish out of water' in the college environment. Bourdieu also writes about the 'symbolic violence' which occurs when a person or group assimilates the negative view taken of them by others. This concept has much in common with that of internalised stigma, which Frank describes well:

“And once you reach that kind of level in life ... it kind of sticks to you ... You’re kind of different from...they’re all more upper class than you or something”.

The different degrees of self-stigma adopted by Frank and Karen illustrate the paradox that “personal reactions to the stigma of mental illness may result in significant loss in self-esteem for some, while others are energized by prejudice and express righteous anger. Added to this complexity is a third group: persons who neither lose self-esteem nor become righteously angry at stigma, instead seemingly ignoring the effects of public prejudice altogether” (Corrigan and Watson, 2006, p.35).

Some writers in the area of disability studies regard emphasis on the concept of ‘stigma’ as counterproductive. Oliver (1990) argues that Goffman’s (1963) work on stigma has led to placing focus on individual self-perception, rather than on widespread systematic exclusion from economic and social life. Chamberlin (1977) maintains that the concept of ‘stigma’ is itself stigmatising, implying that there is something wrong with the person, while the concept of ‘discrimination’ puts the onus where it belongs, on the individuals and groups that are practising it. Stigma and discrimination are in some ways complementary aspects of the same phenomenon. The fact that internalisation of stigma can facilitate discrimination is illustrated by the experience of Jane, another VTOS participant. Jane, who has schizophrenia, attended a college of further education about ten years ago and did the Junior Certificate there. When she returned to the college to join a Leaving Certificate class, the principal, referring to the fact that Jane was “on medication”, told her she could not continue in the college and called the guards to remove her from the premises. To my question as to how she felt, Jane replied “I couldn’t believe my luck”. She seems to regard this event as her bad luck rather than as unacceptable behaviour on the principal’s part. Not alone may a person who has internalised the stigma attached to their group not stand up for their rights when discriminated against, they may not feel any sense of entitlement to those rights.

A person with a history of mental health difficulties, whatever the degree of their internalisation of stigma, usually has to deal with challenges of disclosure and information management. Goffman, who defined stigma as “the situation of the

individual who is disqualified from full social acceptance” distinguished between discrediting stigma (obvious to others) and discreditable stigma (not obvious to others).

When [a person’s] differentness is not immediately apparent, and is not known beforehand ..., when in fact he is a discreditable, not a discredited, person... the issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where.....

(Goffman, 1963, p. 5)

This is still a very live issue for those who have experienced mental health problems. Nora, for example, is very conscious of information management:

It’s a catch 22 – it is an issue. It depends on who you tell....There are people who’d say ‘she’s a bit mad, keep away from her’..... It only takes one person to say something - if the right person says it to the right person you can be blacklisted ... There is a sort of stigma attached, so like I said there are certain people I tell - friends of mine.

Dinos *et al*, in a qualitative study with 46 participants, found that stigma was a pervasive and serious concern. They report that “concern about disclosure emerged as a major theme... Managing a discreditable identity that is not always apparent to others, such as mental illness, can be a powerful source of anxiety. Participants’ attempts to avoid disclosure resulted in stress, isolation and a sense of shame” (2004, p. 180). Link *et al* list secrecy (concealing history) and withdrawal (limiting interaction) as typical ways people with a history of mental health difficulties cope with the threat of rejection or stigma (1997, p.180). The Irish National Office for Suicide Prevention (2007, p.5) found that six in ten adults would not want others to know if they had a mental health problem.

Issues of stigma and disclosure are of crucial relevance for people with mental health problems when they are applying for courses or for employment. Study participants who took part in focus group discussions in HSE/FÁS-funded rehabilitation training programmes were almost unanimous in saying that they would definitely not disclose their history to potential employers. They were generally very aware of stigma issues. One man spoke of his experience of employers losing interest during interviews when a mental health problem was mentioned. He said that when people realise you have a

mental health problem “it’s like they put on rubber gloves to shake your hand”. There were more mixed views on disclosing to education providers, and some thought that they would consider doing so, seeing education as a less threatening environment. There was a perception among some participants that “education in its own right is a step” to recovery and that disclosure would elicit support. Others, however, would be influenced as to whether to disclose by the attitudes and support policies evident in publicity material and enrolment processes. A young woman in a rehabilitation programme recovering from a nervous breakdown who intends to go to art college at third level next year is certain that she will not disclose her history to the college. This is very understandable, as she hopes to leave this episode in her life behind and that it will not recur, which it may not. People with more longterm or recurrent problems, if they do consider educational progression, are more likely to seek support.

Most of the individual participants in this study were invited to take part on the basis of having disclosed a history of mental health difficulty to the course co-ordinator. They differed, however, in how, when and why they had disclosed their history. Karen had not been sure what she would say when applying for the VTOS programme, but when she met the course co-ordinator at interview, “she was very open and approachable... she said most people in their 30s don’t return to education unless there’s been a hiccough in their life ... I thought, well, that kind of covers me..... So it just seemed very easy to open up.” The co-ordinator’s approach normalised Karen’s experience and gave her confidence.

Frank also disclosed some of his history at the initial interview. In his case, it was partly a policy of enlightened self-interest. “I was afraid that if like they were to find it out later on, [they’d say] you should have told us this or whatever”. He feared that his history might preclude him from a place on the course, but, like Karen, found the attitude of the interviewers inclusive and encouraging. “I was just out straight with them; before you go any further I said I probably won’t get in anyway because I have... I said I’m only out of rehab and all of this. So I just put it all on the table - and then they said ah no ... that wouldn’t be a bother ... so then I had a quick joke with them all of a sudden.... And I just kind of felt more comfortable going here, so I did”.

The experiences Frank and Karen describe reflect Goffman's statement that "the central feature of the stigmatised individual's situation in life... is a question of what is often, if vaguely, called 'acceptance'" (1963, p.19). Frank and Karen were both very positive about the benefits of disclosure. "Once you say it, your life gets so much easier" (Karen). "I think they're great in here. Like they are very helpful, but ...they're not going to help you though if you don't tell them your situation. ...they're not fucking mind-readers. If you have problems ...you need to be able to tell them, explain to them, so they can help you ...they're not psychics" (Frank). Karen and Frank found, as did most of the other study participants, that disclosure of a mental health difficulty elicited supportive attitudes and behaviour from tutors and co-ordinators.

Trust and control of information are hugely important issues in disclosure. Both Karen and Frank disclosed their history fairly spontaneously in the context of an interview, not on an application form. Participants were very reluctant to write personal information about their difficulty on an application form. The interpersonal interaction and the attitudes conveyed by the interviewer(s) can create a level of trust and comfort that the impersonality of an application form never can. As another participant, Ultan, puts it: "It has been told [on the form] that yes I am on illness benefit or I am on disability benefit. I think that is enough for them to know. If you want them to know any more well then you will tell them". The importance of trust is well illustrated by Denise's experience. Nearing the end of her VTOS programme, she has applied, been interviewed for and offered a place in an Accounting Technician PLC in a college of further education. She did not disclose any of her mental health history to the college and asked her course co-ordinator not to mention it in her reference. "I'd have a fear that I might be discriminated against". On being asked why her attitude is so different from when she applied for her current course, she said it's because she had known the course co-ordinator and one of the teachers in the adult education centre from when she had done classes with the VEC before. She felt very comfortable with them and had no difficulty with telling the co-ordinator that she has a diagnosis of bipolar disorder. However, in a new setting where she knows nobody, she feels very differently about disclosure.

It is quite possible that when Denise settles into the college and feels more at ease there, she may choose to disclose her difficulties to some of the staff. Some of the study participants did not disclose any problems at enrolment stage but declared them later as they settled into the course and felt more comfortable and trusting of teaching staff. Frank describes this process: “Bit by bit, as I got to know the teachers, then I told them out straight about the rehab.... the reason why I was telling them as well was because... I’d be missing days, to go for blood tests, or to go for tablets....So, I had to let them know I wasn’t messing them about.” Karen says “Later in the year after Christmas.... I told one of the tutors that I was finding her course very hard going and that I suffered from depression. The tutor hadn’t realised I had that problem and was much more supportive from then on.” To my ensuing question “Would it have been a good idea for the co-ordinator to tell the tutor earlier?” Karen responded very definitely “No, I’d rather tell them myself”. At whatever stage participants had disclosed that they had a mental health difficulty, it was important to them that they were in control of dissemination of that information. “You need to be reassured .... that the information isn’t going to be passed on to anyone else even within the centre unless you want the other teachers to know - but you’d tell them yourself. ... Otherwise, I probably wouldn’t have given the information” (Karen).

Another participant, Lisa, who had started a VTOS programme six months after emerging from rehab, disclosed to the course co-ordinator that she had been in a treatment centre but not that she had a history of depression. “I brought it up and explained because she asked me why I wanted to do the course, so I gave her a very brief, 'I have just come out of the [addiction treatment centre] and feeling more positive. Want to make something of my life, you know.' Gave her a very kind of brief outline.... I think I'd have kept it [depression] to myself for fear that, oh well, they won't allow me onto the course”. Lisa dropped out of the course after four months, having experienced the co-ordinator as unsupportive when she began to become depressed and her attendance became erratic. At this stage, she still did not tell the co-ordinator about her depression. “I was trying to weigh up what I could and couldn't safely tell her. ...I didn't feel safe talking to her about it because I could see the look of panic on her face. For a start I could tell she did not know how to deal with it.....Even if I had said to her 'Look I suffer from depression as well ...!', she wouldn't have known what the hell to do with it. You know there wouldn't have been

much point in me saying it to her because she wasn't trained with it.” There is no way of knowing whether this is an unfair assumption on Lisa’s part and whether the co-ordinator might have been more supportive if Lisa had been more open about her difficulties. However, the fact remains that Lisa experienced the centre’s culture as unsupportive and this contributed to a negative outcome for her. She suggested as a remedy that staff should be “trained to some degree to spot problems before they get out of hand.”

### 5.3 “Part of society”

I really felt after ending up in hospital and everything that my life was over, that I ..... wasn’t able to cope, and this was kind of the end of the line for me, I was never going to work again.... and I had met so many people who’d never returned to work. And I kind of thought am I ever going to be able to get back on my feet and have a normal life?..... It was terrible. I thought I was never going to come out the other side. (Karen)

Karen’s fear of marginalisation was not without foundation. The National Economic and Social Forum Report on *Mental Health and Social Inclusion* notes that “those who experience enduring mental ill-health are among the most socially excluded in Irish society” (2007, p. 11). While people with long-term or recurring mental health problems in Ireland have an extraordinarily low rate of participation in the labour force, social exclusion means more than economic disadvantage and is not reducible to an insufficiency of income or the lack of employment. Social exclusion “variously encompasses unemployment.... inadequate income, the experience of discrimination ... de-motivation and a lack of access to adequate levels of social protection and services... and is increasingly being viewed as encompassing the effective loss of or the incapacity to claim and exercise social and political rights” (Ronayne, 2000, p.3). This is extremely relevant to mental health service users, with whom “consultations repeatedly reveal that, while one of their major goals is to reduce poverty, they also identify the desire for a role(s), for more friends and relationships, for less rejection by neighbours, employers and family and for more opportunities to be part of mainstream groups and communities” (Sayce, 2001, p.121). They do not want to be “on the social horizon of poverty, of incapacity for work, of inability to integrate with the group.... eject[ed], as into another world” (Foucault, 1961, p.59).

Young considers marginalisation, which she defines as “expulsion from useful participation in social life” as “perhaps the most dangerous form of oppression”.

Although groups which are marginalised are potentially subjected to severe material deprivation, this is not the extent of the harm caused by marginalisation... [Marginalisation] blocks the opportunity to exercise capacities in socially defined and recognized ways..... Today the exclusion of dependent persons from equal citizenship rights is only barely hidden beneath the surface. Because they depend on bureaucratic institutions for support or services, the old, the poor and the physically or mentally disabled are subject to patronizing, punitive, demeaning and arbitrary treatment by the policies and people associated with welfare bureaucracies.... Medical and social service professionals know what is good for those they serve, and the marginals and dependents do not have the right to know what is good for them.

(Young, 1990, p. 54)

Ronayne echoes this, in writing that “social exclusion is increasingly being viewed as encompassing the effective loss of or the incapacity to claim and exercise social and political rights..... There is a political dimension to social exclusion, particularly in the sense of the effective denial of access to decision-making fora and power” (2000, p.3).

