

**Improving Care in Longer Term Mental Health Facilities**  
**International differences in quality**  
**and service user experience of care**

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I, Tatiana Taylor Salisbury, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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# Abstract

## **Background**

Although mental health problems are highly prevalent across the world, relatively little is spent on mental health care and a large number of individuals with mental health problems go untreated. Although the World Health Organization has pressed for countries to increase mental health expenditure and deinstitutionalisation of care in the hope of improved care, there is limited evidence regarding the relationships between national characteristics of mental health care provision and quality of care.

## **Aim**

The aim of this study was to evaluate, in a European sample, the association between national mental health expenditure and the deinstitutionalisation of care and 1) the quality of longer term psychiatric and social care and; 2) service user ratings of care.

## **Method**

Facility managers were interviewed using the Quality Indicator for Rehabilitative Care (QuIRC). Service users in each facility provided ratings of autonomy, life satisfaction, experience of care and therapeutic milieu. Mental health expenditure and deinstitutionalisation were measured using national mental health budgets and a novel quantitative tool, respectively. Multilevel models were developed to evaluate relationships between expenditure, deinstitutionalisation, quality of care and service user ratings of care.

## **Results**

Increased mental health expenditure and deinstitutionalisation were significantly, positively associated with all QuIRC domains, except social interface. Increased expenditure and deinstitutionalisation were also significantly associated with more positive service user ratings of autonomy and experience of care. No associations with service user ratings of life satisfaction or therapeutic milieu were found.

## **Conclusions**

Results suggest that financial investment in and deinstitutionalisation of longer term mental health care are integral to the provision of higher quality care. Lack of available data on country-level variables and the cross-sectional nature of the study design limit generalisability. Future work should include a variety of national, facility and service user variables in order to build more robust models with improved generalisability.

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## List of Abbreviations

AIC	Akaike's Information Criterion
CBT	Cognitive Behavioural Therapy
DEMoBinc	Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care
DISC	Discrimination and Stigma Scale
EFA	Exploratory Factor Analysis
EPSILON	European Psychiatric Services: Inputs Linked to Outcome Domains and Needs
EUFAMI	European Federation of Associations of Families of People with Mental Illness
EuroSC	European Schizophrenia Cohort
FTE	Full-time Equivalent
GAF	Global Assessment of Functioning
GDP	Gross Domestic Product
GMI	Good Milieu Index
ICC	Intra-class Correlation Coefficient
IEP	International Expert Panel
Int\$	International Dollars
KMO	Kaiser-Meyer-Olkin
MANSA	Manchester Short Assessment of Quality of Life
MHDM	Mental Health Deinstitutionalisation Measure
MHEEN	Mental Health Economic Evaluation Network
NHS	National Health Service
QuIRC	Quality Indicator for Rehabilitative Care
RCS	Resident Choice Scale
TAPS	Team for the Assessment of Psychiatric Services
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
YTC	Your Treatment and Care

## Introduction

### ***Scope of the thesis***

Mental health problems are common worldwide. An estimated 356.2 million people have a mental health problem at any given time, a prevalence greater than both diabetes and asthma (World Health Organization 2008). Despite these figures, disproportionately low levels of mental health expenditure, as compared to other illnesses with a similar prevalence, and inequitable provision of care has resulted in a substantial treatment gap. An estimated 44% to 70% of individuals with mental health problems in developed countries are untreated (World Health Organization 2003a). In developing countries, this figure increases to 90%. In Europe, the treatment gap for mental health problems has been estimated to range from 17.4% to 62.3%, dependent on the diagnosis (Kohn et al. 2004).

The provision of mental health care has changed dramatically in Europe over the past 200 years. Today, the deinstitutionalisation of mental health services, the process of closing down mental hospitals in favour of community-based services, is the goal of many countries. The majority of individuals diagnosed with a mental disorder are successfully cared for in the community in primary and secondary care settings. However, even in deinstitutionalised countries, a small proportion of people with severe mental health problems continue to require the higher level of support provided in longer term psychiatric and social care facilities. The majority of these individuals have a diagnosis of schizophrenia or schizoaffective disorder with severe, and often treatment refractory, symptoms (Killaspy et al. 2008). During the period of rapid deinstitutionalisation of mental health care provision towards the end of the 20<sup>th</sup> century, research focused on its effect on the care and outcomes for service users.

Overall the findings are positive, even for those with more severe and complex problems. Comparisons of hospital and community-based care suggest that community-based services are associated with improved service user outcomes and greater satisfaction with care (see section 1.4).

In its report entitled *Mental Health: New Understanding, New Hope* (2001), the World Health Organization (WHO) highlighted the importance of making mental health a global priority by recommending increased mental health expenditure and greater deinstitutionalisation of services. However, the relationship between national variables, such as expenditure on mental health care and the degree to which services are deinstitutionalised, has not been explored. Research in this area may help develop a greater understanding of how government spending and the organisation of services affect the quality of mental health care and service user outcomes. As service users with severe mental health problems in longer term care represent a small but costly group, evaluating the impact of national characteristics on their outcomes may lead not only to improved care but greater cost-effectiveness. This thesis evaluates the relationships of two national characteristics, mental health expenditure and deinstitutionalisation, and (1) the quality of care provided in longer term psychiatric and social care facilities and (2) service user ratings of this care in a European sample.

Chapter 1 begins with a description of the population of interest and an overview of the provision of mental health care from almshouses to community-based facilities in light of societal changes and scientific advancement. I then describe the current state of mental health service provision internationally, focusing on the degree to which countries have been able to deinstitutionalise care, and critically assess recent literature suggesting a shift toward 'reinstitutionalisation'. A reduction in the soaring cost of



mental health care was one of many arguments made for the implementation of deinstitutionalisation in the 1950s. This chapter continues with an evaluation of the costs associated with mental health care. Finally, the literature on the measurement of quality of care in mental health settings is presented and the evidence regarding associations between mental health expenditure and deinstitutionalisation and (1) quality of mental health care and (2) service user outcomes is reviewed.

A systematic review of the current evidence on effective mental health care for service users with severe mental health problems is presented in Chapter 2. This is followed, in Chapter 3, by a description of the development of the Quality Indicator for Rehabilitative Care (QuIRC), an internationally agreed and validated tool which evaluates the care provided in hospital or community-based psychiatric and social care facilities for individuals with severe mental health problems. The QuIRC is used to assess quality of care in my research.

The aims, objectives and hypotheses of my research are summarised in Chapter 4. The development of a novel, quantitative measure of deinstitutionalisation is presented in Chapter 5. Chapter 6 describes the method used to evaluate the associations between expenditure and deinstitutionalisation and (1) the quality of longer term care and (2) service user ratings of care. In Chapter 7, I present the results of my research and discuss their clinical applications. A discussion of the results, their implications, methodological considerations and potential future work is presented in Chapter 8, followed by my conclusions in Chapter 9.

### ***Description of original work***

Research for this thesis has been conducted as part of the ongoing work which has stemmed from the Development of a European Measure of Best Practice for People

with Long Term Mental Illness in Institutional Care (DEMoBinc) project. As a researcher on the DEMoBinc project, I contributed to the development of the QuIRC, by conducting a systematic review of the international literature to identify key components of care. This was used in the development of the QuIRC and is presented in Chapter 3. I also assisted in the compilation of the European dataset by interviewing managers and service users of longer term mental health facilities in the UK.

Data relating to quality of care and service user ratings used in this thesis were necessarily guided by the parameters used in the DEMoBinc protocol:

- The aim of the systematic review of components of care in longer term mental health facilities focused on those related to service user recovery;
- The participating countries were chosen to reflect a range of countries at different stages of deinstitutionalisation;
- The choice of longer term mental health facilities; and
- The random selection of service users were randomly selected from these facilities to participate in interviews regarding their experiences of care and other outcomes.

Except where acknowledged, this thesis represents my own work.

