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Introduction

Peter Ryan, Shulamit Ramon and Tim Greacen

The chapters that follow offer a European and international perspective on empowerment, lifelong learning, social inclusion and recovery in mental health. In particular, they explore the contribution that lifelong learning – a hitherto neglected concept in the area of mental health – can make in linking these concepts into a coherent whole. The thesis of the book is that these four concepts are closely connected. We believe that together they contribute to a new paradigm in mental health, one that locates the service user as the central driver of their own life, a life of their own choosing, in a community in which they are citizens with equal rights to all other citizens and with mental health services configured so as to support this process rather than perpetuating the traditional ‘client’ or ‘patient’ roles.

The field of mental health is undergoing a considerable paradigm shift in terms of rethinking core issues that, until recently, have been taken for granted, such as chronicity, deficits and strengths, capability for social inclusion, peer support, education, training and employment, and the meaning of empowerment and recovery from mental illness. Inevitably, a change of this magnitude within a complex system in which mental health services operate everywhere attracts responses ranging from the enthusiastic right through to the dismissive and hostile. How to enable service providers, users, carers and the general public to be open to the possibilities this shift can lead to, and to actively participate in the process of this change, forms a central part of the contributions to this book.

Despite promising beginnings, the evidence-based knowledge of how to achieve empowerment, recovery, social inclusion and the potential contribution of lifelong learning is at its infancy. As these notions become increasingly recognised across Europe, and indeed internationally,
more and more service users are participating as partners in many aspects of health and social care delivery, policymaking and professional training. While there are recent publications on recovery (Slade 2009, Repper and Perkins 2003), relatively less has been produced on empowerment (Barnes and Bowl 2000) and less still on lifelong learning in terms of its links and application to mental health.

This book explores new ground in identifying the barriers and obstacles to empowerment as well as good practice examples in developing effective approaches to integrating these concepts in both mental health services and educational institutions. In particular, the book highlights the role lifelong learning can play in offering a bridge to the achievement of recovery. The mutual benefits of this approach to all stakeholders are emphasised, without glossing over the difficulties inherent in it, and it will, we hope, be relevant and of interest to a wide audience including health and social service professionals and managers, service users and those involved in higher education.

The book is divided into three interlinked sections. The first gives an overview of recovery. The second focuses on the closely linked issues of social inclusion and employment. The third part views empowerment and lifelong learning as essential processes by which recovery can occur at the individual level.

**Part I Recovery**

Early longitudinal research by Ciompi (2005) in Europe, Harding et al. (1987) in the US and others challenged the pessimistic assumption held by many professionals at the time that severe mental illness is long-term and chronic, and that remediation of long-lasting and chronic symptoms coupled with dependency upon mental health services is the best available outcome. Implicit in this traditional conceptual framework was the view of the service user as a passive recipient of specialist medical and social care, with little input from the service users themselves. The importance of these longitudinal studies was to uncover the multiple outcomes associated with severe mental illness and to show that many people did progress beyond a state of merely chronic remediation. Thus the concept of recovery began to obtain legitimacy (Sullivan 1997).

Although there are many perceptions and definitions of recovery, Anthony (1993) developed a definition that many regard as cornerstone:

[A] deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It is a way of living
a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.

Implicit in this view of recovery is a highly individual process of coming to terms with one’s own life experience and of redefinition of identity from ‘patiencethood’ to citizenship, a process in which lifelong learning plays a crucial part. A similar point is made by Deegan when she stated that ‘any person with severe mental illness can grow beyond the limits imposed by his or her illness’ (Deegan 1993). If, as Deegan implies, developmental learning is a core part of the recovery process, then this has major implications for mental health services. One of the necessary and sufficient preconditions of recovery is that it occurs in a context in which the recovering individual is fully included in and able to engage in work and other meaningful activities, and that these are so organised that social inclusion is possible. The experience of mental illness can and usually does profoundly affect the individual’s sense of self, of personal identity. In times of crisis, the self can cease to be capable of independent functioning and retreats to being an institutionally or service-defined ‘product’ or ‘entity’. At this point, services capable of ‘holding’ people when in acute crisis are certainly necessary and indeed essential. Catastrophic events such as involuntary admission negatively affect many areas of life, and many of those who experience mental disorder hope for a return to or recovery of aspects of their life that they had before. Desire for a return of self-confidence, self-esteem and positive hope for the future, coupled with being believed by others to be capable of recovery, help provide an individual with the drive to seek to recover, to learn how to adapt to the challenges they face and to find new ways of ‘being in the world’.