After completing her VTOS programme, Karen obtained a Community Employment placement in the same centre where she had done the course. Finding herself bored, she was able, with the support of the centre, to switch to another CE scheme where she loves working with people with intellectual disabilities. “To be able to say I’m doing such and such a job and be proud of what I’m doing means a lot. You kind of feel you’re more acceptable”. Today, three years after she applied for the VTOS programme, with a Level 5 FETAC award, in a new relationship, working very happily and doing training funded by the CE scheme to gain a qualification in working with people with intellectual disabilities, Karen, who now feels “part of society” again, says “I wonder what would have happened to me if I hadn’t seen that leaflet? Would I be still at home in the house every day?” She would probably have engaged with another route to recovery, but the educational opportunity she took worked very well in supporting her recovery, rebuilding her confidence, building up her skills and bringing her back into mainstream life.

Participation in education is a significant route which fosters social inclusion for people with mental health difficulties. This is evident in the experiences of participants in this study. At one extreme, Louise, who lives in a high-support hostel for mental health service users, is learning to read in a VEC Adult Literacy Service evening class. The class is the only time she spends in a group of people who are not mental health service users, and the only evening of the week she doesn't spend in the hostel watching television. In Louise's case, education is not a means to qualifications, progression or employment. Her participation in the literacy class has value not just, in "the human resource/employability paradigm... in which the role of measures to combat educational disadvantage is to enhance individual employability, promote adaptability in the labour market and underpin economic competitiveness and growth" (Ronayne, 2000, p.6). For Louise, education brings the potential for personal development and broadening of horizons and for building her capacity for active citizenship and participation in society. It could also enhance communication with her family. Louise's son, now in his late teens, has been living with her sister for the past ten years and Louise sees him only every few weeks. The Adult Literacy Officer in the centre Louise attends pointed out how beneficial it would be to Louise and other students in her position to be able to communicate with their children by email or text messages.

Other participants, at a different point on the mental health continuum, were able to use and engage with education as a capital to facilitate their reintegration into wider society and possibly employment or further education. Education can be a more likely route to employment for people with mental health difficulties than for other people, allowing them to develop the stamina and interpersonal skills required for work in an environment that is more flexible and supportive than open employment.

Having done well in Leaving Certificate Business Studies, Maths and Accounting, Denise engaged in discussion with the guidance counsellor "about maybe doing a PLC, maybe in accounting technician". She later applied and obtained a place in a further education college where she plans to start an accounting technician course later this year. Frank is now on a degree-level animation course. He describes how the VTOS year was "the best possible foundation" for this. There, he learnt things like "what a portfolio holder was", managing assignments, etc. in a "homely" supportive

environment. He was also supported in applying and presenting a portfolio for entry to the degree course. These are examples of how accumulation of cultural capital enables people to progress and can perhaps enable a person with a history of mental health difficulties to “sidestep the problems of an impoverished work or educational history” (Little (1990, unpublished) cited Wertheimer, 1997, p.14).

Social and personal benefits are often subsumed in the term “self-confidence”. Most participants mentioned growth in self-confidence, e.g. “This is after giving me more self confidence... a bit of security in myself” (Frank). Lack of self-confidence is one of the most common characteristics of learners with mental health problems (Wertheimer, 1997) and was noted by learners, educators and HSE staff who participated in this study. Denise described her experience: “The first class I went into ...I thought oh my God this is rocket science get me out of here I can’t cope with this .. I just thought to myself, I want to run home”. Thanks to a very encouraging tutor, “it’s now absolutely my favourite class”. Several learners mentioned how they appreciated not being made to feel stupid by the tutors, e.g. “The teachers are lovely you never felt as if you’re a bit stupid” (Nora); “I could never say they’ve made me feel stupid or anything like that...I’d never be worried that they’d kind of make me feel like oh this one she’s kind of slow she’s not getting it” (Denise). Lack of confidence can cause fear of failure, inhibit requests for help or support and lessen interaction with other learners, apart from being a barrier to applying for courses in the first place.

Those who took part in mainstream programmes sometimes spoke of social benefits in terms of friendships. “I made such friends in the group” (Karen); “I made a friend ... and I can ring her any time now” (Jane); “I get on great with them all, but [name] and I are really close - we get on great - she’s a good friend” (Denise). These are experienced as ‘strong ties’. However, benefits in terms of social capital through the ‘weak ties’ of networking, though not articulated as such by participants, were also evident. Bourdieu’s conception of social capital as an asset belonging to the individual rather than a property of communities is applicable. “It has long been established that ‘weak ties’ between people – such as acquaintances – may lack intimacy, but facilitate the distribution of influence and information .... Informal social networks are influential in helping people to find work. ... thus people with

mental health problems could improve their employment or promotion prospects by extending their informal social networks” (Webber, 2005, p. 101). Engagement in education potentially provides access to new social networks. This can be compared to Putnam’s ‘bridging’ form of social capital, which, as opposed to ‘bonding’, has an outward focus and is likely to foster social inclusion. It is worth noting that bridging is more likely to be fostered for people with mental health problems when they engage in educational opportunities in mainstream education settings rather than in segregated settings.

Many participants in this study, and particularly those in dedicated provision, named structuring their time as a benefit of participation in education or training: “It’s something to do with my time”; “Let’s face it, what would I be doing now if I hadn’t joined this programme – I’d be at home in bed”. The more marginalised or isolated a person’s lifestyle, the more likely the structuring of time was to be named as a benefit. Jane, who had never had a job and whose joining a VTOS programme was her first re-entry to education or training in many years, said of the course “It was good to get me out of bed”. This is not surprising of people whose lives are restricted by poverty and social exclusion.

Mental health service staff involved in training centres all mentioned the importance of participation in some form of day centre, club or training. “Social and personal benefits are very important – many participants live alone”. Focus group members spoke of the benefits of “mixing with people”, “meeting new people”. Many of those in dedicated programmes spoke feelingly of the importance of support gained from being in a group of people who have all experienced mental health problems. In a group like this people’s problems “are acknowledged”, whereas in other settings they may have to be hidden, “people don’t understand”. However, there is also the danger that “socially segregated programmes frequently serve as entrapping niches that reinforce social stigma, reduce access to normative feedback and resources, encourage passive adjustment and solidify social withdrawal” (Rapp, 1998; Sullivan, 1997, cited in Ridgway, 2001, p.342).

#### 5.4 The value of learning

Extrinsic benefits of returning to education outlined above include growth in social and cultural capital, qualifications, progression and moving into employment. A benefit that seemed to be centrally important to many participants is learning itself as of intrinsic value. This value is experienced and expressed in a variety of ways – learning as affirmation, as a sign of recovery, as therapy, as occupation, as salvation.

For Karen, learning is an affirmation and a sign of recovery:

I just felt great that I was able to remember stuff... And I'd be just delighted that I was able to do it....With the depression you kind of feel that you go through so many months and months of feeling numb and feeling nothing - my memory was terrible and all that not being able to concentrate... Once you feel that coming back - it makes you feel so much more normal again when you can learn...because you kind of thought I'll never be able to learn anything again ... you do feel like you're losing your mind when you're depressed.

The process of recovery includes recovering your 'mind', your ability to concentrate, to remember, to learn. Karen conveys a sense of the joy which that experience brings her.

Lisa, in contrast, sees studying almost as a preventative - a way of occupying her mind and preventing it going down the pathways of depression and negative thinking.

I wanted to go out and actually use my brain because if I am not using it, it kind of turns in on itself. It actually turns in on itself... [Studying] brings me forward instead of my own brain actually just, I don't know, turning against me or sending me back into depression or to whatever because it's not being used... it's not being occupied.

Some focus group participants also mentioned learning as a positive way of engaging their thinking, e.g. "the course occupies my mind" or "it gives me something to think about". This is not a new idea. "Robert Burton, an Oxford don who spent his entire life researching, writing and revising his *magnum opus*, *Anatomy of Melancholy* (1621), himself a sufferer, wrote: 'I write of melancholy by being busy to avoid melancholy'. And, with an eye to fellow-sufferers, his mammoth work concluded with the admonition. 'Be not solitary, be not idle.'" (Porter, 2002, pp.52-3).

This has something in common with Denise's experience. "Being here in VTOS basically has been my saviour, and studying ... it's my therapy". Denise has carried on with her studies in spite of their being interrupted by several hospitalisations for episodes of depression. Denise's doctors "swear by it, it's basically my prescription. Even before returning home my doctors actually sent me back here first ...they know what's pulled me through my darkest days". Though the social aspect of being with people and the support Denise gets from tutors and co-ordinators on the course are important, it does seem that learning in itself is very important too. Denise says "I've actually been in intensive care and I've still had my books in there." Studying seems to provide a refuge from the distress and turbulence of an episode in her diagnosed rapid-cycling bipolar disorder: "It's a kind of escape for me". It is interesting to note that, although Denise describes studying as "my therapy", she rejected her doctor's suggestion of "a little course", a term which carries the implication of education as a form of occupational therapy rather than of value in its own right. "I thought no, no ... my mind needs to be challenged". She chose instead to undertake a Leaving Certificate programme, which is working for her as a personal recovery strategy.

Louise, who has a general learning disability as well as being a longstanding mental health service user, finds it harder to express herself. "I prefer the [literacy] class [to the day centre she attends] because I'm learning more.... I can't explain why... It's good for me". She says that, in taking on the class, the chance to learn was more important to her than the fact that it would give her occupation for the evening.

Adults who return to second-chance education often see it as a chance to compensate for missed opportunities earlier in life. Dominice, reporting on a study of education biographies which were composed using group reflection, writes: "As they trace their education throughout their lives, people reveal that they often enter adult education classes to repair, compensate for or fill in the gaps of their past" (1990, p.206). Study participants voiced this experience in varying ways. "[The course] kind of brought me back to when I was a kid, all the things I've fucked up on" (Frank). "I wanted to go back to school... to fix some of the stuff from my childhood" (Lisa). "It wasn't my Mam's fault I had to leave school ... she used to say 'I scrubbed floors to get you a good education'. I kind of thought 'I'll make you proud of me' sort of thing and even to this day 'I'm sort of doing it for you' in a sense" (Denise).

The “reformulatory and reparative nature of education” (Walters, 2000, p.275) is important for adult learners in general. For people who, after leaving school early, have had their lives disrupted by mental health problems, return to education may carry particular weight as a symbol of recovery of, or proof of, mental functioning. The stigma attached to mental illness often includes an assumption of intellectual incapacity. One of the main aspects of stigma identified by focus group participants was “people thinking you are stupid” or “people assuming you’ve lost your intelligence”. Individual participants in this study had also had this experience. Lisa acknowledges that “Part of me childishly wanted to show my family ‘I can do this. You’d better start sitting up and kind of going well Lisa actually does have a brain’. Because of the drinking and whatever they just completely dismissed the idea of me being intelligent”.

Jane, who has schizophrenia and who attended a mainstream VTOS programme, objects strongly to the fact that people sometimes “treat me as if I’m a bit simple... like a child... There’s certain things that have happened to me in my life as things have happened to everybody in their lifetime. All of us... But ..they say ‘Are you sure?’ ‘Yeah it really happened’ ‘Did that really happen?’” She is not the first person with schizophrenia to express such frustration. Leete wrote in 1989: “Life is hard with a diagnosis of schizophrenia. I can talk, but I may not be heard. I can make suggestions, but they may not be taken seriously. I can report my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies. To be a patient or even ex-client is to be discounted” (1989, p. 199). As Ridgway writes “Questions of credibility are routinely levelled against people in groups that have carried social stigma, especially people labelled with psychiatric diagnoses, whose life experiences, standpoint and preferences are too often discounted or completely ignored” (2001, p.335).

It is common for disorders such as schizophrenia and bipolar disorder to have their onset in the late teens or early twenties, which can have a very disruptive effect on completing education and obtaining qualifications and thus possibly on life-course. Hazel, a participant with a diagnosis of schizophrenia, had her first nervous breakdown during the Leaving Certificate examination, which she was unable ever to

complete. During her interview she placed repeated emphasis on the fact that she is “a straight A student and a scholar”. She has achieved many FETAC and other certificates in training programmes over the years: “I have eleven certs, I mean I can't be stupid.”

Conflation of mental illness and intellectual disability is not rare. I have been surprised at how frequently, when I mention the topic of my research, even highly-educated people seem to assume that participants will also have learning disabilities, or else to assume that mental illness and intellectual disabilities are one and the same thing. Several studies have observed confusion between intellectual disability and ‘mental illness’ among the general public in other countries (Eggert and Berry, 1992; and Kyle and Davies, 1991, cited in Shevlin and O’Moore, 2000). In an Irish project involving structured contact between mainstream students and students with severe/profound intellectual disabilities, it was found that “this type of misunderstanding [confusion between intellectual disability and mental illness] was evident... among the intervention group pupils before their involvement in the schools link programme. However, over time this perception had altered” (Shevlin and O’Moore, 2000, p.231).