## Chapter 1

### **Review of the Literature**

This chapter provides a review of the evidence regarding the care of a small proportion of individuals who, due to the severity and complexity of their mental health problems, are described as difficult to care for. First, the population of interest is defined and the reasons underlying the difficulty of caring for them is discussed. This is followed by a brief history of the care provided for individuals with mental health problems, including the reasons for the development and dissolution of asylums, the development of community-based care and deinstitutionalisation, and a description of the current provision of mental health care internationally. The next section examines the costs associated with mental health problems. The measurement of quality of care in longer term facilities follows. Finally the evidence relating to the associations between the variables of interest is presented.

#### ***1.1 Defining the population of interest***

Schizophrenia accounts for a relatively small amount (1.1%) of the global burden of disease (World Health Organization 2001). However, globally it ranks fifth and sixth in the leading causes of years lived with a disability among males and females, respectively (World Health Organization 2008). Schizophrenia is characterised by “fundamental and characteristic distortions of thinking and perception, and affects that are inappropriate or blunted” (World Health Organization 2004). In addition to delusions and/or hallucinations, individuals also commonly experience ‘negative’ symptoms such as apathy, amotivation, poverty of thought – “reduced, slowed or impoverished spontaneous cognitive productions” (Harvey et al. 1992, p. 149) – and

cognitive impairment affecting their organisational skills. Individuals diagnosed with schizoaffective disorder experience affective and schizophrenic symptoms to an equal degree but do not meet the diagnostic criteria for schizophrenia.

Individuals with these disorders may experience a continuous illness or episodes in which symptoms may become more pronounced or remain stable. Although schizophrenia is a major mental health problem, the long-term prognosis for the majority of individuals is relatively good. International evidence suggests approximately 20% of people diagnosed with schizophrenia make a full recovery and around 40% make a partial recovery (Jablensky 2009). The suicide rate among individuals with schizophrenia has reduced from around 10% (Miles 1977) to 5% (Palmer 2005) and this usually occurs early in the course of the illness. The remaining group suffers ongoing problems with a chronic or fluctuating course. Recovery is also often further complicated by the treatment refractory nature of symptoms (Meltzer 1997) and the severity of the negative symptoms and cognitive impairments that are a consequence of the disorder itself (Wykes & Dunn 1992; Wykes et al. 1992; Green 1996; Green et al. 2000). It is also common for this latter group to simultaneously experience other disorders and problems, known as co-morbid disorders, which impair recovery (World Health Organization 2001). It is estimated that up to 50% of service users with schizophrenia have co-morbid disorders such as depression (Buckley et al. 2009), problems with substance abuse (Buckley et al. 2009) and pre-existing learning disabilities (Strauss & Carpenter 1974). These complex problems culminate in impaired everyday and social function that result in high levels of support needs.

A small proportion (approximately 1%) of people with a diagnosis of schizophrenia require longer term care provided in psychiatric or social care facilities (e.g.

rehabilitation wards and residential care homes) due to the complexity and severity of their condition (Holloway 2005). These service users primarily suffer from treatment resistant, severe schizophrenia, with characteristics and co-morbidities that impact negatively on their recovery and functioning. Nevertheless, even within this group, with appropriate rehabilitation and support, the majority will improve in functioning over a number of years and be able to move on successfully to less supported community accommodation (Trieman et al. 1998; Killaspy & Zis In press).

## ***1.2 The provision of institutional care for those with longer term mental health problems***

### **1.2.1 Early provision of mental health care**

“At the outset of this period [mid-18<sup>th</sup> century], mad people for the most part were not treated even as a separate category or type of deviants. Rather, impoverished madmen 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; and their richer (though not necessarily more fortunate) counterparts were for the most part coped with by their families” (Scull 1993, p.1).

Systems for coping with individuals with mental health problems have existed for hundreds of years and been transformed by changes in culture and society, as well as developments in science and increased wealth. To deal with the growing problem of poverty in England and France due to the end of feudalism, both governments developed systems of confinement. In 1601 England enacted the poor laws which made families and local communities responsible for taking care of the poor (Levine 1981). In 1656, the French parliament, burdened by the increasing numbers of poor, authorised the opening of the Hopital Generale. However, these systems did not distinguish

between criminal homeless and those suffering from mental health problems. If an individual was unable to be cared for by his family, he was sent to an almshouse, hospital, private madhouse or jail (Shorter 1997; Melling & Forsythe 2006). Unsurprisingly, these institutions provided no treatment but rather served a custodial role, isolating those considered undesirable from the rest of society (Shorter 1997).

Several institutions specialising in the care of individuals with mental health problems existed, although the experience was equally unpleasant. An example of one such institution was the London-based St. Mary of Bethlehem Hospital, later known as 'The Bethlem'. Opened in the 13<sup>th</sup> century, the hospital came to cater solely for patients with mental health problems shortly thereafter. Daily life at the hospital was led with little treatment, intervention or activity. Residents were often treated without dignity. Medical practitioners were banned from visiting and, "in the second half of the eighteenth century, going to Bethlem to laugh at the lunatics was a popular entertainment for the idle and curious" (Jones 1993, p. 9). In France, two Parisian hospices, Bicêtre and Salpêtrière, "...were known as scenes of horror, the inmates regularly flogged, bound in chains and objected to stupefying hygienic conditions" (Shorter 1997, p. 6). Although the treatment of individuals with mental health problems was generally far from acceptable, there were some notable exceptions during this time such as the Maristan Hospital in Grenada, Spain. Built by Muhammad V in the 14<sup>th</sup> century, the hospital provided treatment and kindness to individuals suffering from mental health problems (Galton 1997).

The mid-17<sup>th</sup> century ushered in the age of the Enlightenment. During the following century a focus on science and treatment led to the development of charitable asylums across England (Bewley 2008) and improvement in care across existing institutions. In

1792, Philippe Pinel set about changing the treatment of patients in Bicêtre and Salpêtrière by demanding that patients be unchained and developing a therapeutic programme based on firmness and kindness (Goodwin 1997). Several patients showed improvement in their symptoms as a result of the changes. In 1796, English Quakers, led by William Tuke, opened the York Retreat in response to the death of a young Quaker in an institution for the mentally ill (Whitaker 2002). Moral treatment, the therapeutic approach Tuke developed, was based on kindness and respect with care focused on individual needs. Occupation was viewed as a vital component of recovery and patients were encouraged to take up music, sport and other leisure activities (Shorter 1997). The results of this form of care were highly positive. In the fifteen years following the opening of the York Retreat, Tuke reported that 70% of individuals whose duration of illness was less than one year and a quarter of those described as chronically ill at admission had not experienced a relapse (Whitaker 2002).

The shift in cultural and societal beliefs coupled with developments in science during the latter years of the 18<sup>th</sup> century led to the large scale building of asylums (Shorter 1997; Goodwin 1997). In Europe, asylum building first began in Italy and France, subsequently multiplying across the continent (Shorter 2006). The development of asylums varied across Europe. In France, Germany, Austria and Switzerland, the organisation of care was highly centralised, regulated nationally or by province (Shorter 1997). Conversely, in the UK, small local reforms sparked a national movement for mental health care reform (Jones 1993). Ideology had changed and mental health problems became largely viewed by the public as medical conditions which required treatment. The *County Asylums Act of 1808* placed responsibility for the care of those with mental health problems on local communities which built asylums to serve regional catchment areas (Jones 1993).

The Oxford English Dictionary (1989) defines an asylum as “a benevolent institution affording shelter and support to some class of the afflicted, the unfortunate, or destitute”. Although asylums are now commonly associated with negative images of poorly treated individuals isolated from the rest of society, they were developed with the intention of improving patients’ lives and living conditions and it was widely believed that large institutions would provide improved levels of care. The philosophies and treatments of Tuke and Pinel influenced the development and objectives of asylums across Europe. In 1837, Dr W.A.F. Browne addressed the Montrose Royal Lunatic Asylum in Scotland. He described the importance of institutions that were clean and bright with extensive grounds and gardens where patients lived without fear of abuse and took part in leisure activities and work (Browne 1837).