Lifelong learning is key to the process of recovery, putting into motion a process in which the person reclaims their ‘sense of self’, in which the painful episodes and experiences of mental illness form an ensemble around which a new sense of self can grow, a sense of self which is not institutionally or externally defined. To recover, the service user employs existing learning and acquires new learning alongside unlearning, which together form a new identity as someone who has been profoundly influenced by, but who has moved beyond, the traditional mental health service identities of ‘patient’ or ‘client’. The paradox for mental health services is that they themselves are institutions, complex organisational bureaucracies, and it is at the very least
challenging for such services to provide the intensely personal and private fulcrum for change that many point to as the essential starting point for recovery.

Recovery from mental illness involves many different factors and is 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 side effects of unemployment; and from crushed dreams’ (Deegan 1993). A great deal of new learning is required for different aspects of an individual’s recovery in a complex and often lengthy process. Lifelong learning and recovery are in this sense both part of the process of forging a meaningful, coherent pattern out of the disparate and disjointed experiences that are often created through the experience of ‘being mentally ill’. Ralph, Kidder and Phillips (2000) concluded that ‘recovery can be defined as a process of learning to approach each day’s challenges, overcome our disabilities, learn skills, live independently and contribute to society’. According to the European Commission, lifelong learning is ‘all learning activity undertaken throughout life, with the aim of improving knowledge, skills and competence, within a personal, civic, social and/or employment-related perspective’ (EU COM 2001). Both these approaches are describing lifelong learning and recovery as ways to generate a strengthened locus of control, gains in empowerment and increased independence.

Part I of this book comprises five chapters. Helen Glover starts out with a comprehensive overview of the whole agenda covered in this book from a service-user perspective and explores the possible linkages between recovery, social inclusion, empowerment and lifelong learning. She discusses whether this does, or potentially could, constitute a new paradigm for mental health. She cautions that this might, in certain circumstances, be ‘just words’ and warns against mental health services badging themselves as ‘recovery-oriented’ when in reality nothing much may have changed. Chapters 2 and 3 describe two alternative views as to under what conditions recovery can best be fostered and encouraged. In Chapter 2, Wilma Boevink describes her work in the TREE programme (Towards Recovery, Empowerment and Experiential Expertise) at the Trimbos Institute in the Netherlands, an approach driven and led by service users, which sets out to provide effective methods and strategies developed by people with mental health vulnerabilities in order to help themselves as their own programmers of recovery. The TREE programme runs user self-management groups and is staffed by trainers
who are themselves service users who pass on their own knowledge and experience to others with respect to mental health difficulties, with the long-term aim of facilitating empowerment in as many ways as they can. Chapter 3 also focuses on a user-led and user-driven approach, but this time located in the voluntary sector in the United Kingdom. Barbara Evans and Kate Sault describe how the Wellness Recovery Action Planning (WRAP) approach, based initially on the American work of Mary Ellen Copeland, has been applied in a European context. Again, this approach is user-driven and puts forward a systematic and structured approach through which service users can self-manage their own difficulties. In Chapter 4, Robert Surber describes his journey from his initial assumption that he could, as a service provider, run, plan and manage recovery for the service user, to the realisation that this was precisely what he could not do – again emphasising that recovery is an intensely personal experience and that perhaps his best contribution as a service provider was to step out of the way and, to put it bluntly, to stop interfering. Boardman and Shepherd, in Chapter 5, describe a model and methodology for the total reconstruction of mental health services so that they might in fact offer the new perspective and direction in order for recovery to happen in practice. This chapter also gives an early indication of how successful this approach can be when actually implemented.