This confusion may be due to a general tendency to conflate different types of disability in a process of ‘othering’ people who are ‘different’. It may also be due to assumptions that people with mental health difficulties cannot benefit from education. In the field of mental health, “1980s proponents of psychiatric rehabilitation emphasized that mental illness not only causes mental impairments or symptoms but also causes the person significant functional limitations, disabilities, and handicaps” (Anthony, 1993, p.525). This thinking still influences the delivery of mental health services and may affect attitudes of education personnel as well. In the Irish context, another influence may be the history of Irish social services, which were extremely slow to provide separate services for people with mental health difficulties and those with intellectual disabilities as described in Chapter One.

## **5.5 Recovery**

Ridgway, in a study of first person accounts of recovery from psychiatric disability, found that “the recovery journey, while unique for each person, has many broad

passages that are held in common” (Ridgway, 2001, p.340). Common elements included “overcoming assaults of stigma, discrimination and abuse; developing a renewed sense of free will and self-control; undertaking self-directed coping strategies; participation in valued activities and important human relationships; feelings of hope; and a sense of personal meaning” (2001, p.340). Choosing an opportunity to engage in education and learning can be a powerful way of gaining/regaining autonomy, self-efficacy, meaning and hope for many individuals.

The participants who had returned to mainstream education were examples of the recovery model in action. They had taken proactive steps to apply for their courses as a step on the route back “into society” and on their individual recovery journey. All had applied for the programme without the intervention or support of mental health services. Although there had been encouragement in varying degrees from family or friends, it seemed that most participants had come up with the idea of return to education themselves, and after coming up with the idea had acted on it personally. For some, education was a means to gain qualifications and skills which might lead to employment, for others it carried emotional resonance as a chance to make up for opportunities not taken earlier in life, and for others again it was simply “something to keep the brain active”. In every case it was an example of the undertaking of “self-directed coping strategies”.

Writings on recovery emphasise the individuality of the process. “It is self-directed and defined by the individual - there is no single path to recovery” (Frak, 2005, p.5). Returning to education is not a necessary ingredient in recovery programmes for everyone with mental health problems, but it was one which appealed to the participants in this study. For most of the participants, it was an effective step on their recovery journey and was seen by some, like Karen, as crucial. However, Frank makes it clear that return to education is just one factor that is helping him to survive. When asked how important he thought it was, he answered “Yeah well to me it is but then again so is martial arts, so is getting on with people, so is a lot of things ... it’s something once you’re occupied. It’s not the full thing, it’s a drop in the water, it helps”.

“The recovery movement believes the process of experiencing mental illness has consequences that take the person to a different position. There is no going back, so there may be a sense of loss” (Frak, 2005, p.3). A sense of loss emanated from many participants’ accounts. Denise described how she lost “a very good job” through repeated episodes of depression and hospitalisation and can “remember very little of my first three to four years after diagnosis because I was totally over-medicated”. Nora “was there in body but not in mind” during her children’s early childhood. “Well the only thing I think that went for me when they were younger was that really they won’t remember, which for me is a good thing”. Karen described how “everything fell apart” when she had a breakdown and she lost her job and care of her children. Frank reflected that “the only thing I held onto was my fucking life. And even that was a fucking accident”.

On the other hand, recovery can be more than just living with loss, but can lead to growth and development.

Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness..... There is the possibility that efforts to affect the impact of severe mental illness positively can do more than leave the person less impaired, less dysfunctional, less disabled, and less disadvantaged. These interventions can leave a person not only with ‘less’, but with ‘more’—more meaning, more purpose, more success, and more satisfaction with one’s life.

(Anthony, 1993, pp. 528 and 530)

Learners whom I interviewed sometimes spoke of how their mental health problems had led to a return to education and thus to a different road in life. “So I suppose I came back to education – I would never have done it if I’d been able to carry on working” (Karen). “I feel that I am on the right path now” (Nora). A student in his fifties whom I met in Southwark College in London, who had completed a programme for mental health service users in the college and then progressed to full-time studies in art and design said “I never thought I was particularly good at anything ... and the funny thing is I’d never have realised I had a talent for art if I hadn’t been mentally ill”.

In the recovery model, taking medication is seen as a possible part of a recovery strategy, but not as a ‘cure’ in itself. Karen sees her medication as contributing to but

not providing a solution. She knows she needs to be proactive in using other strategies as well. “The medication’s doing its job but if I’m not doing anything it wouldn’t be long before I got depressed again”. She is involved in decisions about her medication rather than passively accepting the doctor’s prescription. “I’ve learned a lot through other people. So I kind of question a lot now and...I don’t think medication is always the answer.... I’ve tried loads of different medications, and I kind of know that lithium works for me, and I don’t want to introduce anything else if I can avoid it.” She describes how she has become more assertive: “I’ve kind of learned to argue my case if I don’t want extra medication....I don’t give them [doctors] 100% say in how things go...”.

Nora had been prescribed anti-depressants. “I just felt they weren’t doing anything for me, I just felt the same... so I thought the only way to do it was just me – mind over matter kind of thing.” She sees her participation in a VTOS programme as both a sign of and a cause of recovery. “I’m feeling a bit better and it’s mainly because I’m doing the course, because if you work it out after I did the course probably about a month or two after I began I went ‘oh I don’t need these tablets [anti-depressants] any more, I feel a bit better”” She sums it up: “I was able to get out of it [depression] and I was able to feel better about myself and I was able to do it myself.”

This echoes the experience of Bernadette, a member of the Traveller community, who attends a Traveller Training Centre. Bernadette, after a serious car accident, became depressed. “I went on treatment – anti-depressants. They made me very tired, just kind of blanked out things. Anti-depressants does not help whatsoever. I took them for five or six years. I went off them too quickly first but then I got off them gradually. The best way to come off anti-depressants is to go on a course - go off gradually, get yourself on a course, start working.” Bernadette now attends a Senior Traveller Training Centre. “It has completely given me a different life. It gave me confidence.... It’s like a bit of life I never got – a chance in life... I want to learn to read and write with all my heart. I really want to educate myself. I want to be recognised as something – somebody”. She describes how what she sees as her greatest achievement to date – passing her driving test – inspired her to do more. “I thought, if I can do that without being able to read or write, I can learn to read and write too”.

Denise describes how “the first few years were a nightmare. I was basically a guinea pig. They were trying out everything on me. I mean I can’t remember, to be honest I remember very little of my first three to four years after diagnosis. I was totally over-medicated.” She has survived. “People even say to me ‘my God, Denise, you’re such a different person in comparison. You used to just sit in the one chair and stare at ceilings’. It’s scary actually to think about it now really but I’ve come such a long way since, thank God”. Denise has suffered a great deal from side-effects of medications but feels that the ones she takes now work for her and manages them to some extent herself. “The last time I went in they gave me a tranquilliser because I was suffering a little bit with anxiety and I tend to take it now when I finish the course in the morning, because I was taking it before I came in and it made me drowsy and I don’t like that. I like to be coherent and awake in the mornings”. Denise talks of her return to education in medical terms: “basically it’s my prescription, it’s my therapy”. Her doctor also sees it as important for Denise. “They said to me look we think that what has saved you all along is your education, your dedication to study that sort of thing so even before sending you back even into the home environment we’d like actually to get you back into education. Now it was a fairly long trek in the morning, it meant actually getting up at six in the morning and coming over from [the hospital to] the other side of the city, but they thought no we need to get you back over there so it just goes to show the importance of what they think of it too”

Growth in confidence about their future, development of aspirations and setting of goals were striking in some participants. When Denise applied for the VTOS course, “I didn’t really think work, I was thinking more of study, college that sort of thing. I didn’t want to think too far ahead. I didn’t want to scare myself completely. I thought of myself getting in, getting the brain active again mainly”. When I met her early in her third year of that course, she had been talking to the guidance counsellor about “maybe doing a PLC course”. At our second meeting, four months later, she had applied for and obtained a place on an Accounting Technician PLC course for next year. This has been the first January for many years that she has not been hospitalised and she feels strongly that having the goal of doing the course and getting the qualification will help her to stay out of hospital. Her experience reflects the findings of other qualitative studies of recovery: “The purpose of vocational activities

[including education] seems to shift from simply serving as a means of being active to serving as a source of personal meaning and purpose” (Young and Ensing, 1999, p.238).

Charmaz, in a study of the experience of chronic illness, writes that “people experience chronic illness in three ways: as an interruption of their lives, as an intrusive illness, and as immersion in illness” (1991, p.9). For Charmaz’s participants, the usual trajectory is from initial interruption to complete immersion, though not always in a linear progression. This metaphor can be extended to serious mental health problems, whether or not defined as ‘mental illness’, with the difference that a “slide into a life founded upon illness” (Charmaz, 1991, p.10) may not be an inevitable outcome. Denise’s description of her early mental health difficulties and treatment paints a picture of immersion due at least partly to iatrogenic factors. However, she has progressed to a situation where, for the past few years, her mental health problems have caused intrusions or even only interruptions in her life. She has moved in the direction of recovery rather than being trapped in the role of passive ‘patient’ or ‘sufferer’. Returning to education has been a crucial factor in Denise’s recovery journey.

Several participants mentioned that they viewed their participation in the study as worthwhile because it might eventually be of benefit to others through influencing policy with regard to learners with mental health problems. Karen thought that “if it was suggested that maybe others like me had benefited, it would help people get back confidence and get back out there again”. She has offered to take part in training for staff or to talk to learners or potential learners about her experiences, to show “that there was somebody ... [who had] come out the other side. They’d know exactly where we’ve been and where we were coming from. Otherwise you can feel it’s them and us”. This may be possible: the involvement of ‘experts by experience’ is increasingly common in mental health training initiatives. Other participants planned to do voluntary work, helping others, e.g. Frank, who said “I want to learn how to draw properly. I can draw but I want to be able to do it properly, then do volunteer work in the inner city – give something back to the environment”. Ultan plans that “when I do my two years here I will be bringing the skills” into [addiction centre] where he does voluntary work at present and plans to teach computer skills in the

future. He sees this as “a calling”, his path in life. There is an interesting resonance here with another dimension of the recovery process, where “many people report finding meaning and purpose by serving as a helper or role model for others” (Young and Ensing, 1999, p. 226).

Recovery is partly dependent on intrapersonal factors such as a person’s resilience, self-efficacy and hope, as demonstrated by study participants. However, it is important not to view recovery as a purely personal individualistic challenge to be met independent of social structures and supports. Intrapersonal qualities cannot be effective in a vacuum without external contextual factors which provide triggers, opportunities and supports. “The process of recovery can only work if the external environment enables people.... Recovery is totally dependent on civil rights and opportunities for inclusion” (Sayce, 2000, p.143). Access to education programmes is one such opportunity, which, as participants’ stories show, can contribute significantly to recovery through promoting the development of confidence and re-integration into mainstream society. The acquisition of cultural capital in the form of educational qualifications, as well as the social capital generated through participation in mainstream education settings, can increase a person’s life chances and can contribute to social inclusion and equality of opportunity.

## **5.6 Support**

“There are key themes which have to be in operation for participation in education to be successful. It is not enough simply to enrol people with mental health difficulties in an education environment” (Austin, 1990, p.260). Appropriate and supportive attitudes and behaviour on the part of staff are needed to enable learners to overcome barriers to learning, both practical and emotional. In interviews with participants in this study, their experiences and opinions as to what practices and procedures were supportive were explored and discussed.

The support that was most valued by participants in VTOS programmes came in the form of encouraging and positive attitudes from staff. The significance of a welcoming and inclusive environment should not be underestimated. Frank found that the staff in the college of further education he attended “don’t look down on you... they give you a bit of confidence you know what I mean? And you can have a laugh

and a joke”. Although when he started the course he planned to stay only long enough to get his back to education grant, “it’s not the reason why I’m staying here because I forgot all about the bleedin’ thing, I really did.... [the college] is kind of homely. That’s the way I can explain it, you know, everyone is down to earth. And it’s a grand little bleedin’ college”. Frank mentioned several times during his interviews how out of place he felt in the college at first. “When I got into here ...I met people I never thought I’d meet – people that I probably would have thought of mugging them... I never met them before end of story. If they met me on the street they probably would have dialled 999 or something”. Not alone did Frank come from an inner-city background, but he had been ‘on the skids’, living rough for years. It was a remarkable move for him to take on further education, but one that would not have worked without a very non-judgmental, accepting and welcoming attitude from college staff. This attitude is important for the flourishing of adult learners generally, who very commonly, even if their story is not as dramatic as Frank’s, feel like ‘fish out of water’ in a further education environment.

The attitudes displayed by staff at the initial enrolment interview were very important. The experiences of Frank and Karen have been described above. Denise had a similar experience: “I told [coordinator] at the interview that I had the bipolar... She just – she wasn’t shocked or anything, she was quite just normal about it as if I was telling her I had a tummy-ache... she didn’t treat me anyway different.” The participants in this study had all disclosed their history of mental health problems even though some were actually afraid this might preclude their entry on to the course. Some decided on the spot to declare their history only because of a very welcoming and accepting attitude on the part of the interviewers. Afterwards, they found that this disclosure elicited positive support from teaching staff. Teaching staff also prefer to be informed if a student has difficulties and to know what extra accommodation or encouragement may be needed. Nevertheless, there is a significant and unknown number of learners with mental health difficulties who do not disclose their history to the education centre or college. This is their right and prerogative. However, this may lessen the support they can access.