Although improvement in care was received by some, this was patchy. In Paris asylums were hailed as a triumph. However, reform failed to take shape outside the capital where these institutions remained largely custodial in nature and failed to provide therapeutic treatments (Shorter 1997). Asylums were largely built in isolated areas and were self-sufficient. Although this was, in part, driven by best practice at the time, unfortunately, isolation from the general public did nothing to decrease the stigma attached to mental health problems and allowed abuses of care to go unnoticed. Stigma was further heightened by the process of compulsory admission which required certification by judicial bodies or an appointed medical representative (Shorter 2006). Length of admission was generally indefinite and, while a patient, certain rights (e.g. voting) could be withheld. As a result, admission was often resisted by those with mental health problems, their families and their doctors (Jones 1993).



The largest blow to the success of the asylum was the somewhat unexpected surge in patient numbers across Europe.

“The therapeutic asylum bore within it the seeds of success, for people with major psychiatric illnesses are indeed helped by sheltering in places they believe to be safe, by efforts to help them organize their time and lives, and by medication. The early asylum attempted all of these, yet under the assumption that physicians and attendants would be able to spend time treating patients rather than simply warehousing them. What happened was the overwhelming of the therapeutic asylum by numbers. By 1900, any hope of achieving the early reformers’ ideals had been dashed by the flood of inmates hurled against the gates” (Shorter 1997, p. 46).

As soon as asylums were built, the number of admissions increased exponentially. Because patients were rarely discharged, the asylum population reached unanticipated levels. By 1909 the asylum population had quadrupled and continued to increase (Shorter 1997). Although it was clear new institutions were needed, financial pressures meant it was often more economical to add a wing to an existing asylum. This only further strained the system, making it more difficult to treat patients as individuals and provide therapeutic care. Asylums were fast becoming another version of imprisonment and increasingly unviable. However, a change in public attitudes and political will would bring significant change to the provision of mental health care.

### 1.2.2 Deinstitutionalisation

The provision of care in alternative, community-based settings was undertaken by a small minority as early as the mid-19<sup>th</sup> century. In Belgium, individuals with mental health problems were sent to live with local families if they could not be cured (Goodwin 1997). Although the practice spread across the neighbouring countries of

France, the Netherlands and Germany as well as Scandinavia, it remained small in scale and asylums continued to dominate as the primary locus of care.

Driven by a cultural and political shift towards altruism and social welfare, changes to the provision of mental health services began in the early 20<sup>th</sup> century (Rose 2001; Mechanic 2001). During this time, mental disorders began to be recognised as a public health problem, prevention became a national priority and steps to integrate mental health into routine medical care were taken. Some psychiatrists began enacting open-door policies whereby patients would be allowed to leave the hospital for short periods of time (Goodwin 1997). In the UK, the *Mental Treatment Act of 1930* made voluntary treatment to address early indications of poor mental health more widely available in general hospitals and allowed for temporary psychiatric admissions (Jones 1993). The legislation made an attempt to cut ties with the negative connotations associated with asylums by rebranding them as mental hospitals (Rose 2001). Similar changes in terminology were enacted across Europe (Goodwin 1997). However, in the mid-1900s the viability of the mental hospital was becoming increasingly tenuous due to soaring costs and rising admission rates.

### **The concept of deinstitutionalisation**

The term deinstitutionalisation is generally defined as the shift in the provision of mental health care from hospital settings to community-based services (Thornicroft & Bebbington 1989; Bachrach 1997; Lamb & Bachrach 2001; Knapp et al. 2011). In 1976, Bacharach described successful deinstitutionalisation as the accomplishment of three goals: (1) the release of individuals from hospitals into the community; (2) their diversion from hospital admission; and (3) the development of alternative, specialised community services. As time progressed and more service users were diverted from

hospital to a variety of service settings, the definition of deinstitutionalisation expanded in the literature to describe whole systems of mental health service provision, integrated into general health care, and the policies, legislation and funding required to implement it (Funk et al. 2010a; 2010b).

The word ‘deinstitutionalisation’ may no longer match the concept we are now assessing service provision against, but it is a term widely used by researchers in this area to describe systems of care which include a wide range of community facilities (Priebe et al. 2005). When deinstitutionalisation began, it was a backlash against any form of institutionalised care and its goal was the transfer of all service users into the community. However, not all mental health service users can be treated as outpatients. Various forms of institutional care, such as acute inpatient treatment and supported housing, are also needed to provide individualised care based on need. Therefore, for the purposes of this research I have combined Bachrach’s 1976 description of deinstitutionalisation and the WHO’s (Funk et al. 2010a; 2010b) broader conceptualisation, to define deinstitutionalisation as the transition from hospital-based mental health care to a system of care fully integrated into general medical care, strengthened by the establishment of mental health legislation, policies and budgets, with a range of mental health services provided in the community and based on the needs of service users to support service user autonomy.

### **Reasons for change**

Political and public support for plans to deinstitutionalise or shift the locus of mental health care from hospital to community settings, emerged in the mid-1900s across much of Western Europe (Rose 2001). Reasons for the rise in popularity of deinstitutionalisation have been examined by a number of experts and several

competing arguments have been made. The most cited arguments include growing public pressure for more humane treatment of asylum patients, spiralling costs of psychiatric care and the development of effective psychotropic medication.

### *Public pressure*

Following the end of the devastation caused by World War II, there was a trend towards humanitarianism and a desire to break from the past (Novella 2008). Although outpatient treatment was now available, individuals with mental health problems were still largely cared for in mental hospitals. During the mid-1900s, public awareness of the harsh conditions faced by patients grew as advocates continued to raise the issues of overcrowding, limited therapeutic treatments and violations of human rights. In 1961, Erving Goffman branded the mental hospital as a type of 'total institution' – a highly insular setting which isolated individuals from society. Segregation from society and the highly ordered day-to-day life disintegrated the identity and personality of patients leaving little to no chance of improved outcomes. This effect was described by Barton (1959) as 'institutional neurosis' and was asserted to occur even in well-run institutions (Wing 1962). Growing concern for the treatment of mental health patients, led to greater political pressure for mental health care reform. The solution was to end institutionalised systems of care. These sentiments were echoed by the general public.

### *Rising costs*

The steadily rising costs incurred to provide care in mental hospitals due to growing admissions added to the pressures faced by politicians to change the system of mental health care provision. By the 1950s, mental hospitals in the UK were overcrowded (Scott 1993; Rose 2001) and heavily constrained by insufficient budgets. It was becoming increasingly clear that service provision in its current form could not be maintained. Some believed shifting the locus of care out of institutions and into the

community would be more cost-effective as the shift in responsibility of care from hospital to community would also transfer some of the financial burden onto local governments. However, this belief would later be found untrue (Knapp et al. 2011).

### *The advent of psychotropic medication*

The development of effective psychotropic medications in the mid-1900s has also been cited as the impetus for community care as they helped to make the move from institution to community a practical reality for individuals with more severe mental health problems (Whitaker 2002). However, the discharge of psychiatric patients was already on the rise prior to the widespread use of psychotropic medications (Novella 2008). The use of bromides and other sedatives from the late 19<sup>th</sup> century allowed patients with less severe symptoms to be discharged prior to the 1950s. Therefore, the availability of psychotropic medication was likely not the singular reason for the implementation of deinstitutionalisation. Instead, the development of psychotropic medication allowed politicians to deinstitutionalise mental health care by allowing patients with more severe mental health problems to be discharged from hospital.

Although reasons for the uptake of deinstitutionalisation continue to attract debate, it is unlikely to have been attributed to a single factor. It is more likely that the amalgamation of a variety of political, ideological, scientific and economic factors contributed to the adoption of deinstitutionalisation as a major objective of mental health care reform around the world.

### 1.2.3 The current state of mental health care provision

All cultures recognise mental illness but reactions to and behaviour towards people with mental health problems and their care differ (Mechanic 2001). In many countries mental

**Table 1.1 Presence of community mental health care facilities by region**

Region	Countries (%) N=185
Europe	79.2
Americas	75.0
Eastern Mediterranean	68.2
Western Pacific	66.7
Africa	56.5
Southeast Asia	50.0

Note: From "2005 Mental Health Atlas" by World Health Organization, 2005, p. 17

health service users have been discharged from mental hospitals and new admissions have been diverted to community care, where possible. However, the development of alternative community-based services has lagged behind (Lamb & Bachrach 2001). In 2005, availability of community care was highest in Europe and the Americas and lowest in Southeast Asia where only half of countries in the region provided community care (see Table 1.1; World Health Organization 2005).