**Part II: Social Inclusion and Employment**

While social inclusion certainly includes the critically important issue of ensuring that people with mental health difficulties get back to the open employment market, it is also about participation in society in a broader and deeper sense. Social inclusion is about more than access, or improving access to mainstream services. It is about participation in the community, as employees, students, volunteers, teachers, carers, parents, advisors, residents, as active citizens. People with mental health difficulties have a right to access social, economic, educational, recreational and cultural opportunities, as well as physical health services, that are available to the general population. Promoting a social inclusion and employment agenda for those with mental illness is part of the shift of paradigm from a model of care that saw the ‘mental patient’ as an essentially passive recipient of care, whether delivered by a social worker, nurse, psychiatrist or peer support worker, to a far more active and dynamic partnership model where the service user is not only seen as defining and steering their own care in the community, but also where they are seen, and see themselves, as citizens with human rights.
As a reflection of the importance of these issues, social inclusion policy and legislation against social exclusion have been developed over the last few years both at the European and national levels (MHE 2006). Social exclusion refers to the extent to which individuals are unable to participate in key areas of economic, social and cultural life: ‘An individual is socially excluded if he or she does not participate in key activities of the society in which he or she lives’ (Burchardt, LeGrand and Piachaud 2002). The major indicators of social exclusion relate to a combination of linked, inter-related problems: unemployment, poor skills, low incomes, poor housing, high crime, poor physical health and family breakdown. Social inclusion therefore needs to address all these problems.

Social inclusion and employment in particular are vital issues for those experiencing mental health difficulties. From an ethical viewpoint, the right to work is included in the Universal Declaration of Human Rights (United Nations 1948) and has been incorporated into national legislation such as the UK Disability Discrimination Act 1995 (Crowther et al. 2001), as well as in the social policy and legislation of many other European countries (MHE 2006). If a person with mental illness is in paid employment, then society benefits from the contribution made by the person through their work and also from the reduction or elimination in state aid paid out to the individual. Employment can also bring many advantages for the individual who suffers from mental illness. It can increase the level of financial and social independence, reduce the stigma associated with mental illness, and increase self-esteem and self-worth through, for example, improving his or her social standing within community (Linhorst 2006). Employment can strengthen self-identity because people define themselves, and society defines people, in part by their work (Linhorst 2006). Employment provides a means of structuring life (Rinaldi et al. 2004) and increases lifestyle regularity, both of which can be important in the maintenance of prescription drug schedules. Employment also facilitates greater social interaction and allows people to develop new social relationships. Additionally, it can increase a mentally ill individual’s acceptance within society (Kinsey, Hyde and Jackson 2003) and, because employment raises the standard of living of an individual, it provides the individual with an increased range of lifestyle and consumer choices (Linhorst 2006).

Severely mentally ill service users tend in most European societies to have very low levels of employment. Unemployment or poorly paid, temporary jobs have been shown to have a negative impact upon the mental health of the people concerned (STAKES 2000). Two decades or so ago, employment opportunities for people with severe and enduring
mental illness were almost completely absent. Ryan et al. (1999) found that 99 per cent of the severely mentally ill were unemployed, and had been so for over three years. Similar findings were made by Burns et al. (1999) and Thornicroft (1998). More recently, Burns et al. (2007) found unemployment levels of 77 per cent amongst those with long-term mental illness in the European study EQOLISE.

In Chapter 6, Davidson, Flanagan and Styron set the agenda for mental health in terms of a radical model of community inclusion, going far beyond the notion of the service user making an optimal adaptation within the confines of mental health services. They emphasise the important distinction between integration and inclusion: ‘The community inclusion paradigm argues that people with long-term disabilities – including people with long-term psychiatric disabilities – should be accepted and welcomed by their communities as they are, with whatever conditions they may have, without having to be cured, fixed, or otherwise made to conform to selected societal norms first’. In Chapter 7, Schneider focuses on the issue of employment as a crucial aspect of social inclusion. She describes the Individual Placement and Support (IPS) model of facilitating employment for those with long-term mental health difficulties and gives an account of implementing such an approach in Nottingham in the UK. Finally in this section in Chapter 8, Greacen and Jouet, using source material drawn from the EMILIA project, describe a methodology for identifying the barriers and obstacles preventing full social inclusion, as well as identifying evidence-based strategies for overcoming these obstacles.