Teaching staff were perceived by participants as generally very helpful, encouraging and supportive. “I don’t think there’s more without bending backwards that you could

actually do for somebody” (Nora). “All the teachers here, they’re all fantastic when it comes to support.... They’ve just always been there to support me and help me when I needed anything. ... If anything they’ve been 100% behind me” (Denise). Ultan speaks highly of the support he and other students get from their tutors, particularly the course co-ordinator: “She does make herself available, you know, she is genuinely interested in us. We are not just more pupils - she is genuinely interested in what she says to us and she is genuinely interested in us learning.” In his case, when he had a bad patch, “I just said to [tutor] like I just need time out, and she said no problem. Because two of the lads actually just live up around where I live so she said look if there is any handouts or that she said she would give them to them to drop into me.”

Participants valued understanding when it came to being absent due to bad episodes. If Denise is absent for a few days “[coordinator] is on the phone straight away to see how I am. ... Yes, she’d ring me and that’s what I mean about how caring and sensitive the people are here. There’s nothing I could say wrong. ... You couldn’t get any more kindness”. Karen also valued her co-ordinator’s concern. “If she saw that I was a bit down she’d kind of call me aside to check if I was OK. And all that was so important, like I wouldn’t have been able to get through it without it.”

Flexibility regarding length of time taken to complete the course was very important. When Karen “got stuck around the Easter time, I just kind of went under really, I just couldn’t cope with everything ... I was taking a lot of time off and stuff... I wouldn’t have got the whole course completed enough to get all my certs and everything. [Co-ordinator] just said to me ... if you need to take another year.... that is a possibility.... And then that was all the pressure off me, I was able to come back and continue on, and do a few more of the modules... and know that anything that I hadn’t got done, I could just come back and do next year. Which was great, because then the next year I was coming back knowing that I had most of it done ... I really enjoyed the second year.” She made the point that “if you don’t finish the course you feel it’s another failure, it’s another time you couldn’t cope, which is the way I’d have felt if I hadn’t got the opportunity to come back for the second year”.

Denise’s programme has been extended to a third year on foot of recommendations from her psychiatrist. This is the same psychiatrist, mentioned earlier, who

encouraged Denise to return to the VTOS programme while still in hospital before being discharged to go home. It is worth noting that, as Denise's health insurance covers private health-care, she avails of a private psychiatric hospital and has been seeing the same psychiatrist regularly for the past ten years. This continuity of care does not often happen in public mental health services.

Not all feedback was positive, however. Lisa, who abandoned a VTOS-funded programme after four months, did not find the course co-ordinator understanding or supportive. She had disclosed to both the co-ordinator and class that she was in recovery, having spent time in an alcoholism treatment centre six months before starting the course. After about two months, a classmate, with whom she seemed to have a personality clash, began taunting her, saying at coffee break 'wouldn't you wish this was a glass of gin'. Lisa complained to the course co-ordinator, "but she just seemed flustered as in she did not know what to do." She doesn't know whether the co-ordinator spoke to the other student, but there was no follow-up with Lisa. At around that time she began to feel quite depressed and began missing days. She felt that the staff "must have taken it as disinterest, I don't think they were aware that it was sort of emotional problems ... I am kind of struggling to get through it, struggling to get up in the mornings ... to feel that it was looked on like 'Oh God look she bothered to come in' .... After a while I eased off and then I just stopped going in".

Since then, Lisa has been working on and off and is now, after another bout of depression and on the recommendation of a FÁS placement officer, taking part in a FÁS-funded vocational training programme. The staff there are encouraging her to apply to a further education college for next year and see her as capable of going on to third level. This is something Lisa would like eventually to do. "I suppose it is a long term kind of goal. Almost like a little dream with parts of me being afraid to try it because I couldn't fucking cope with a VEC course down the road". It is possible that Lisa started the VTOS programme before she was 'ready', and too soon after rehab. "I do have to keep concentrating on that it wasn't the right time. It wasn't that 'Oh God, I didn't have the brains to do it'". Nevertheless, the experience had a negative effect on her confidence.

Jane also has reservations. She felt that the course co-ordinator “had her pets” and Jane felt discriminated against. On one occasion she felt that the co-ordinator “actually made fun of me”. Jane found it difficult to explain what had happened in concrete terms. It was rather as if she sensed an attitude. It seems as if this co-ordinator did not have a very inclusive attitude to difference. In spite of this, Jane did stick with attending the centre for two years and obtained certification. The lack of support from the co-ordinator was balanced by a very positive and inclusive ethos in the centre. Jane said she found all the other staff “very nice”.

It seems that for some participants the course co-ordinator played a key role in providing both moral and practical support. Denise’s opinion on the importance of a ‘key person’ is that “It’s good to have one person who knows the whole story.... You can go to them to discuss problems, issues”. While tutors have some awareness but not detailed information, Denise likes the fact that “the co-ordinator knows more about my situation...she keeps a watchful eye over you”. The co-ordinator, while experienced in more negative terms by a few participants, did not stand out as particularly significant for others, but rather was seen as one member of a supportive teaching team. For these participants, a particular tutor may have been particularly encouraging and helpful, as in the experience of Frank, who described as the most helpful staff member one of his art tutors who pushed him a lot while being very encouraging and caring.

VEC education programmes are what might be called ‘low-support’ environments in comparison to the high-support environments of mental health service day centres and rehabilitation programmes. VECs are not highly staffed in terms of support personnel. The Adult Education Guidance Service offers information and guidance but not personal counselling. Most participants did not perceive the guidance service as being particularly relevant to them: “They did visit the class but they dealt with CAO and third level”. Greater personal or counselling support is an issue raised by some of the mainstream programme participants, when asked for suggestions as to what could be done to improve the service and support offered by their education centre/college. “It would be a good idea to have a kind of support person you could talk to – about what you might do after the course and about other problems. If [co-ordinator] wasn’t so easy to talk to, it would be good to have someone else” (Karen). “It would be

something good now actually, if they had kind of a counsellor here ... if anything personal is bothering you, or depression. Anything like that, or even just give leaflets around. Get in touch with them if you needed.” (Frank). Denise, on the other hand, does not experience a lack in this area “because if I ever have a problem I talk to [co-ordinator] or [tutor/guidance counsellor]. They’re both fantastic - to me they would be my counsellors. So I’ve never felt there was never anybody there to talk to”.

Although personal counselling is not within the remit of the guidance service, the fact that the service can offer educational as well as vocational guidance may be an under-utilised resource. The service may have some capacity for individual mentoring, which has proved to be very supportive for learners with mental health difficulties. This possibility is discussed in Chapter Five.

## **5.7 Difficulties**

Shaky confidence and worries about being unable to cope with the demands of the course are common to most adult learners returning to education. These difficulties may be more marked in the case of people living with mental health difficulties, who are bringing with them the effects both of their mental health difficulties and also of the outcomes of these difficulties. “Recovery from mental illness involves much more than recovery from the illness itself. People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative effects of unemployment; and from crushed dreams” (Anthony, 1993, p.527). For some people, medication will have more implications for study and learning than mental health difficulties themselves.

“I was terrified to be honest because I thought to myself oh my God with the medication am I going to be able to retain information and all that sort of thing - they were obviously my big concerns. Would I be able to keep up with the others sort of thing. I found myself saying to the teacher ... I’m taking medication, I’m a little bit slow on the uptake. I was already making excuses for myself” (Denise). Denise, however, is actually achieving well on her programme. Not everyone may be able to cope as well as Denise. Anxiety can cause a short attention span or even make it difficult to remain sitting in the classroom; obsessional thoughts may make it hard to

concentrate on learning tasks; people can be distracted by auditory hallucinations or may find interruptions or noise hard to tolerate; and some psychiatric medications have detrimental effects on ability to concentrate.

Swings in mood can cause learners to experience more difficulty at some times than others. “With the depression when I’m down I can’t concentrate so I did have periods where I felt nothing was going in, I was sitting there and I was doing the thing but I just wasn’t absorbing it. ... I would think I couldn’t concentrate and I’d just get real frustrated and stuff. You’re just getting panicky” (Karen). Many mental health problems are sporadic, in that a person may have periods of being well interspersed with episodes of mental ill-health. Recovery does not mean that these episodes will necessarily disappear. However, “as one recovers, the symptom frequency and duration appear to have been changed for the better. That is, symptoms interfere with functioning less often and for briefer periods of time. More of one’s life is lived symptom-free” (Anthony, 1993, p.532).

Organisation of work is a challenge for most early school-leavers who return to education and more so for those challenged by difficulties in concentration. Jane’s medication has quite an effect on her concentration, particularly in the mornings. She found assembly and organisation of her portfolio for assessment very difficult: “We had to have so much and all your pages together and this section and that section and then you had to remember where everything went and you had to know where everything went. But I didn't because I used to lose my patience with the folders.” Ultan says “it's just that I find it very hard to concentrate. I wonder sometimes if I have this AD, what is it HD or whatever you know what I mean because at times I’d be looking at something and it could be of interest to me but I just can't hack it.... I just have to put it down.” Nevertheless, Ultan is managing to get successfully through a demanding programme. Frank also found organisation and planning of his work challenging. “[The work is] more or less confusing because you don’t know whether you’re coming or going. Some of the things you start doing, before you know it you’re onto something else, so you haven’t...you’re kind of half finished one thing, and you’re going onto something else, and...you don’t feel... I don’t feel I’ve actually done anything.” A year later, in a third level programme, he says he would never be

able to cope at this level had he not learnt the basics of self-organisation in his year in further education.

## **5.8 Summary**

The findings reported above indicate the potential for great personal and social benefits for people with mental health problems through participation in adult education. Most of the core group of participants, who had attended VTOS-funded programmes, reported gains in self-confidence, in cultural and social capital and in aspirations for their future. Learning in itself was of intrinsic value, playing an important role ranging from occupation to affirmation to salvation for different participants. The majority of participants had found education staff encouraging and inclusive, and rated this as the most important factor in support. The course co-ordinator was perceived to play a key role in support by most but not all participants. All participants were aware of stigma issues, but differed in the extent to which they had internalised stigma. Those who had disclosed their mental health problems to the course co-ordinator found this beneficial in eliciting support, but wanted to be in control of dissemination of this information to other staff.

Mainstream programme participants were on a recovery journey. They demonstrated the qualities of hope, agency and taking charge with self-directed coping strategies which are essential factors in recovery. Return to education enabled them to take a significant further step.

## CHAPTER SIX

### CONCLUSIONS AND RECOMMENDATIONS

The first section in this chapter summarises the systemic deficiencies in adult education opportunities for people with mental health difficulties. The second section outlines conclusions drawn from the experiences of individual learners. Finally implications and recommendations for policy and for further research are discussed.

#### 6.1 The big picture/Missing links

“Mental health is an issue that cuts across traditional sectors and includes health, welfare, justice, education, housing, communities and NGOs. These sectors therefore need to collaborate for improved mental health care of the population” (WHO, 2007, p.31). Countries which are recognised as exemplars of good mental health practice, such as Scotland, Finland and New Zealand, have adopted cross-sectoral approaches, including building links between mental health and education services. In Ireland, however, while the establishment of the Office for Disability and Mental Health with responsibility for driving policy implementation has been a positive development, “most departments have not taken substantial specific mental health action and ... it is clear that critical gaps remain” (Amnesty, 2010, p.7).

One of these ‘critical gaps’ is the building of systemic connections between mental health services and adult education. The potential of participation in education as a step in individual recovery has been explored throughout this study/thesis. This participation also has potential to generate wider social and economic benefits. “If more educational opportunities were made available, not only would more people benefit personally, but the economic costs of mental illness might be reduced too” (Tomlinson Report, 1996, cited Wertheimer, 1997, p.14). Opportunities and support for participation in education could contribute to lessening the overall national economic cost of mental health problems, which was estimated to be just over €3 billion in 2006 (O’Shea and Kennelly, 2008).

However, this study has confirmed that there has been little development of systemic links between adult education services and mental health services, other than

provision of tutor hours in mental health settings. This type of education provision, while it has value, does not contribute to the progression of individual learners towards integration in mainstream education provision, or even progression towards taking part in targeted programmes in mainstream adult education settings. In fact it may act towards perpetuating the social segregation of people with mental health difficulties. Exceptions to this state of affairs were found, where individual learners were encouraged and supported to progress. However, these were exceptions because they were not the outcome of any systemic links or development of policy, but rather depended on the interest and commitment of individual HSE or VEC staff. As such, although they benefited individuals, these interventions last only as long as the individual staff member remains *in situ* and committed enough to continue without systemic support.