When the availability of community care is examined by the level of gross national product per capita, a distinct dichotomy develops with wealthier countries more likely to provide care in the community (see Table 1.2). However, the availability of community mental health facilities is often restricted to larger urban centres (Saxena et al. 2007). This is not surprising as individuals with mental health problems have diverse needs requiring the synchronisation of various government systems (e.g. health care, social care, employment). However, under-developed community services result in inappropriate care and increased risk of negative service user outcomes (Saxena et al. 2007). The WHO (2003b) recommends that the development of community services should occur before and during the decommissioning of hospital services. However, this is often difficult as the release of funds to ease the transition is too often poorly

**Table 1.2 Presence of community mental health care facilities by country income group**

Income group	Countries (%) N=181
High <sup>1</sup>	97.4
Upper middle <sup>2</sup>	90.9
Lower middle <sup>3</sup>	51.9
Low <sup>4</sup>	51.7

Income groups are based on gross national product per capita: <sup>1</sup>>\$9266; <sup>2</sup>\$2996-\$9265; <sup>3</sup>\$756-\$2995; <sup>4</sup><\$755

Note: From "Mental Health Atlas 2005" by World Health Organization, 2005, p. 17

managed, resulting in the under financing of community-based services. There has also been reluctance to accept community based mental health care – especially residential care facilities – from members of the community due to stigma (Brockington 1993; Fakhoury & Priebe 2002).

Current levels of deinstitutionalisation in Europe are the result of progress made over the last 50 years. In 2007, the Mental Health Economics European Network (MHEEN) reported data collected on the provision of mental health care in 32 European countries (Knapp et al. 2009). Each country's overall progress towards deinstitutionalisation was categorised as either advanced, transitioning, in the initial stages or institutionalised (see Figure 1.1). A country's allocation to a category was determined by national mental health experts. Fifteen countries were described as being at an advanced level of deinstitutionalisation, four as in the middle of their transition to community mental health services, ten as at the initial stages of deinstitutionalisation and two had not taken steps towards deinstitutionalisation (Knapp et al. 2009).

<b>Advanced</b>	Austria Belgium Denmark Finland Germany Iceland Ireland Italy	Liechtenstein Luxembourg The Netherlands Norway Spain Sweden United Kingdom
<b>Transitioning</b>	Greece France Malta Portugal	
<b>Initial stages</b>	Bulgaria Cyprus Czech Republic Estonia Hungary	Latvia Lithuania Poland Slovakia Slovenia
<b>Institutionalised</b>	Romania Turkey	

Note: From "Balance of care (deinstitutionalisation in Europe) Results from the Mental Health Economics European Network (MHEEN)" by Knapp et al 2009

**Figure 1.1 Description of the deinstitutionalisation of mental health care in European countries**

### **WHO recommendations on the provision of mental health care**

In the majority of Western European countries the provision of mental health care has changed significantly since the 1950s to a system which aims to provide tailored care based on the needs of service users. Although the original goal of deinstitutionalisation was to provide mental health care almost solely in community settings, recent literature suggests that neither hospital nor community-based care alone can provide effective and comprehensive care (Thornicroft & Bebbington 1989; Thornicroft & Tansella 2003). While community care can improve quality of life for those with severe mental health problems, there will be continued need to provide hospital care for those with the lowest levels of functioning who require extremely high levels of support and regular supervision. Only a system which incorporates treatment in both settings, determined by individual functioning and needs, can provide efficient and effective care. This balanced



care model is currently recommended by the WHO as best practice in the provision of mental health services (Thornicroft & Tansella 2003).

As the deinstitutionalisation of provision of mental health care has progressed at different rates in different countries, the WHO has used the experiences of countries further ahead in the process in order to develop its guidance on best practices. In the WHO's *Mental Health Declaration for Europe* (2005) the development and implementation of "comprehensive, integrated and efficient mental health systems that cover promotion, prevention, treatment and rehabilitation, care and recovery" (p.2) is set as a priority. Actions relevant to deinstitutionalisation agreed upon by the Ministers of Health of European WHO member states include:

- provision of mental health care in primary care services;
- availability of comprehensive mental health treatment in a variety of settings;
- multidisciplinary mental health workforce; and
- adequate funding of mental health services for the provision of effective care.

Ministers also agreed upon their country's responsibilities for the following:

- replacement of institutional care with community-based services;
- collaboration between mental health agencies and relevant government agencies (e.g. social services, education, employment and housing);
- clearly defined budgets specifically for mental health care provision which consider the cost of care and burden of mental health problems; and
- enforcement of mental health legislation and policies.

In 2003 the WHO published guidance on the organisation of mental health services as part of a series on the development of mental health policy and services. Six key principles of organisation (accessibility, comprehensiveness, coordination and continuity of care, effectiveness, equity and respect for human rights) were described which should guide national, regional and local service provision (World Health Organization 2003b). Integration of mental health care into general health services, primary care and general hospitals, provision of community mental health services and continuity of care between all levels of service provision is also necessary. As previously discussed, many of the problems associated with deinstitutionalisation may be a result of inadequate infrastructure and organisation of community care (Lamb & Bachrach 2001). Therefore, the WHO recommends that the following components of care are in place prior to the transition to community care:

- provision of mental health care and treatment in primary care settings;
- provision of acute inpatient care in general hospitals;
- primary care staff trained in mental health and mental hospital staff trained for transition to general health care settings;
- availability of psychotropic medication in primary care settings and general hospitals; and
- availability of community mental health services (World Health Organization 2003b).

Once these aspects of care are established, mental health service users can be diverted from mental hospitals to appropriate community settings. However, discharge from mental hospitals should be gradual and dependent on severity with the least impaired service users discharged first. Service users and their carers should receive practical and

emotional support prior to discharge to prepare them for living in the community (World Health Organization 2003b). This support should continue for a period after discharge to improve transition outcomes.

Additional aspects related to the provision of community-based mental health care which should be incorporated into mental health plans and policies include:

- integration of mental health legislation and policies with other, relevant, legislation and policies (e.g. general health law, disability law, social welfare policy);
- coordination and management to oversee the development and implementation of services;
- involvement of service users, carers and advocates in development and implementation of services;
- strategies for quality improvement; and
- research and evaluation (Funk et al. 2010a; 2010b).

### **Mental health care in the ten European countries of the DEMoBinc project**

#### *Bulgaria*

Until recently, mental health services were delivered separately from physical health services in Bulgaria (Tomov et al. 2004). A national mental health policy was published in 2004 (World Health Organization 2005). The policy's objectives included improved outpatient care, improved community mental health services, integration of mental health care into the health system and social integration of service users (Georgieva et

al. 2007). A national implementation plan was agreed in the same year. Aspects of the plan which aimed to deinstitutionalise the provision of care included:

- incorporating mental health into primary health care services;
- establishing psychiatric wards in general hospitals;
- establishing accreditation and monitoring processes for inpatient services;
- establishing psychiatric services in geographic areas with higher morbidity;
- establishing crisis intervention services, day centres and group homes;
- making case management and psychosocial interventions available in community settings (Ministry of Health 2004).

The Bulgarian government has indicated their intent to improve the standard of mental health care provision throughout the country. Although half of mental health beds are still provided in psychiatric hospitals (Jacob et al. 2007), from 2001 to 2003, the number of beds fell by 11% (Georgieva et al. 2007). Community-based services (e.g. day centres and supported housing) are available but are very limited throughout the country (World Health Organization 2005). Pilot programmes of psychosocial rehabilitation services and other forms of community care have recently begun (Georgieva et al. 2007). Community mental health services are supported by non-government organisations as well as local and national government. In addition to the care provided through the health department, Bulgarian social services provide day centres and longer term residential care for children and adults with medical services provided by general practitioners, nursing staff and psychiatrists (Georgieva et al. 2007).