Part III: Empowerment and Lifelong Learning

Empowerment can be seen as the process by which people take control of their own lives and make their own choices, acting where necessary to overcome obstacles preventing that fulfilment. It is about increasing the capacity of individuals to become more in control over their lives and is a means which allows greater participation in decisions, along with increased dignity and respect and a sense of belonging and contributing to a wider community. It is important to view empowerment in this broader context, as referring to the level of choice, influence and control which service users can exercise over all events in their life, and about their rights as citizens. This issue is well summarised by WHO (2010). ‘The key to empowerment is the removal of formal or informal barriers and the transformation of power relations between individuals, communities, services and governments. Power is central
to the idea of empowerment’. With regard to mental health services, empowerment can be seen as referring to the level of choice, influence and control which service users can exercise over services provided. With respect to their experiences of services, it is often the case that they are at a minimum poorly informed, and often poorly consulted and/or poorly treated by mental health service. Historically, people with mental health problems did not have a voice; they and their families were not involved in decision-making processes in policy and practice of mental health services, and they had to face social exclusion and discrimination in all facets of life. Current reports on mental health in the European region show that this has not changed significantly in recent years (WHO 2009). Disempowerment of mental health services users has operated at societal, service provision and individual levels. At the individual level, many service users remain traumatised for long periods of time with damaged internal senses of identity and self-worth through their difficult experience of living in society with a mental illness – a process of internalisation of the external stigma which society itself has traditionally imposed upon them.

For the European Commission (EU COM 2001), lifelong learning is ‘learning that is pursued throughout life: learning that is flexible, diverse and continues in many different contexts and settings’, with four broad and mutually supportive objectives: personal fulfilment, active citizenship, social inclusion and employability/adaptability. Lifelong learning is considered as an important part of the European Union’s Lisbon strategy according to which the European Union aimed to become by 2010, the most competitive and dynamic knowledge-based economic area in the world, as well as a more cohesive and inclusive society. Acquiring and continuously updating and upgrading skills and competences is considered a prerequisite for the personal development of all citizens and for participation in all aspects of society.

Delors (1996) refers to the four ‘pillars’ of lifelong learning:

- **Learning to know** – learning how to learn rather than specific sets of knowledge
- **Learning to do** – developing the capability to adapt and respond creatively to new challenges and new demands
- **Learning to live together and with others** – peacefully resolving conflict, discovering other people and their cultures, and fostering community capability
- **Learning to be** – learning that contributes to a person’s complete development, of mind and body, aesthetic and cultural appreciation, and spirituality
Delors’ model shows that there are clearly important links between empowerment and lifelong learning. It views lifelong learning as a central component of a process leading to personal fulfilment, social inclusion, employment in meaningful work activity and a role within society as an active and valued citizen. It is arguable that a significant component of personal fulfilment is both the capacity and the experience of making one’s own life choices – the central feature of empowerment. Equally, social inclusion is central, and in this sense, lifelong learning can perhaps best be seen as a core mechanism facilitating for the individual concerned a fully socially inclusive role in society.