Overall, there is a lack of awareness on the part of both mental health and adult education services of the potential recovery benefits of educational participation for mental health service users. This lack is evident in policy documents, both local and national, as well as in practice. Some Irish initiatives and many models of good practice in other jurisdictions give examples of possible positive development.

## **6.2 ?Summary of experiences of individual participants**

The majority of individual participants taking part in VTOS programmes reported very positive experiences of return to education. Significant personal gains were named as growth in self-confidence, increase in social networks and achievement of accreditation. Growth in social and cultural capital was evident, giving the potential for progression. Learning as positive and affirming in itself seemed to be a benefit intrinsic to the education experience and meaningful to participants. Education staff were in general perceived as encouraging and supportive. Overall, it was evident that return to education constitutes an important step in mental health recovery for many individuals, fostering growth in skills, confidence and autonomy.

### **6.2.1 Recovery**

The recovery model, which underpins this study, was exemplified by participants. If the notion of recovery were to be summarised in one phrase, that might be ‘taking charge’. Recovery means moving beyond the passive role of ‘patient’ and taking

positive steps towards managing one's own life. The distinction between cure and recovery is relevant here. The former implies passivity, while the latter entails action on one's own part. "Curing is the domain of the medical professionals, who heal or make better; recovery is more the domain of the client and is a process of working towards mental health..... [T]aking control of one's life is an important element in the complex and often idiosyncratic definition of recovery" (Foster, 2007, pp.99-100). While medical treatment may have a part to play, it no longer dominates as a hoped-for solution. Other activities, strategies and choices come into play, engaging social and psychological dimensions. Within this framework, the choice to return to education may be a very positive step in recovery, as it was for many of the participants in this study.

For the participants in full-time programmes, return to education was a proactive choice. It is noteworthy that all of these participants had shown personal initiative in applying for the courses they attended. All had called or phoned to obtain information and an application form, had completed the form and had attended for interview. One person said he had applied reluctantly, with encouragement from friends. Some had heard about the course seemingly by chance when they were ready to move on to the next step. Others had gone to great lengths to apply and obtain a place. None, however, had been encouraged or supported in their application by health or support services.

Each of these individuals had demonstrated agency in undertaking return to education as a step, explicit or implicit, in their recovery process. In turn, the experience of doing the course had, in most cases, progressed recovery further, and for some was a transformative experience. Participants described growth in confidence, making friends, learning skills and developing goals and aspirations beyond what they envisaged as possible before the programme. As articulated by one participant, when applying for the course she "didn't want to think too far ahead. I didn't want to scare myself completely. I thought of myself getting in, getting the brain active again mainly". By the end of the programme she was planning to progress to a college of further education to take an accounting technician course.

Participants were also taking more charge with regard to their medication. Some questioned the efficacy of anti-depressant medication in comparison to engaging in a project such as an education programme and had stopped their medication. Others engaged more in discussion with their doctors about their medication. “I’ve kind of learned to argue my case if I don’t want extra medication....I don’t give them [doctors] 100% say in how things go”. Recovery may include using medication, but it involves many more strategies and approaches than simply taking prescriptions and waiting for them to work. It also means that the individual engages with medical personnel as a partner in planning their treatment programme rather than passively following instructions.

Making a contribution to helping others through activism, advocacy or other voluntary work is a common feature of recovery. This too was evident in the plans of participants, two of whom planned to undertake voluntary work in their community or in an addiction centre and one of whom offered to contribute to staff training. In general, participants were motivated to take part in the research at least partly because it might be of value to other people with mental health difficulties.

### ***6.2.2 The value of learning***

Learning, a benefit in terms of leading to accreditation and qualifications, emerged also as intrinsically valuable to participants. Its value was experienced and expressed in a variety of ways – learning as affirmation, as a sign of recovery, as therapy, as occupation, as salvation. One participant expressed joy at the experience of being “able to remember stuff... just delighted that I was able to do it” after going through “months and months of feeling numb and feeling nothing ... you do feel like you’re losing your mind when you’re depressed.” For another, “studying is my salvation.... it’s my therapy”. Another participant saw study as a way of “occupying my brain because if I am not using it, it kind of turns in on itself”.

Although lack of confidence and fear of failure are commonly acknowledged issues for many second chance learners, these factors may operate with particular intensity for people who have experienced the disruptive effects of mental distress and in some cases the side-effects of psychiatric medication. Several participants mentioned difficulties in concentration - in some cases sporadic, in others worse early in the day

- and their fears of not being able to cope. “I was terrified ... am I going to be able to retain information...”. “When I’m down I can’t concentrate so I do have periods where I felt nothing was going in”. Many psychiatric medications can have negative effects on concentration.

Mental health problems may lead to difficulties in perceiving oneself as being able to learn, or as belonging in a learning environment, but do not necessarily mean an inability to learn. However, confusion between mental health difficulties and intellectual disabilities is common in the general public (Shevlin and O’Moore, 2000). Even among educators, this confusion sometimes occurs, with comments from some education staff revealing assumptions that people with mental health difficulties will also have learning difficulties and inability to achieve learning goals. The conflation of mental health difficulties with intellectual disabilities was an issue which arose frequently in discussion with both individual and focus group participants. Within focus groups, the opinion was expressed on a number of occasions that “people think[ing] you’re stupid” was part of participants’ experience of stigma. Among individual participants, those with a diagnosis of schizophrenia particularly resented the experience of not being listened to or believed.

The issue of intellectual functioning arose in a number of cases, usually expressed as appreciation of tutors’ not making learners feel stupid. “You never felt as if you’re a bit stupid” “I’d never be worried that they’d make me feel like oh this one she’s kind of slow she’s not getting it”. This gratitude may be common to adult second chance learners, or in the case of these participants it may be partly due to some internalisation of attitudes which equate mental health problems with learning disabilities. The importance of achieving educationally, sometimes referring to family of origin, in terms of either “doing it for [parent]” or of wanting “to show my family ‘I can do this.. [I] actually do have a brain’” may also be common in second-chance learners or may have particular resonance for people with a history of mental health difficulties.

### **6.2.3 *Marginalisation***

Some of the “five faces of oppression” as explicated by Young (1990) had been experienced by participants. Marginalisation was a fear (“am I ever going to be able

to get back on my feet and have a normal life?”) and a reality. Each of the two male VTOS participants had been homeless for periods of time. Two other participants had experienced loss of employment as a direct result of their mental health difficulties. Three of the mental health service user participants and one of the VTOS participants had never been in the workforce except, in one case, through Community Employment schemes.

Participation in education can be powerful in countering marginalisation through facilitating gains in social and cultural capital. Study participants in general valued the friendships and social contacts established through being part of a class. Cultural capital in the form of accreditation and qualifications has accrued or will accrue to those who had completed their courses or were heading for completion. In some cases, the participants reckoned that they might never have gained any further educational qualifications but for their mental health problem, which had led them to take a different path than they otherwise would have travelled. One participant has progressed to third level and another is planning a further education course as a next step. All who had completed the VTOS programme perceived their options as having opened up and increased, an outcome described by one participant as “rejoining society”, and only one of the VTOS participants seemed unmotivated to progress, either in work or in education. Progression was more problematic for the participant who had not completed the programme undertaken.

The study participant resident in mental health service provision who is attending a part-time literacy class represents a gain in cultural capital at a different level. Her participation in adult education may lead to her attaining literacy, possibly the most significant type of cultural capital a person can gain through education. Only one study participant came into this category, no others of the small number of such learners taking part in Adult Literacy classes across County Dublin VEC being accessible for interview. However, the potential for gain and empowerment on their part must be very significant, as confirmed by an Adult Literacy Organiser who had worked with a number of such learners over the years.

The fact that the two participants from the Traveller community had also never been in employment is likely to be due at least as much to their membership of a

marginalised community as to their history of mental health problems. One described participation in education as central in her recovery from depression. The other participant saw it as helping, but to a lesser extent than her religious beliefs did. Both are motivated to progress and gain employment. For one, the next step is to “mix with settled people” in another educational setting and she is beginning to make enquiries in that direction. For the other, who has begun flower-arranging classes and has also completed a FETAC Level 2 award in the centre, “I’d love to know everything about flowers and be able to teach like this woman is teaching me – to have my own little job”. Both of these learners are attending Senior Traveller Training Centres, and their participation is developing their skills and self-confidence, contributing to their recovery from mental health difficulties and also broadening their horizons. However, education in segregated rather than mainstream adult education settings raises equality and inclusion issues similar to those discussed in relation to learners with mental health difficulties.

Government policy plans a move from discrete education provision for the Traveller community towards integration into mainstream adult education over the next number of years (Department of Education and Science, 2006, 2008). Whatever the setting, it is likely that a significant proportion of participants will be experiencing mental health difficulties, a number of studies having indicated high rates of mental distress among the Traveller community. In a survey carried out on behalf of Pavee Point in 1997, 34% of Traveller women reported long-term depression compared with a finding of 9% among their settled peers. More recently in the Traveller Health Survey (Traveller Health Unit, 2004) one third out of a total of 365 respondents reported depression in their family. Another study found the suicide rate among the Traveller community to be three times greater than that of the settled community (Walker, 2008).

#### ***6.2.4 Stigma and disclosure***

“To experience cultural imperialism means to experience how the dominant meanings of a society render the particular perspective of one’s own group invisible at the same time as they stereotype one’s group and mark it out as Other” (Young, 1990, pp.58-59). This study aims to bring visibility to the experience of people with mental health problems and to counter traditions of disregarding their views and opinions. However,

many difficulties and barriers were encountered. Being rendered invisible by others was evident in some instances of prevention of access to participants by mental health service staff. In some education centres, particularly in school and college settings, the number of learners who had declared mental health problems was extremely small or even non-existent, and this limited significantly the number of potential participants for the study. There was also a high rate of possible participants rendering themselves invisible through unwillingness to take part in the study. This non-participation may have been partly due to their internalisation of “the dominant culture’s stereotyped and inferiorised images of the group” (Young, 1990, p.59). This self-stigma may be reflected in low self-confidence, inhibiting willingness to come forward and engage in an interview process.

Surveys of attitudes among the general public repeatedly find greater levels of prejudice towards people with mental health difficulties than towards people with intellectual or physical disabilities on questions such as rights to employment, relationships and parenting (National Office for Suicide Prevention, 2007; National Disability Authority, 2002). It is not surprising, therefore, that stigma was an important issue for participants in this study. Individual participant reactions ranged from feeling that stigma permeated their identity (“It kind of sticks to you ... You’re kind of different”) to refusing to take it on personally (“It’s not something that I’m ashamed of ... I don’t think of it as being something terrible”). Members of focus groups of mental health service users were very aware of stigma issues and generally adamant that they would not disclose their history of mental health difficulties to potential employers. They had more mixed feelings about disclosure to educational institutions, some viewing education as a less excluding or threatening environment than employment.

In general, mental health difficulties are not immediately evident to others as would be the case with a physical disability. Such a situation, of ‘discreditable’ as opposed to ‘discredited’ stigma (Goffman, 1963), brings with it the issue of information management. Most of the participants in this study had declared their mental health problems to some extent to education staff and in general they found that this disclosure brought benefits in the form of support, encouragement and flexibility. “Once you say it, your life gets so much easier.” However, being in control of the

dissemination of this information was important. Participants wanted to decide who or when to tell rather than having the co-ordinator inform tutors of their history. Trust was central to this process: it was common for learners to tell tutors of their difficulties as they got to feel more comfortable in the centre and more trusting of the staff. It was noteworthy that one participant who had disclosed her difficulties from the start and had received excellent support in an adult education centre went to lengths not to have her history disclosed when applying to progress to a college of further education because of her “fear of being discriminated against”. She does not feel trusting of a supportive attitude in a new and unknown environment.

### ***6.2.5 Support from education staff***

Accepting and encouraging attitudes on the part of staff were central and rated by participants as the most crucial factor in successful course completion. Participants placed great value on being treated with respect, with such comments as: “They don’t look down on you .... they do give you a bit of confidence”; “The teachers just treat you like ... you know you are ordinary and they are ordinary”. Other comments evidence the importance of encouragement from tutors and the problems with confidence experienced by participants: “I could never say they’ve made me feel stupid or anything like that. If anything they’ve been 100% behind me and that’s fantastic”. “Genuine interest” in students, along with being friendly and “down to earth” were highly valued. Some participants rated a particular tutor as being especially influential in their success.