The number of mental health professionals within the country is low relative to the number of health professionals in other specialties. Georgieva and colleagues (2007)

report psychiatrists account for 2.2% of doctors in the country. The majority of these psychiatrists practice in and near major cities. Numbers of mental health nurses, social workers and psychologists are also low. The lack of adequate numbers of mental health professionals provides a barrier to ensuring the availability of mental health care across the country.

### *Czech Republic*

Czech national mental health policy was first published in 1953 and focuses on treatment, rehabilitation and social integration (World Health Organization 2005). The provision of mental health care in the Czech Republic is the responsibility of social care and health systems (Rokosová et al. 2005). Medical issues related to mental health problems are handled through the health system and funded by national health insurance while non-medical care is provided by social services and financed through the national budget. Progression of deinstitutionalisation in the country is slow. The number of mental health beds decreased throughout the 1990s and early 21st century (Raboch 2006). However, this decline has recently slowed. Very limited community-based services are available. In the early 1990s, comprehensive home care was introduced (Rokosová et al. 2005). This allowed service users to obtain outpatient and social care services in their homes through visits from multidisciplinary teams and support agencies. Social and community care facilities operated by charities and non-government organisations have increased in recent years (Rokosová et al. 2005). Nevertheless, the majority of mental health patients are cared for in psychiatric hospitals (World Health Organization 2005; Jacob et al. 2007). Due to insufficient coverage of social care (Raboch 2006) and the funding structure for mental health services (Rokosová et al. 2005), the majority (86%) of those requiring longer term care as a result of high support needs are cared for in hospital rather than the community (World

Health Organization 2005; Rokosová et al. 2005) and face extended or lifetime hospitalisation (Bryndová et al. 2009).

### *Germany*

Deinstitutionalisation in Germany occurred relatively late in comparison with other European countries. In 1975 a government report on the state of mental health care in West Germany described the provision of mental health care as inadequately resourced, highly institutionalised and isolated from physical health care systems (Salize et al. 2007). A national mental health policy was created in the same year (World Health Organization 2005). It proposed four basic principles: (1) provision of community-based care, (2) needs-based comprehensive care, (3) provision of care in defined catchment areas based on need, and (4) access and quality of mental health care equal to that of physical health care (Salize et al. 2007). The implementation strategy for this new policy included:

- discharge of psychiatric inpatients to the community;
- introduction of community-based care including day hospitals, hospital-based outpatient services, outreach and day care activities; and
- improved access to psychiatrists outside of hospital settings.

In 1988 a review of mental health reform took place and new goals were stated which included the introduction of policies to give mental disorders equal status to physical disorders (World Health Organization 2005).

Nationally, community-based mental health care, which includes supported housing, is available, but limited. Psychiatric hospitals have halved their number of beds since the 1960s (World Health Organization 2005). However, Jacob and colleagues (2007)

reported 60% of mental health beds are located in mental hospitals rather than in community settings. Hospital inpatients have little access to the community (Fakhoury & Priebe 2002) and limited opportunities for vocational rehabilitation (Busse & Riesberg 2004).

Variation in the provision of mental health care is both historical and geographical. At the time of reunification, mental health care provision in East Germany was similar to that of West Germany before its reform (Busse & Riesberg 2004). Although reunification improved mental health care in the east, structural improvement was hampered by insufficient financial resources. As a result, “an east-west divide still persists in some sectors of mental health care, e.g. there is an under provision of office-based psychiatrists in East German outpatient mental health care” (Salize et al. 2007, p. 93).

Only basic general health care and welfare legislation is set by the national government (Salize et al. 2007). Mental health care planning and regulation are controlled by the country’s 16 federal states (Salize et al. 2007). Consequently, mental health care provision is subject to regional variation in implementation, resources and quality.

### *Greece*

Until the 1980s, mental health care provision in Greece was confined to psychiatric hospitals and was primarily custodial in nature (Karastergiou et al. 2005). Reform officially began in 1983 with the establishment of the National Health System. Mental health policy focused on advocacy, promotion, prevention, treatment and rehabilitation (World Health Organization 2005). Community-based mental health care provision was seen as a priority (Karastergiou et al. 2005).

In 1984, the Greek government received financial assistance from the European Community to assist in the implementation of mental health reforms (Ministry of Health and Social Solidarity 1995). However, momentum flagged when implementation efforts were met with social opposition and a lack of human resources. The 1989 revelation of the inhumane conditions experienced by service users at Leros Mental Hospital placed a spotlight on the state of mental health care in Greece (Karastergiou et al. 2005). In response, the European Community suspended funding until specified improvements were met (Ministry of Health and Social Solidarity 1995). This event reignited the implementation of deinstitutionalisation and funding resumed in 1991 (Ministry of Health and Social Solidarity 1995). By 1995 considerable advancement in community care provision had been achieved and in 1999 a new national mental health plan called ‘Psychargos’ was established to build upon and continue the progress of deinstitutionalisation (Ministry of Health and Social Solidarity 2010). The plan included the following goals:

- increased community mental health facilities across the country;
- availability of vocational training for service users;
- training of mental health professions to act as directors for psychosocial rehabilitation;
- improved specialist care; and
- assurance of continuity of care.

To date, community-based treatment is limited and inadequate to reduce admissions to psychiatric hospitals and accommodate yet-to-be deinstitutionalised long-stay patients (Fakhoury & Priebe 2002). The country has expanded the availability of supported housing and the number of long stay inpatients in mental hospitals has decreased by



70% between 1984 and 2004 (Karastergiou et al. 2005). However, mental hospitals still provide the majority of psychiatric care and admissions are still high (Karastergiou et al. 2005).

### *Italy*

Community-based mental health care in Italy dates back to the small, local initiatives of the 1960s. It was not until 1978 that legislation was passed to force the implementation of deinstitutionalisation. Law 180 stipulated drastic change in the provision of mental health care. The establishment of new mental hospitals was outlawed, new admissions to mental hospitals ceased and existing mental hospitals were closed – some almost overnight (Lo Scalzo et al. 2009). Nearly all aspects of mental health care were to be provided within the community – with the exception of small psychiatric wards in general hospitals. Inpatient admissions could be initiated only in extreme circumstances (i.e. ineffectiveness of outpatient care or refusal of care). “For the first time in Italy, the dignity of the acutely ill patient, rather than the need for their restraint, was made the central focus of a statute to change medical intervention for the mentally ill” (Altamura & Goodwin 2010, p. 261). Shortly after its publication, Law 180 was incorporated into general health legislation, Law 833 (Tansella et al. 1987). Although bold in nature, implementation was stifled by inadequate resourcing of community structures and a non-existent plan for the delivery of these new services (Tansella et al. 1987; Lo Scalzo et al. 2009; Altamura & Goodwin 2010).

In 1994 a national plan for mental health was introduced. It focused on advocacy, promotion, prevention, treatment and rehabilitation (World Health Organization 2005).

Deinstitutionalisation was to be achieved through:

- the provision of comprehensive mental health care services within a specified catchment area which included crisis intervention and rehabilitation services;
- the closure of mental hospitals; and
- the creation of mental health departments responsible for local mental health services (Lo Scalzo et al. 2009).

Today, acute psychiatric care is provided in general hospitals and most patients are transferred to community care within a week. Community mental health care is provided by multidisciplinary teams through community mental health centres, general inpatient wards, day hospitals, day centres and residential facilities (Lo Scalzo et al. 2009) and is widely available throughout the country (World Health Organization 2005). Although implementation of Law 180 has not been perfect, it is difficult to argue that its objectives were off the mark. Globally admired, it was the strongest commitment to deinstitutionalisation and the human rights of those with mental health problems at the time. However, the lack of national implementation policies has led to inconsistent levels of the quality of care and regional variability in service provision (de Girolamo et al. 2007; Lo Scalzo et al. 2009).