In Chapter 9, Ryan, Baumann and Griffiths give an overview of empowerment, both in terms of clarifying a variety of ambiguities surrounding the use of the term and describing its evidence-base. In Chapter 10, Crepaz-Keay, coming from a service-user perspective, gives recommendations for practice and advocates the use of a set of indicators of empowerment, applicable at the national level. In Chapter 11, Anderson and Holmshaw address the issue of empowerment in terms of exploring service-user involvement both as researchers and teachers in the higher education setting. The remaining chapters of the book discuss lifelong learning drawing in different ways upon the experience of the EMILIA project, a recent European project on the role of lifelong learning in the social inclusion of mental health service users. Ogunleye, Griffiths, Dawson and Nybjerg, in Chapter 12, give a broad overview of the meaning and policy context of lifelong learning and outline the health benefits of lifelong learning to disadvantaged groups such as those experiencing long term mental health difficulties. Kaunonen and Ramon in Chapter 13, drawing on qualitative research evidence from the EMILIA project, give an account of organisational mechanisms, such as the Learning Organisation, necessary to promote lifelong learning. The following two chapters describe lifelong learning from a service-user perspective. In Chapter 14, Nilsen gives a powerful account of the barriers, obstacles and difficulties in developing systems and structures which genuinely enable empowerment. In Chapter 15, Nieminen, Nilsen, Vila, Solá and the Fenix user group from Tuzla in Bosnia summarise the service-user perceptions of the benefits of lifelong learning, drawing on data from the Emilia project qualitative research. Finally, in Chapter 16, Stenfors-Hayes and Ryan offer a close analysis of the role of the service-user trainer, which was utilised throughout the lifelong learning programmes in the EMILIA project, describing this role in terms of a pedagogic model of teaching and learning.
The EMILIA project

The EMILIA Project (Empowerment of Mental Health Service Users through Lifelong Learning, Integration and Action), described in several chapters of this book, was a large EU Framework 6 action research project, based in eight demonstration sites across Europe (Athens, Barcelona, Bodø, London, Paris, Tuzla, Warsaw, Zealand) and supported by several other key institutions (Aarhus University, the Karolinska Institute in Stockholm, the Faculty of Social Work at the University of Ljubljana, Middlesex University, Tampere University and the University of Vilnius). The overall aim of the EMILIA Project was to reduce social exclusion in people with serious mental illness through lifelong learning. This included improving the way in which service users could experience greater participation both in service delivery and in education and training, including greater social inclusion in general, through paid employment and significant activities, however locally defined.

Throughout the project, the eight demonstration sites varied considerably in culture, economic situation, the structure of mental health services, as well as in readiness and ability to offer social inclusion and recovery opportunities to people with severe mental illness experience. Seven of the sites were providing mental health services, while one site was a university faculty (London); two of the clinical sites were also research centres (Zealand in Denmark and Warsaw in Poland). Of the seven sites, five had a hospital as the core of their service, and three had community services such as day centres and group homes (Athens, Greece), a user group (Tuzla, Bosnia) and an out-patient clinic (Zealand).

The focus of the EMILIA project on enhancing social inclusion and recovery for people with long-term mental illness called for a process of adaptation in the demonstration sites, given that meeting these objectives required an organisational structure and a local social context that not only welcomed service users but also was ready to offer them opportunities far beyond those usually on offer in clinical practice in preparing them for a more independent life, employment and enhancing their social network as means of empowerment (Ramon, Ryan and Urek 2010, Ramon 2011).

The project, funded by the EU under its Framework 6 from 2005 to 2010, recruited adults (aged 18 and above), diagnosed as having severe and enduring mental illness (schizophrenia and bipolar disorder), in contact with mental health services for at least three years and who were not in paid employment. They were offered a series of training modules with other service users, and opportunities for employment or significant activities within the demonstration sites as well as connecting them to potential employers outside the sites in which the project operated.
An extensive quantitative and qualitative evaluation took place at all demonstration sites at baseline, ten months and twenty months in terms of their socio-demographic status, their take up of the training and of unpaid and paid employment, their own evaluation of the impact of participation in the project in relation to employment, social interaction, training activities, opportunities and obstacles, and goals for the near future, as well as related organisational changes in the demonstration sites. The project in many ways succeeded in creating user employment and supported pathways both within demonstration site organisations and in competitive employment.

The final report of the EMILIA Project can be consulted at http://www.mdx.ac.uk/Assets/3a(i)1%20EMILIA%20FINAL%20PUBLISHABLE10610FIN3_predit.pdf.

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