The course co-ordinator was often key to learner success and continued participation. Some participants felt they would not have managed without a very supportive and understanding co-ordinator. In these cases, the co-ordinator took the role of what one participant described as “keeping a watchful eye over you”, checking regularly with the individual student as to how she was doing, or calling her on the phone if she was absent for a few days. For others, though, the co-ordinator was less central and seemed to be seen as a member of a helpful staff team. In two cases, participants found the co-ordinator unsupportive. One of these participants dropped out of the course, partly, in her view, due to this lack, while the other completed the course, experiencing the other staff members as more inclusive.

The attitude conveyed at enrolment interview was considered very important, and encouraged some participants to disclose their difficulties. Flexibility with regard to some absence and occasional extension of course or deadlines was also experienced as helpful, and in some cases was crucial to successful course completion.

### **6.2.6 Summary**

The experience of participants in this study attests to the potential of adult education in promotion of recovery and in counteracting marginalisation. Participants were using the opportunity of education to avoid “expulsion from useful participation in social life” (Young, 1990, p.54), which is a high risk for people with long-term or recurrent mental health difficulties (CSO, 2004). Learners in full-time programmes showed agency and initiative in applying for courses, and experienced gains in confidence and in social and cultural capital (Bourdieu, 1986) as a result. Learning in itself was valued as an affirmation of, and as an aid in, recovery - “basically it’s my prescription”, said one participant. Although participants had mostly disclosed their mental health difficulties and found that this elicited support from staff, information management (Goffman, 1963) was an important issue, with trust and control of information being central.

Most participants in this study had positive experiences of education and of support from education staff. They were unaware that the *ad hoc* nature of this practice, unsupported by policy, leads to lack of consistency between centres and also to dependence on very effective individuals whose good work may not be replicated when they leave or retire. One principal referred to the wonderful work of a few individual staff members who are near retirement, and whose standard of support for adult learners he does not expect to continue thereafter. There is no need to accept the inevitability of such a cycle of events, which is reminiscent of the fading away after his retirement of Dr John Lalor’s education initiative in the nineteenth century Richmond Asylum, as described in Chapter One. It is incumbent on twenty-first century providers to develop policy and staff in order to ensure dissemination, consistency and continuity of good practice.

### **6.3 Recommendations**

For some people with mental health difficulties, an inclusive approach will mean ensuring that they have the necessary supports to use mainstream provision and enjoy a positive learning experience. For others an inclusive approach will involve the provision of specific classes to enable them to access continuing education on an equal basis with other adults.

#### **6.3.1 Best practice and Universal Design**

Creating learning opportunities for people with mental health problems is not about sending people into mainstream classes without support and then leaving them to sink or swim.

(Wertheimer, 1997, p.3)

VECs have been described by a centre co-ordinator in the mental health service as ‘low-support organisations’. It is true that VECs are low in allocation of staff employed specifically to provide support. However, participants in this study have in general experienced the staff who are *in situ* to be very supportive. While VECs may and should lobby for funding for extra support staff (unlikely to be forthcoming under the present post-Celtic tiger falling skies), their best way of providing support is to enhance and support the effectiveness of existing staff. Many examples of excellent practice have emerged in this study, and, applying the motto that policy should reflect best practice, these should be disseminated and promoted.

Although the majority of participants in this study who attended mainstream provision had positive experiences of support from education staff, there were some who did not. Furthermore, the good practice which students experienced on the part of individual staff members was not supported by guidelines, procedures or staff development and was therefore dependent on individual personalities rather than on organisational policy. It is necessary to translate best practice into policy and then to support its implementation through training and professional development for staff.

Building up good policies and procedures to promote inclusion of learners with mental health difficulties will improve quality of service for adult learners in general. “Good practice in relation to students with mental health problems is simply good

adult education practice” (Co-ordinator, Mental Health and Inclusion Project). This is analogous to the concept of Universal Design, defined as

the design and composition of an environment so that it may be accessed, understood and used to the greatest practicable extent, in the most independent and natural manner possible, in the widest possible range of situations, and without the need for adaptation, modification, assistive devices or specialised solutions, by persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability.

(Disability Act, 2005, p.46)

Design which facilitates people with disabilities can actually improve function for everyone. The more organisations move towards Universal Design, the less they need to worry about the nuts and bolts of reasonable accommodation. The concept of Universal Design is usually applied to tangible products, as in the following example:

If more than one option is available for a design feature, choose the more inclusive feature. For example, when installing a handle on a door, it is always better to opt for a lever handle, rather than a door knob, as the lever handle can be opened using the elbow or a closed fist, benefiting people carrying shopping bags as well as people with limited strength in their hands.

(National Disability Authority website)

Universal Design can apply to services as well as products. Policies and practices which are inclusive and supportive of learners with mental health difficulties will improve the experience of learners in general, as well as developing the quality and equality of the education service. Most of the guidelines below could be a blueprint for equality and inclusion in overall adult education practice, with a few extra items particularly important for learners with mental health difficulties.

The following recommendations reflect this study’s learning from participants’ experiences, supplemented by some adaptations of proven good practice from other education providers.

### ***6.3.2 Application and enrolment***

Informational and publicity material conveys messages about the inclusiveness of an education centre or college long before students come in the door. Brochures, leaflets, etc. are influential in encouraging enquiries and applications. Most of the VTOS

participants interviewed for this study found out about the course through seeing a leaflet or advertisement.

For the potential student with mental health difficulties, the initial ‘contact’ – which may be meeting someone from the centre face-to-face, picking up a leaflet or seeing a poster – is critical. If an initial meeting is too intimidating or a leaflet makes the course sound too daunting, this can make all the difference between someone saying ‘Yes, maybe that’s for me’ or feeling ‘I couldn’t possibly do that’ (Wertheimer, 1997, p.99)

As part of the process of developing a policy for inclusion and support of students with mental health difficulties in County Dublin VEC, two staff members (a psychologist and a county co-ordinator) consulted with focus groups of mental health service users as to the wording used in publicity material. The preference of focus group members was for ‘mental health’ not to be mentioned specifically, but for a generally inclusive and encouraging message to be conveyed. The statement eventually agreed is included in the guidelines summarised in appendix 4 on p.146.

Information on individual learners’ mental health difficulties is an important and sensitive issue. The application/enrolment form should include a question on disability in order to identify and plan for learner support needs. However, asking for details of disability or special needs on the application form is not recommended. Most people with mental health problems will not be willing to write down details on a course application form. Participants in this study were very reluctant to supply personal information about their difficulties at application stage. Apart from a fear that declaring a mental health difficulty will lead to exclusion from the course, issues relating to stigma, privacy and confidentiality come into play. On the other hand, providers prefer to know of specific problems or learning needs as this enables them to put supports in place if possible. Disclosure of this information is usually in the student’s best interest, as it elicits support.

Disclosure at application stage may be particularly important for applicants to Post Leaving Certificate (PLC) courses because they may be eligible for support funded by the Higher Education Authority Access Office. Ideally, application should be made well in advance, so that support can be in place from the beginning of the course. Students with mental health difficulties (certified by a psychiatrist or clinical

psychologist) may be eligible for funding for an hour per week of one-to-one learning support. There has been a small uptake of this possibility, with, nationally, only three further education students with mental health difficulties receiving such support in 2007 and ten in 2008. The HEA Access Fund pays for supports for students with disabilities in higher and further education who are doing courses accredited at level 5 and above on the National Qualifications Framework. There is real inequity in the fact that students taking courses in adult education centres (as opposed to schools/colleges) are not eligible for this support.

Asking a general question as suggested in the guidelines (appendix 4, p. 146), including a reassurance that the purpose of the question is inclusion rather than exclusion, is recommended by education providers with well-established inclusion and support policies. If an applicant answers they have a difficulty, this should be followed up in an individual interview. Ideally, the centre will have a Disability/Student Welfare/Access Officer who can carry out the interview, clarify the student's needs and negotiate possible support. At present, there are no such personnel in County Dublin VEC (or in most other VECs), a lack which will need to be addressed in the future. In this situation, it is recommended that the course co-ordinator and/or guidance counsellor follow up with an individual interview, the purpose of which will be to discuss what difficulties the learner may have and what support they may need.

Information about a person's mental health should only be requested where it may affect their learning, on a 'need to know' basis. Requests for psychiatric diagnoses should be avoided. They are not likely to be very helpful to teaching staff as they say nothing about how an individual learns or about the implications of the mental illness for their learning. There is also the danger of evoking negative and inaccurate stereotypes about mental health difficulties.

It was important to participants in this study that they were in control of dissemination of any information on their mental health difficulties. Because of the stigma associated with mental health difficulties learners may well be concerned about who will have access to information, and providers need to be able to justify their policies on confidentiality and avoid unnecessary discrimination. The co-ordinator – or

whoever the person is to whom the learner has disclosed a mental health difficulty at interview - should ask the learner whether they want the information disclosed to be shared with tutors. It should be made clear to the learner that any information given will be passed on to another person only with the learner's knowledge and permission. Information to tutors should be in the form of information on learning needs rather than on mental health difficulty or diagnosis – functional rather than diagnostic information.

As with any information held in confidence, there are exceptions to confidentiality with regard to legal obligations to disclose information related to crime or if a person is a danger to self or others.

### ***6.3.3 Providing a supportive and inclusive environment***

The support most valued by participants in this study was an inclusive and encouraging attitude on the part of staff. The simplicity of this is sometimes surprising to adult education staff, who take for granted “an inclusive and encouraging attitude” as intrinsic to their practice. A HSE manager in the mental health service who is involved in developing a recovery approach confirms that mental health staff are also often “confounded by the simplicity” of the effectiveness of respect and encouragement in promoting recovery. It is easy to underestimate the lack of self-confidence experienced by learners with mental health difficulties. “Oh, it has knocked [my confidence] I have to say it has definitely knocked it. I think basically a lot of it is to do with the stigma that's still attached to mental illness anyway” (Denise, VTOS student). Participants generally valued encouragement and support from tutors, and in some cases particularly from co-ordinators, as the most important factor in their successful completion of their course.

It is important for vulnerable learners, including those with mental health challenges, that there is a key staff member whom they experience as supportive and approachable. This may be the course co-ordinator or another designated staff member, e.g. class tutor. It is important for this staff member to maintain awareness of the learner's progress. Keeping in touch may sometimes involve initiating contact with the learner (e.g. phoning or texting the learner if s/he is absent) rather than

waiting for the learner to approach them. Other guidelines for key staff and for tutors are included in appendix 4, pp.148-150.

The value of Supported Education for people with mental health difficulties has been outlined on pp.115-6. This model essentially involves individual mentoring on goal-setting, planning and organising learning and study. Its effectiveness has been reported in many studies in adult, further and higher education, and by the Centre for Inclusive Learning in Metropolitan College Belfast, as reported above. In an Irish adult education setting, this support could most suitably be provided by the adult guidance service, where their workload allows. Guidance Counsellors in the adult guidance service have the skills to provide this mentoring, which falls within their remit of educational guidance rather than personal counselling. In further education, the existence of guidance provision varies greatly between colleges, but where it is in place mentoring should be considered. Colleges running PLC courses should also be aware of the possibility of funding from the Higher Education Authority Access Fund for one-to-one mentoring for students with mental health difficulties.

It is important to recognise that for some learners who experience recurrent serious mental distress, 'interrupted learning' may be the best option. They may need negotiation of part-time attendance or of leave of absence and support and liaison to organise an effective return to learning. Other learners may need a longer time to complete the course. Successful course completion by two of the participants in this study was contingent on an extension of the length of the course and of their VTOS funding, which was negotiated by their course co-ordinators.

If a student decides not to complete a course, whether due to mental health difficulties or for other reasons (such as a mismatch between the demands of the course and the student's learning to date, personal difficulties or change of preference away from a given course), he/she should be offered an exit interview, if possible with the guidance counsellor. This meeting should facilitate discussion around the reasons for wishing to leave the course, the implications of this decision and the exploration of plans and options for the future. The aim should be to ensure that the student sees the benefits of the learning experience even where it is incomplete and has feasible plans for moving forward.

#### ***6.3.4 Staff development***

Policy, to be effective, needs to be developed with the active involvement of staff and then to be disseminated through training rather than simply being sent out by post or uploaded on to a website. This training should take place within the context of equality training and equality planning.

All staff, including reception and ancillary staff, should have training in basic awareness of equality issues and of inclusion and support policies. Key staff should have the opportunity to confront their prejudices and biases and to reflect on their practice. Tutors may need more in-depth training on issues such as classroom practice and management. It is important that staff development emphasises the importance of boundaries, the distinction between education and counselling roles and a professional model of caring, which promotes independence as opposed to a culture of dependency.