### *The Netherlands*

Deinstitutionalisation in the Netherlands began in the 1970s (Ravelli 2006). In 1974 the Dutch government announced their aim of reducing the number of beds in psychiatric hospitals and developing regional community mental health centres, or RIAGGs, whose purpose was to make mental health care more easily accessible and reduce hospitalisation levels (Schene & Faber 2001). However, RIAGGs did not provide inpatient or day-patient facilities. As a result, psychiatric hospitals began to increase their capacities for outpatient and day-patient care. In 1984, the government published

the New Note on Mental Health Care. This policy document announced the government's objective of closing psychiatric hospitals and providing care in the community (Ravelli 2006). Objectives of mental health care reform in the Netherlands included the introduction of ambulatory care, community mental health centres to provide general mental health care, discharge of psychiatric patients to community care, provision of supported housing and organisation of mental health care provision by region (Ravelli 2006). In order to achieve these aims, mental hospitals were merged with RIAGGS. Through these mergers planners hoped to create regional networks which would provide similar services in a single facility, improve continuity of care, provide care closer to service users' homes and fill service gaps (Ravelli 2006).

The national mental health policy was introduced in 1999 and focused on advocacy, promotion, prevention, treatment and rehabilitation (World Health Organization 2005). The government's mental health plan was created in the same year which emphasised deinstitutionalisation (World Health Organization 2005). Specialist mental health programmes for minorities, refugees, disaster affected people, indigenous populations, the elderly and children were adopted.

Today, community care is widely available in the Netherlands (World Health Organization 2005) through community mental health centres (Ravelli 2006). Although intensive community-based care has increased five times faster than the reduction of hospital-based care (Fakhoury & Priebe 2002), the majority (82.4%) of mental health beds are still located in hospitals (Jacob et al. 2007).

### *Poland*

Following the Second World War, Poland began to rebuild its healthcare system which was largely destroyed during German occupation (Puzynski & Moskalewicz 2001). By the 1960s, Polish mental health care provision was similar to care provided in Western Europe and the USA. The Polish *Mental Health Act* became law in 1995 and highlighted mental health promotion, prevention, treatment and rehabilitation as its objectives (Balicki et al. 2000; World Health Organization 2005). It also set guidelines for involuntary admissions and highlighted patients' rights (Balicki et al. 2000; Puzynski & Moskalewicz 2001). The *Mental Health Programme*, accepted in the same year, included a commitment to accessible mental health care and an increase in the levels of deinstitutionalisation (Balicki et al. 2000; Puzynski & Moskalewicz 2001). Components of Polish mental health policy include provision of care:

- through defined catchment areas;
- by general practitioners in primary care where appropriate;
- through psychiatric facilities in general hospitals, day centres, outpatient clinics, community mental health centres, supported housing and crisis units;
- near the service user's place of residence; and
- integrated with social services (Puzynski & Moskalewicz 2001).

Despite the positive nature of these policies with regard to increasing the provision of community mental health care, current community-based treatment is limited and varied, with two-thirds of psychiatric beds located in large psychiatric hospital settings (World Health Organization 2005; Jacob et al. 2007). A shift to smaller psychiatric hospitals may be taking place. Although 19 psychiatric hospitals were built between 1970 and 2003, the number of psychiatric beds in hospital settings has fallen from

31,558 in 1990 to 19,966 in 2003 (Medeiros et al. 2008). However, unavailability of alternative, community-based services has meant that many service users receive care far away from their homes and families (Puzynski & Moskalewicz 2001). Inadequate numbers of psychiatrists and other mental health professionals compound upon the problems of care provision resulting in increase the risk of out of area placements, longer term mental health care provided by the private sector, usually far away from services users' last places of residence (Balicki et al. 2000).

### *Portugal*

Following the development of regional mental health centres in the 1960s, the integration of mental health into general health care became a priority. The first mental health law was published in 1963 (Caldas de Almeida et al. 2008). Further progress was made in the 1980s to create mental health centres in urban areas. In 1992 a law was passed which provided for the integration of general hospitals and mental health care centres (Barros & de Almeida Simões 2007). The country's mental health policy was created in 1995 and focused on advocacy, promotion, prevention, treatment and rehabilitation (World Health Organization 2005). Community care was given priority over institutional care with emphasis on local, rather than regional, mental health services (Barros & de Almeida Simões 2007).

In 2007 the *New Mental Health Policy and Plan* set the country's new objectives for mental health care for the years 2007 to 2012 (Caldas de Almeida et al. 2008).

Objectives included:

- increased decentralisation of mental health care;
- availability of local mental health services;
- integration of mental health into general health services;

- continuity of care; and
- increased availability of specialised care.

A National Coordination Body for Mental Health was created in the following year to oversee the implementation of the new mental health plan (Caldas de Almeida et al. 2008).

Although community mental health care facilities have been available in Portugal for several years, the number of these facilities is limited (World Health Organization 2005). Psychiatric hospitals provide the majority of acute and longer term care (Barros & de Almeida Simões 2007), although the number of psychiatric beds in hospitals decreased by 40% in the 15 years prior to 2005 (World Health Organization 2005). Integration of mental health into physical health care provision has evolved, and the country's current mental health policy also acknowledges the importance of integration with both physical health and social services (Barros & de Almeida Simões 2007). The need for multidisciplinary mental health teams is also highlighted. Recently there has been a push to increase the availability of community rehabilitation facilities (National Mental Health Coordinating Board 2008).

### *Spain*

In 1983 the Spanish government established the Commission for Psychiatric Reform which authored a report conceptualising the organisation of mental health care provision (Vázquez-Barquero et al. 2001). The commission's objectives included the provision of care by catchment area, a greater role of primary care services in the treatment of mental health problems, the creation of psychiatric facilities in general hospitals and the availability of adequate community mental health services (Vázquez-Barquero et al. 2001). Although the government provided the framework for the provision of mental

health care, it did not establish a national mental health policy. Instead, legislation was created independently by Spain's 17 autonomous regions, the first of which was formulated in 1985 (World Health Organization 2005).

In 1986, the General Law of Health was introduced which included the most important aspects of the commission's report (Vazquez-Barquero & Garcia 1999). A national mental health programme was adopted in 1996 and several specialist mental health programmes were put in place for at-risk groups (e.g. the elderly, children and adolescents) and individuals with specific mental disorders (e.g. depression and substance abuse) (World Health Organization 2005).

Community-based care is limited throughout the country with treatment primarily provided in hospital (84.1%, World Health Organization 2005). Primary care settings serve as the main gateway to specialised psychiatric care (Vázquez-Barquero et al. 2001). Marked differences in the provision and quality of mental health care occur largely by regional boundaries (Vázquez-Barquero et al. 2001). For example, although all mental health centres maintain a basic complement of staff, including a psychiatrist, psychologist, nurse and administrator, the number of staff can vary markedly by region. Regional differences are also seen in available resources and mental health facilities. Availability of community mental health centres ranged from one per 35,600 inhabitants in the autonomous region of Pais Vasco to one per 93,809 inhabitants in the region of Galicia (Vázquez-Barquero et al. 2001).

### *United Kingdom*

In 1957, The Royal Commission on the Law Relating to Mental Illness and Mental Deficiency published the Percy Report which is widely credited as the foundation of modern mental health legislation in the UK (Rapaport & Manthorpe 2009).

Recommendations from the commission included a widening of the scope of voluntary admissions, improving patients' rights and changes to the vocabulary of mental health and provision of care aimed at reducing stigma. However, the most important recommendations were for the increased availability of community mental health services and that treatment should be provided in the community, if appropriate services existed, rather than hospital. The Mental Health Act of 1959 followed on from the Percy Report and was the first legal document stating the objectives of mental health care reform (Department of Health 1959).

In 1961, the Minister of Health, Enoch Powell, gave his famous 'Water Tower' speech in which he argued for a decrease in the number of mental hospital beds and the closure of the majority of mental hospitals in the UK (Jones 1972). A year later, the government published the *Hospital Plan for England and Wales* which called for the closure of psychiatric hospitals, the integration of mental and general health services and the development of further community care services.