Surveys in adult and community education services in the UK suggest that areas addressed in training should include exploration of fears and prejudices, increased awareness of one's own mental health needs, the safety and personal boundary issues that may arise with the very small number of learners who are disruptive, and enabling staff to identify networks of support and referral agencies (Boulton and Hatton, 1991; Leach, 1996). "The single most effective staff development has been an exercise which leads people to consider their own mental health. After this, the students aren't 'them' any more and we are all 'us'. This leads to a much more relaxed, confident and normal approach" (Wertheimer, 1997, p.142). Similarly, County Dublin VEC staff who attended two days of training in mental health issues in 2008 found "understanding the 'continuum' - realising that I am dealing with people, not just symptoms" very helpful. Other valued aspects included "the importance of self-care - can never hear it enough" and "the importance of recognising the limitations of my role - what is my role and what is not."

### ***6.3.5 Developing access and progression***

Providing opportunities for people with mental health problems to access adult education means more than being supportive and encouraging to learners who make their own way to the service. It also means developing a culture of inclusion, integration and outreach. The outreach in question may be different from the traditional model of outreach to mental health services, in that it will develop progression and integration opportunities for people with mental health problems.

Different types of provision are needed for people at different stages of the mental health continuum, the range to include:

1. programmes in sheltered mental health settings
2. targeted programmes for groups of mental health service users in adult education settings
3. participation of people with mental health problems in part-time programmes
4. participation in full-time mainstream programmes.

Provision should include supports and links which enable people to progress.

The first type of provision (classes in mental health settings) has been the traditional model of VEC classes for learners with mental health difficulties, and still exists, although hard hit by budget cuts in the current recession. The third and fourth (participation in part/time or full-time mainstream classes) do happen to a certain extent, and the experiences of a number of learners in such settings have been reported in this study. An example of the second model (programmes specifically for mental health service users in education settings) has been reported above (p.111-2), but is rare. This is a significant gap in provision because “educational provision in the community, targeting people with mental health difficulties, can be a ‘bridge’ between hospital and the community, particularly for those who do not feel ready to move straight onto general (mainstream) classes” (Wertheimer, 1997, p.6). Focus group members in mental health service day centre programmes, as well as participants in the targeted initiative reported on pp.111-2 expressed reluctance to join mainstream groups due to lack of confidence, feeling that in a discrete group of mental health service users, “you can be yourself, you don’t have to put on a front or watch your p’s and q’s”.

A pilot initiative is recommended, located in an adult education service or college of further education, and planned in collaboration with local mental health services. A start on a modest scale such as this would facilitate careful planning, monitoring and evaluation, providing guidelines for other such initiatives. Liaison with mental health service providers would be essential in planning the project, so that mental health staff are familiar with what will be provided and its aims. This discussion is important in order to avoid the dangers of inappropriate referral, or of pressure being put on a person to do a course even though it is not what they want to do or is not at the right level for them. Community Education Facilitators report on instances of inappropriate referral from mental health services in the past and emphasise the importance of a three-way dialogue, including learners, so that there can be realistic expectations on what can be offered and what goals achieved. Discussion should give consideration to recruitment of students, curriculum, timing and length of course, and responsibilities of both education and mental health services in providing support.

The curriculum in the proposed pilot programme should be planned in consultation between education staff, mental health service staff and prospective students. Some models of this type deliver programmes in particular vocational or interest areas, e.g. the successful *Choices* programme in Southwark College London which offers classes in Art, Pottery, Catering and Computers. Others focus on a programme tailored to empower people with mental health problems, a successful example being the *Health and Wellbeing* course developed in New Zealand and delivered in a Polytechnic college. This course includes subjects such as stress management, taking care of your physical and emotional health, lifeskills, intercultural awareness, communication skills, assertiveness and pre-vocational preparation (Clayton and Tse, 2002). The curriculum areas in the BTEI programme in Dun Laoghaire VEC vary from year to year according to student needs, currently covering basic education in Communications, Maths and Computers along with classes on Personal Effectiveness and Culture.

The question of accreditation also needs to be discussed. Personal development and the growth of social skills and confidence may be more crucial for many learners than the development of measurable and accredited skills and knowledge. Dun Laoghaire VEC report that people who join their targeted programme are often very wary

initially about assessment and accreditation, but usually are willing to put their work forward for assessment as they gain in confidence.

A model of Supported Education should be implemented as far as practicable. Educational mentoring could be provided by the guidance service if resources would allow. Another possibility might be linking with a Clubhouse. Clubhouses, of which there are two in the County Dublin VEC area, are “intentional therapeutic communities composed both of people who have a serious mental illness and generalist staff who work within the Clubhouse. Consumers who are part of this community are called *members*, not patients, consumers, or clients” (Macias et al, 1999, p.182). Harnessing “the dynamic potential offered by the clubhouse model to provide educationally focused support” (Dougherty, 1992) has proved successful in many education programmes (Unger *et al*, 2000; Dougherty, 1992) and the possibility of a link should be discussed with mental health services.

Whatever the curriculum, certain factors are crucial:

- Location in an education rather than a mental health service setting: the opportunity for learners to move into a mainstream setting in the community as opposed to their everyday segregation in mental health services is intrinsic to the value of such an initiative. “Students unanimously appreciated having this course located at an educational institution” (Clayton and Tse, 2002, p.75). Having VEC tutors visiting a mental health centre to teach classes will not have a comparable effect in encouraging learners to come in from the margins.
- Possibilities for progression: “I’ve seen too many initiatives that don’t lead anywhere. People [mental health service users] get excited about an opportunity for a class or course, but in the end they’re back where they started with no opportunity to progress” (Mental health practitioner, HSE). Information and guidance about progression routes and options should be built into the programme, so that those learners with the capacity and motivation to progress to another more demanding learning programme get the chance and

encouragement to do so. Ideally, this support will be provided by the adult guidance service.

- Protocols agreed between the education centre and the mental health service as to the responsibilities of each service in areas such as recruitment, support and communication.
- Training and support for staff involved in delivering the course.
- Clear ground rules as to boundaries between therapy and learning: a New Zealand student commented “I liked the professional behaviours that have been set out. A lot of us have been patients having group therapy and I like the way it was very clear that it wasn’t that” (Clayton and Tse, 2002, p.75). Some learners may expect the same kind of support as a day centre offers, and both they and tutors need to be clear on boundaries.

Of course, the guidelines for inclusion and support of learners with mental health difficulties as outlined in Sections 6.3.2, 6.3.3 and 6.3.4 above should also apply.

### ***6.3.6 Areas for further investigation***

This study focused mainly on County Dublin VEC, with some contact with City of Dublin and Dun Laoghaire VECs. The findings, although not representative of overall provision, will contribute to understanding by other providers of the equality issues and of the experiences of learners. However, a survey investigating other initiatives across the country, where adult education services have established links with mental health services and have provided bridges to participation in education for mental health service users, would contribute to the development of VEC equality policies and to the promotion of social inclusion for people with mental health problems. A survey of initiatives in other VECs which promote inclusion of learners with mental health difficulties is recommended.

The experiences of mental health service users taking part in part-time VEC education provision are represented in this study by only one participant. Difficulties in accessing this group have been outlined in Chapter Three. Participation in education may be the only experience these learners regularly have in a non-mental health

setting and thus has important potential in terms of recovery and integration. It is recommended that a further study be carried out, starting with negotiations with HSE personnel to agree a way in which these learners can take part in research.

This study focused on VTOS-funded full-time education programmes, but the effectiveness for people with mental health difficulties of part-time provision, such as BTEI-funded programmes which offer part-time education to people who have not completed second-level education, is worthy of investigation.

The proposed pilot programme for mental health service users outlined above should be evaluated, with user experience as well as educator and mental health service staff feedback taken into account.

#### **6.4 Summary**

In spite of the recommendations and recovery-based aspirations of policy documents (Expert Group on Mental Health Policy, 2006; NESF, 2007; Mental Health Commission, 2005, 2008), there has been slow progress in Ireland towards a social model of mental health service provision and of links with other agencies such as education providers. Concurrently, VEC adult education provision for mental health service users has not changed sufficiently from the traditional model of classes in segregated mental health settings. Initiatives in other jurisdictions such as New Zealand, the USA, Northern Ireland and the UK, as well as some Irish projects, point the way to more inclusive possibilities.

In order to progress towards inclusive practices and initiatives, there is a need for VECs to develop and operationalise equality policies. These policies should comprise development and implementation of guidelines for support and inclusion of learners with mental health difficulties, supported by staff development set in the context of equality and inclusion. As an expression of the concept of Universal Design, staff development with regard to support of learners with mental health difficulties will improve practice in relation to all students. Policy should also include development of links with mental health services and of mainstreaming frameworks to provide opportunities for integration, inclusion and progression of learners with mental health difficulties in adult and further education settings. Opportunities to participate in

education in inclusive mainstream settings will offer to people with mental health difficulties bridges and stepping stones through which they may progress towards recovery and social inclusion.

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## **Appendix 1**

### **INFORMATION FOR PARTICIPANTS**

#### **RESEARCH PROJECT**

#### **RETURN TO LEARNING: THE EXPERIENCE OF PEOPLE WITH MENTAL HEALTH PROBLEMS**

#### **WHAT IS THE PURPOSE OF THIS RESEARCH PROJECT?**

I want to find out about the experiences of people with mental health problems who attend or have attended VEC-run education courses. The aim of the study is to develop guidelines for colleges and education centres to improve support for learners with mental health problems. My report on the project will also be part of my thesis for an Education Doctorate in NUI Maynooth.

#### **WHAT WILL HAPPEN IF YOU TAKE PART?**

I will meet you for a one-to-one interview, where we will discuss your experience of return to education. The interview will be recorded and then typed up. Then I would like to meet you a second time to give you a copy of the interview and to get your opinion on the points I have taken from it. The first interview will take about an hour, the second will be shorter.

If you decide to take part, you are free to change your mind and withdraw from the research project at any time.

#### **ANONYMITY**

In any reports or publications resulting from this study your identity will remain anonymous. Your name and any other things that might identify you will be changed. Your name will not be published or disclosed to anyone.

#### **BENEFITS AND RISKS**

This study will draw upon your expertise in order to understand better what is helpful or unhelpful to people with mental health problems who attend VEC courses. By taking part, you will make a contribution to developing VEC policies and improving educational opportunities for people with mental health problems.

A possible risk of participating in this study is that thinking about your own experiences may make you feel uncomfortable or sad. Remember you do not have to answer any questions you do not wish to. If you need to speak to somebody during or after the study or if you have any concerns or questions regarding this study please feel free to contact me at any stage.

[Contact details]

## Appendix 2

### PARTICIPANT CONSENT FORM

PLEASE TICK YOUR RESPONSE IN THE APPROPRIATE BOX

- I have read and understood the Participant Information YES  NO
  
- I have had the opportunity to ask questions and discuss the study  
YES  NO
  
- I have received satisfactory answers to all my questions  
YES  NO
  
- I have received enough information about this study YES  NO
  
- I agree to take part in the study YES  NO
  
- I understand that I am free to withdraw from the study at any time  
YES  NO
  
- I agree to have my interview tape-recorded YES  NO

Participant's Signature: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## **Appendix 3**

### **NOTICE SEEKING PARTICIPANTS**

#### **RESEARCH PROJECT**

#### **RETURN TO EDUCATION**

#### **WOULD YOU LIKE TO HELP?**

**I am trying to find out about the experiences that people with mental health problems have when they return to education.  
I am interested in VEC courses in particular.**

**If you have attended a course of at least ten hours per week  
in a VEC college or adult education centre  
I would like to meet you to discuss questions like:**

**What was good/bad about the experience?  
What did the college or education centre do to help?  
What could have been more helpful?**

**If you started a course and didn't complete it, I would be particularly interested in meeting you.**

**The interview would be confidential.**

**The aim of the project is to develop guidelines for colleges and education centres to improve support for learners with mental health problems.**

**If you think you would like to take part, give me a call on**

**Thanks!  
Marie Rooney**

## Appendix 4

### **COUNTY DUBLIN VEC ADULT AND FURTHER EDUCATION DRAFT GUIDELINES FOR INCLUSION AND SUPPORT OF LEARNERS WITH MENTAL HEALTH DIFFICULTIES (*These guidelines are to be piloted in County Dublin VEC full-time adult and further education programmes in 2010*)**

Many adult learners in VEC programmes have experienced or are living with mental health difficulties. Mental health can be viewed as a continuum, ranging from well-being to extreme distress, on which our position may vary at different times in our lives. Some learners will be dealing with or recovering from experiences of mental distress. This is to be distinguished from intellectual disability, although a minority of learners will be living with both forms of disability

Returning to education can be a significant step in the process of mental health recovery, with the potential to bring growth in personal confidence and self-esteem, a sense of hope and direction, increased social inclusion and the benefits of gaining/regaining abilities and skills.

The development of policies for inclusion and support of learners with mental health difficulties is an important step in County Dublin VEC's aim of promoting equality. Disability, including mental illness, is one of the nine grounds covered by equality legislation. These guidelines support equality of participation for students with disabilities and will benefit all our learners by promoting good adult education practice.

#### **Background**

In 2007-8 County Dublin VEC delivered two training days in response to requests from co-ordinators and tutors across our Adult Education Service for guidance and support in relation to working with learners with mental health difficulties. Feedback on the training was very positive and participants suggested that as a next step, guidelines on working with learners with mental health difficulties be developed and disseminated to all teaching staff in County Dublin VEC's Adult Education Service. To develop the guidelines, a working group was formed which included County Co-ordinators, an Adult Education Officer, an Adult Literacy Organiser, a Guidance Counsellor, a VTOS Co-ordinator and a Psychologist from the Psychological Support Service. The working group met on six occasions between April 2008 and May 2009. It consulted with focus groups of adult learners in our Adult Education Service; with trainees in rehabilitation training programmes for mental health service users run by the HSE and FÁS; and with County Dublin VEC's Adult Education Guidance Service.

## ACCESS AND ENROLMENT

### Publicity material/written information

We aim to convey a positive message through the use of inclusive and friendly language. It is recommended that the following statement be carried in the publicity and advertising material of all FE colleges and local adult education services:

*[County Dublin VEC/College/Service] aims to provide an inclusive education service in which individual differences are welcomed and respected. We recognise the right of every person to learn and develop through education and we are committed to supporting you in working towards your educational goals.*

### Application/enrolment forms

The Application/Enrolment Form should include a question on disability in order to identify and plan for learner support needs.

*The [college/service] may be able to provide some additional supports to [students/learners]. Do you have a health issue, a disability or specific learning difficulty you would like to discuss with us?*

Yes  No

*This information is not used as part of a selection procedure, but in order to help towards planning a successful learning experience.*

If yes, consult with the applicant re carrying out an assessment of learning support needs (see p.2)

The Application/Enrolment Form should ask for an emergency contact name and phone number:

*In the event of an emergency, who should we contact?*

<i>Name</i>	<i>Phone Number</i>	<i>Relationship/Role</i>

[Prompt for Next of kin, General Practitioner, Community Nurse or Support Worker]

### Interview

As is current good practice for all applicants, when the applicant arrives for interview, reception staff should be friendly, welcoming and helpful. The interview should take place in a private area where learners can discuss their needs and provide information. The interviewer(s) should try to make the interview as relaxed and informal as possible.

### **Follow-up on application form**

If an applicant indicates on the enrolment form that they have a problem for which they may need support, they should be interviewed in the first instance by the course co-ordinator with, if possible, the guidance counsellor. If participation by the guidance service in the interview process cannot be arranged, it is recommended that the co-ordinator consult with the guidance counsellor with regard to suitable support for individual learners.

This interview is an opportunity to discuss what difficulties the learner may have and what support they may need. The aim should be to ascertain what a person's learning needs are, not necessarily their diagnosis or 'label'.

- It is important to make it clear to applicants that any information given will not be used to exclude them but that it is needed in order to help in planning for successful inclusion. Although every eventuality cannot be planned for, it is better to try to put in place the supports a learner needs before they start their course, rather than wait until a concern, problem or crisis arises.
- It is important to be clear about what can be offered and not to make promises or offers that cannot be fulfilled.
- Arrange a review meeting between the learner and either the course co-ordinator or the guidance counsellor after e.g. a month to see how arrangements are working out.
- Remember that disclosure is at the discretion of the learner and a person's right not to disclose difficulties must be respected.

### **Information and Confidentiality**

Requests for information should be on a 'need to know' basis. Information about a person's mental health should only be requested where it may affect their learning. Requests for psychiatric diagnoses should be avoided. They are not likely to be very helpful to teaching staff as they say nothing about how an individual learns or about the implications of the mental illness for their learning. There is also the danger of evoking negative and inaccurate stereotypes about mental health difficulties.

Because of the stigma associated with mental health difficulties students may well be concerned about who will have access to information, and we need to be able to justify our policies on confidentiality and avoid unnecessary discrimination. The co-ordinator – or whoever the person is to whom the learner has disclosed a mental health difficulty at interview - should ask the learner whether they want the information disclosed to be shared with tutors. It should be made clear to the learner that any information given will be passed on to another person only with the learner's knowledge and permission. Information to tutors should be in the form of information on learning needs rather than on mental health difficulty or diagnosis – functional rather than diagnostic information.

Although learners have a right to disclose information about themselves to other staff members, this does not give staff a right to discuss the information with each other. A student's personal circumstances or difficulties should

never become the subject of casual conversation among staff. Ensure that information about the learner is not left exposed to public view on computer screens or papers on desks.

As with any information held in confidence, there are exceptions to confidentiality with regard to legal obligations to disclose information related to crime or if a person is a danger to self or others.

## **SUPPORT**

Learners who are challenged by mental health difficulties may need extra support in order to complete their course successfully. An inclusive and encouraging attitude on the part of staff is the most important support.

Establishing clear boundaries is important. Maintain a balance which acknowledges a person's mental health difficulties and their potential impact on learning, but also recognises that people are learners or students, not 'clients' or 'patients'. It is important to remember that the focus of support should be on learning needs, not on mental health difficulties.

Show empathy – try to understand what is of real concern to the student. But avoid judging or advising them about non-educational matters.

Promote independence and empowerment. Encourage the student to make their own decisions.

There are particular times when students may need more support:

- During the first few weeks of a course
- 6 – 8 weeks into course, when motivation may dip
- Around holidays and breaks
- Before and/or during an exam or assessment
- When there are unforeseen changes, e.g. new tutor, change of venue
- Towards the end of course and in preparing for progression

Learners experiencing mental distress often find organisation of work and time management very challenging. Sometimes concentration may be affected by medication.

It is important for vulnerable learners, including those with mental health challenges, that there is a key staff member whom they experience as supportive and approachable. This may be the course co-ordinator or another designated staff member, e.g. class tutor. It is important for this staff member to maintain awareness of the learner's progress. Keeping in touch may sometimes involve initiating contact with the learner (e.g. phoning or texting the learner if s/he is absent) rather than waiting for the learner to approach them.

### **Course co-ordinator**

The course co-ordinator can play a crucial role in supporting successful learner participation. S/he should consider ways of:

- Conducting initial interview if applicant indicates need for support on application form.
- Giving tutors appropriate information/advice on learning needs of individual students
- Organising induction for new class groups to foster integration and the development of a good group dynamic
- Building in regular review times for discussion and problem-solving with the learner. Ideally these would be on a one-to-one basis (with co-ordinator or other support person, e.g. guidance counsellor) if resources or time allow. Mentoring such as this, to support the student in planning and organising their learning, has been found to be very helpful for students with mental health difficulties. For one-to-one work such as mentoring with these and other students, use of a suitable private room or office is necessary. As with any one-to-one work with learners, health and safety protocols should apply.
- Allowing some flexibility to facilitate attendance at medical/ counselling appointments

For many learners the above support will be sufficient for their successful participation. Others may experience difficulties which necessitate enlisting further supports:

- Referring learners, with the help of the guidance service, to support services such as counselling and social welfare services
- Making contact or consulting with the learner's community mental health nurse or other support worker, with the student's permission.

It is important to recognise that for some learners who experience recurrent serious mental distress, 'interrupted learning' may be the best option. They may need:

- negotiation of part-time attendance or
- negotiation of leave of absence and support and liaison to organise an effective return to learning.

If a student decides not to complete a course, whether due to mental health difficulties or for other reasons (such as a mismatch between the demands of the course and the student's learning to date, personal difficulties or change of preference away from a given course), he/she should be offered an exit interview, if possible with the guidance counsellor. This meeting should facilitate discussion around the reasons for wishing to leave the course, the implications of this decision and the exploration of plans and options for the future. The aim should be to ensure that the student sees the benefits of the learning experience even where it is incomplete and has feasible plans for moving forward.

### **Tutor**

Much of the support which tutors can provide is simply good adult education practice:

- Being friendly, interested and encouraging
- Creating a climate in which the learners' preferences and views can be expressed

- Creating a climate of learning, respect and safety within the classroom
- Using a variety of teaching methods to suit different learning styles
- Showing where progress is being made and helping learners recognise their achievements
- Providing positive, encouraging and constructive feedback (see County Dublin VEC guidelines on learner feedback on [www.codubvec.ie](http://www.codubvec.ie))
- Encouraging peer-support, e.g. suggesting to students that they form study groups or building in peer support sessions in class time (e.g. planning/review work in pairs or small groups)

For some learners with mental health difficulties the tutor could also help by:

- Providing written notes/handouts or tape recordings that learners can refer to when they recover from a concentration lapse or a 'bad patch'
- Consulting, in some cases, with the course co-ordinator about possible special arrangements for assessment /reasonable accommodation (e.g. extra time)

### **CHALLENGING BEHAVIOUR**

Crisis situations, emotional outbursts or difficult behaviour are by no means limited to learners with mental health problems. The following are general guidelines for conflict resolution. They are also applicable in situations where the learner has a mental health difficulty.

#### **Be aware**

- Recognise early signs of potentially difficult situations, such as agitation in the learner.
- Try to find ways to defuse the situation.
- Be aware of your own behaviour as a starting point for managing the behaviour of others.

#### **Listen**

- Try to find out what the problem is and give the learner the opportunity to talk about it.
- Ensure the learner knows you are taking them seriously and that you are really listening to them by:
  - Trying to clarify and summarise what the learner has said, e.g., 'Let me check that I've understood what you're saying...'
  - Acknowledging the learner's feelings, not by naming an emotion or telling them how they feel, but by saying something like 'It seems to me that you're upset / that this issue is very important to you'
- Offer the learner other ways of making their point, e.g. by making a formal complaint.

#### **Be calm**

- Stay calm, be patient and consistent
- Try not to express undue emotion. Avoid mirroring the other person's anger or annoyance.
- Be aware it is not necessarily you the emotion is aimed at, but the organisation or a particular situation. Try to remain focused on the issue rather than the emotion.

### **Communicate clearly and simply**

- I-language ('I feel', 'I think') is less critical and judgmental than you-language ('you are', 'you do')
- It may be necessary to repeat the same information, e.g. "As I said earlier ...".
- If the learner is not giving you the opportunity to speak, use their name, e.g. "Brian, I'm just going to interrupt you here...." or "Let me just check / summarise what you've been saying ..."
- Sometimes a difficulty may arise which disrupts the learning environment. In order to defuse tension in the class group you might suggest deferring discussion with the learner to a different time and setting.

Crisis incidents can be useful learning experiences and some time spent reflecting on the situation can be very helpful. Ask yourself:

- Can I see a reason behind the learner's behaviour?
- Was it possible to deal with the cause or reason for the learner's behaviour?
- Could I have anticipated it?
- Could it have been avoided?
- What would I do differently?

If a difficulty arises that substantially disrupts the learning environment, consideration may need to be given to implementing procedures for managing problematic behaviour. Such procedures would normally be published in advance and be applied in a fair and consistent manner with all students. Individual cases may require some degree of flexibility, but the primary goal is to ensure that learning can occur and the environment is safe and respectful for both students and tutors.

At times it may prove beneficial to have a meeting with an individual to address ongoing or serious issues related to the learning environment. It is good policy to try to resolve issues as quickly and as fairly as possible. The possibility of bringing an advocate (partner, family member, friend, class representative, key worker) to such a meeting could be offered to the student. The goal of this meeting is the development of a plan forward that will maintain the integrity of the learning environment for all and seek to meet the needs of the individual.

On occasion it may be appropriate to take external advice on such matters, for example from a student's key worker in mental health services or from the Psychological Support Service (PSS). The PSS is available to consult with staff members and to provide short term support if necessary. The guidance counsellor may also have a positive role to play.

In some cases a student may be unable to adhere to the requirements of a learning centre in terms of behaviour. An exit interview could be utilised here. The possibility of bringing an advocate (partner, family member, friend, class

representative, key worker) to such a meeting could be offered to the student. Also the student should be offered a meeting with the guidance counsellor.

### **SELF-CARE**

Dealing with a crisis situation, difficult behaviour or an emotional outburst can be difficult and upsetting for the tutor. It can help to talk about the situation and your feelings with someone else who has some experience, but who is non-judgmental or non-managerial, e.g. a more experienced colleague. The Psychological Support Service is available to provide short term support to members of staff where appropriate. All such queries are treated with discretion and staff members link directly with the Psychological Support Service themselves. It is not a sign of failure or inadequacy to ask for this opportunity - it is a very reasonable and professional response.

### **Boundaries**

Maintenance of professional boundaries is important. There are danger signals that a tutor is becoming over-involved in a learner's problems if a tutor sees it as a personal responsibility to sort everything out, feels they are the only one who can help or if their involvement is beginning to affect their private life and free time. Remember the distinction between the role of a counsellor/therapist and that of an educator or facilitator of learning.