Throughout the end of the 20th century the Department of Health continued to specialise and differentiate mental health care with their policies. *The National Service Framework for Mental Health* (Department of Health 1999) and *The NHS Plan* (Department of Health 2000) encouraged the development of specialist community mental health services (e.g. crisis resolution, early intervention and assertive outreach) and facilitated further reductions in hospital-based care.

Mental health services in the UK have more recently focused on service user recovery. In this context, recovery is defined by as "A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a



satisfying, hopeful and contributing life even with the limitations caused by illness” (Anthony 1993, p. 527). Mental health policy documents such as *New Horizons* (Department of Health 2009) and *No Health without Mental Health* (Department of Health 2011) highlight the importance of recovery-orientated care and social inclusion in mental health services.

Today, alternative, community-based mental health care is widely available throughout the country (World Health Organization 2005). Services include community mental health teams, home treatment and other specialist community teams, liaison services, primary care, community residential facilities and a wide range of services that focus on vocational rehabilitation and social inclusion (Fakhoury & Priebe 2002). Longer term care, dependent on a service user’s level of impairment, is available in hospital and community settings. However, out of area placements in facilities provided by the private sector have become more common due to reductions in NHS run longer term care facilities.

### **Reinstitutionalisation**

It has been suggested that mental health care provision may be moving toward reinstitutionalisation, the process of shifting mental health service provision back to institutional settings, in countries with a history of deinstitutionalisation. Priebe and colleagues (2005; 2008) examined the provision of psychiatric beds across ten Western European countries (Austria, Denmark, England, Germany, Ireland, Italy, the Netherlands, Spain, Sweden<sup>1</sup> and Switzerland<sup>2</sup>) with a history of deinstitutionalisation between 1990 and 2006. During this time, there was a general reduction in the number of conventional inpatient beds in all countries except Italy but a rise in involuntary

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<sup>1</sup> Data on the number of beds in Sweden were not reported for 2006.

<sup>2</sup> Data on the number of beds in Switzerland were not reported for 1990.

admissions except in Ireland and Switzerland. An increase in the number of beds in supported housing and forensic hospitals was reported among the majority of countries (Priebe et al. 2005; Priebe et al. 2008). In Denmark, England, Ireland, Spain, Sweden and Switzerland, the total numbers of institutional places, including supported housing, decreased while the total numbers of institutional places increased in Austria, Italy and the Netherlands. These findings were interpreted by the authors as evidence of reinstitutionalisation. In this section, I evaluate the strength of this conclusion in light of recent literature.

*Supported housing: indicative of reinstitutionalisation?*

The definition of supported housing used by Priebe and colleagues (2005; 2008) includes alternative community-based services ranging from nursing homes to supported flats. It is difficult to argue that living in an individual or shared tenancy with staff support during working hours is akin to an institution. A more appropriate question is whether or not forms of communal supported accommodation (e.g. nursing and residential care homes) are institutions reminiscent of those in existence prior to deinstitutionalisation. Critics of supported accommodation view it as a way of continuing the coercion of the asylum by “more subtle strategies of intervention whose coercive character is more concealed” (Novella 2008, p. 307). It is true that some facilities provide care of poor quality as all residential care facilities are vulnerable to institutional practices. For example, in the UK, there has been increasing worry about the growing provision of longer term mental health care by the private sector, in so called out of area placements, attributed to the limited availability of longer term inpatient and residential care facilities provided by the National Health Service (NHS) as a result of recent disinvestment in mental health (Killaspy & Meier 2010). Although the quality of care provided in many of these facilities is of a high standard, evidence of

poor treatment and care has been documented. Criticism of out of area placements includes a lack of personalised care and skill building interventions (Killaspy & Meier 2010). The long distances some service users are sent to receive care have also been suggested to contribute to the breakdown of their social relationships. In a study following the placement of 70 service users in out of area facilities across the UK, researchers found a lack of evidence-based, client-centred care, poor service user and carer involvement in care planning and high levels of detention (Ryan et al. 2004). Due to poor communication between the NHS and service providers, staff had no case notes or treatment histories for half (n=35) of the study participants, limiting their ability to provide appropriate care. A quarter of service users were assessed by the researchers as having functioning levels indicative of being able to manage in a less supported setting. This suggests they were not being assisted to move towards more autonomous settings. These findings, although based on a UK cohort, are equally relevant to the provision of care in other European countries and highlight the importance of ensuring that the level of care received reflects service users' needs.

The inclusion of supported housing as an institution akin to the psychiatric hospitals prevalent prior to the introduction of deinstitutionalisation fails to consider the goals of this type of care and defines an institution only by bricks and mortar. The availability of alternative residential care settings is crucial to the provision of community-based care for individuals with severe mental health problems due to functional deficits which make it difficult for them to lead independent lives. The goal of supported accommodation is to provide individualised, recovery-orientated care through therapeutic interventions including occupational and vocational rehabilitation which aim to help service users gain or regain skills necessary for independent living. In other

words, in contrast to the total institution, these facilities focus on promoting autonomy and improving social integration.

In response to the inclusion of increased supported accommodation as evidence for reinstitutionalisation, Muijen (2008) comments, “Data should differentiate between ‘community-based facilities’ that offer personalised interventions, which would likely include residential facilities, and ‘institutional places’ that impose standardized care” (p.574). When beds in supported housing are excluded from the numbers of institutional places, only Italy has increased its number of institutional places (Priebe et al. 2005; Priebe et al. 2008). Italy’s increase in institutional places is linked to the rise in the number of conventional inpatient beds. However, at 18.4 beds per 100,000 inhabitants it represents the lowest number of psychiatric beds among the sample and due to the prohibition of longer term inpatient wards, all of Italy’s conventional psychiatric beds are located in acute settings where service users are discharged to community services within seven days of admission (Lo Scalzo et al. 2009).

#### *The rise of forensic mental health care*

Early in the process of deinstitutionalisation, it was suggested that the provision of care in the community would result in an increase in the numbers of individuals with mental health problems being sent to prison. Although there is evidence that deinstitutionalisation has not significantly impacted on crime rates in Europe (Wallace et al. 2004; Hartvig & Kjelsberg 2009), the past 20 years has seen an increase in the number of psychiatric beds in forensic mental health settings across several European countries (Priebe et al. 2005; Salize et al. 2008; Priebe et al. 2008). The underlying reasons for the rise in the number of forensic beds are unclear. It has been suggested that an increase in the incidence of mental health problems, an elevation in risky

behaviour exhibited by individuals with mental health problems and society's growing intolerance toward risk may be factors which explain this trend.

There is limited evidence regarding the rate of change in the prevalence of mental health problems in Europe. In a nationwide study of the prevalence of mental health problems in the Netherlands, no difference was found across the 13 year period from 1996 to 2009 (de Graaf et al. 2012). A similar finding was reported in a UK study which compared the rates of mental health problems in the UK between 1993 and 2000 (Brugha et al. 2004). Neither study included information on the prevalence of schizophrenia and schizoaffective disorder – the most common diagnosis among offenders receiving forensic mental health care (Hodgins et al. 2009). However, a meta-analysis of 83 studies which reported incidence rates suggests stability in the incidence of schizophrenia and other psychoses over a 60 year period (1950-2009) in England (Kirkbride et al. 2012). Therefore, it is unlikely that the increase in the number of forensic beds is due to an increase in the number of individuals with a mental health problem.

Society's tendency toward the containment of risk is evident in the steadily increasing prison populations of Europe (Priebe et al. 2005). This increased level of risk aversion has been suggested as a potential reason for the growing number of forensic beds as individuals with severe mental health problems are generally perceived by the public to be dangerous and prone to violence (Markowitz 2011). Where, in the past individuals thought to be a risk to society due to their mental state would be sent to mental hospitals, deinstitutionalisation has limited the capacity of longer term care. Jansman-Hart and colleagues (2011) suggest that the decreased availability of mental health care results in fewer options for the care of individuals with severe mental health problems

and increases their likelihood of entry into the criminal justice system. Based on this theory, we may be wrongly imprisoning individuals with mental health problems in an effort to prevent them from future crime. The evidence regarding this claim is mixed. In an Austrian study of retrospective data on mental health service provision and crime rates from 1970 to 2008, deinstitutionalisation was found to be associated with increased incarceration of individuals with mental health problems committing less severe crimes (Schanda et al. 2009). Like previous studies, no difference in the number of individuals with mental health problems committing homicide was found, although the increase in convictions for causing severe bodily injury was significant ( $p < 0.0001$ ). Hodgins and colleagues (2006) compared the characteristics of 306 mental health services users discharged from general and forensic psychiatric care in Canada, Finland, Germany and Sweden. Those in forensic care with no previous history of psychiatric admission were more likely to be convicted of homicide. The remaining forensic service users had a higher number of offences and were more likely to have a history of violent offences as compared to service users in general psychiatric settings. The marked difference in service user characteristics does not suggest indiscriminate forensic admissions are occurring.

#### *Interpreting involuntary admission numbers*

It is difficult to interpret the reported increase in involuntary admissions (Priebe et al. 2005; Priebe et al. 2008) due to a lack of transparency in the definition, criteria and calculation of admissions. The reported number of admissions is not necessarily equivalent to the number of individuals detained involuntarily as it is possible for an individual to be involuntarily admitted multiple times within a year. Reduction in the availability of specialist mental health care has resulted in mental health services being described as a 'revolving door' where admissions are shorter and more numerous

(Salize et al. 2008). In a review of the European data on involuntary admissions, Høyer and colleagues (2008) reported substantial differences in the number of involuntary admissions both across and within countries. These differences imply heterogeneity in the way involuntary admission is determined across Europe. Due to these limitations, the comparison of data on involuntary admissions should be interpreted with caution. However, potentially increasing rates of involuntary admission should be regularly monitored and the criteria for admission reviewed in order to ensure that an appropriate level of care is being provided.

#### *Are we moving towards reinstitutionalisation?*

The suggestion that mental health care may be moving away from deinstitutionalisation should not be dismissed without a thorough evaluation of the argument. Priebe and colleagues (2005; 2008) highlight increasing bed numbers in forensic settings and supported accommodation in addition to an increase in the number of involuntary admissions as an indication of a shift toward reinstitutionalisation. The inclusion of supported housing as an indicator of reinstitutionalisation fails to acknowledge the personalised care and focus on recovery that many of these facilities provide. Although these facilities are still potentially vulnerable to institutional practices, before one can 'label' one as an institution, the type of care it provides should be evaluated. When supported accommodation is excluded from the researchers' analysis, the evidence does not unequivocally support the suggestion that we are reinstitutionalising mental health service users. Nonetheless, the rise in forensic psychiatric beds and involuntary admissions is an alarming finding which should cause us to question the success of current community mental health services.

What is happening to the most vulnerable mental health service users who may, as a result of their functional deficits, require longer term care? From the evidence, it is my conclusion that current mental health services are not properly addressing the needs of service users with severe mental health problems, putting them at risk of involuntary admission and incarceration. Hodgins and colleagues (2006) found no differences in age of first admission, diagnosis, co-morbidity or the number of psychiatric admissions between mental health service users in forensic and general psychiatry settings. However, forensic service users experienced shorter lengths of stay in general psychiatric settings prior to incarceration. In another study, service users with severe mental health problems who displayed anti-social behaviour in general psychiatric settings did not receive tailored interventions to improve their social skills (Hodgins et al. 2009). These findings suggest that service users with the most complex problems may not receive care appropriate to the level of their needs.

Clinicians and researchers have also identified the problem of the ‘revolving door’ patient, service users who are recurrently admitted to hospital. A Spanish study evaluating the characteristics of these high users of inpatient care found frequent admission to be associated with a diagnosis of schizophrenia or schizoaffective disorder, involuntary detention during first admission and younger age (Martinez-Ortega et al. 2011). In a nationwide sample of acute inpatients in public and private facilities in Italy, younger age, younger age at first admission, greater number of lifetime admissions and being a victim of verbal aggression or threats in the week prior to admission were significantly associated with multiple admissions<sup>3</sup> (Morlino et al. 2011). Forty-three per cent (n=186) of high users of inpatient care had a diagnosis of schizophrenia. Treating psychiatrists felt that nearly a quarter (21.1%, n=92) of service

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<sup>3</sup> Defined as three or more admissions in a 12-month period.



users deemed to be high users of inpatient care would be better treated in supported accommodation. The findings suggest that the revolving door is indicative of inadequate provision of care.

An integral component of deinstitutionalisation is the provision of appropriate, alternative community-based services. In order to ensure that the services available are appropriate, we must consider the needs of service users with mental health problems in policies, legislation and implementation plans in areas that may also be relevant to this group (e.g. health care, social care, education, criminal justice). Adequate funding is also necessary to ensure high quality community care (Knapp et al. 2011). However, increased financial pressures have reduced provision of community mental health services or negatively impacted on appropriate investment. Inadequate provision of care limits the ability of services to meet the needs of service users and increases the likelihood of inappropriate care.

### ***1.3 The Cost of Mental Health Care***

In this next section I discuss the costs associated with mental health care and compare them with current spending levels to determine if countries are adequately funding mental health services.

#### **1.3.1 Measurement of costs**

There are generally three types of costs associated with mental health problems. They are defined as direct, indirect or intangible costs. Examples of these costs can be seen in Figure 1.2. Direct costs include the costs of providing medical care, social services and infrastructure (Knapp 1997). In most countries, these costs are primarily paid for by national and local governments with costs spread over a variety of departments. However, in some countries service users purchase private insurance for mental health



**Figure 1.2 Examples of the costs associated with mental health care**

treatment or make out-of-pocket payments (McDaid 2007). Charitable organisations also provide mental health services in most countries (McDaid 2007). Indirect costs are defined as costs associated with the loss of service user and carer productivity (Knapp 2000). Intangible costs include changes in service user and carer quality of life as a result of mental health problems (Knapp 2001; Hermann et al. 2006).

The inclusion of indirect and intangible costs in economic analyses has been a subject for debate among health economists. Researchers who include indirect costs in their economic evaluations of mental health problems often report these costs as higher than direct costs (The Sainsbury Centre for Mental Health 2003; Knapp et al. 2004; Centre for Mental Health 2010). They view these costs as vital to understanding the full impact on mental health problems. Arguments against the inclusion of these costs focus on the

difficulty of their measurement. Particularly challenging is the validity of a conjecture regarding the potential lost opportunities for service users and carers and the attribution of this to the mental health problem (Koopmanschap et al. 1995; Szmukler 1996). Furthermore, valuations of intangibles, such as decreased quality of life and increased emotional problems, raise concerns regarding the standardisation of valuations which may differ due to personal, national and cultural values. As a result, indirect and intangible costs are largely excluded from most economic evaluations of mental health care (Koopmanschap et al. 1995; Roberts et al. 2005).

Although more easily quantifiable, variability in estimates of direct costs still occurs due to differences in the services and activities included in these assessments and the monetary values placed on them. For example, estimates of the direct costs associated with mental health problems in the UK were £12.5 billion for the financial year 2002/2003 (The Sainsbury Centre for Mental Health 2003), £22.5 billion in 2007 (McCrone et al. 2008) and £21.3 billion for the 2009/2010 financial year (Centre for Mental Health 2010). Furthermore, the allocation of costs as direct, indirect and intangible is not necessarily agreed among researchers. The Centre for Mental Health defined direct costs as the costs of health and social care, while McCrone and colleagues defined direct costs as direct health and social care costs in addition to the costs associated with criminal justice services and informal care. The inclusion of informal care as a direct cost of mental health problems by McCrone and colleagues and differences in the types and number of costs included in these estimates highlights the difficulty in making comparisons across studies.

### 1.3.2 Estimates of the costs of mental health problems

The literature on European evaluations of the costs associated with mental health problems is not as plentiful as research into treatments. However, estimates from existing research indicate that associated costs far outstrip current spending. In 2004, estimated costs associated with psychotic, affective and anxiety disorders and substance abuse in Europe was €240 billion (Andlin-Sobocki et al. 2005). This estimate included health care (i.e. hospital, medication and outpatient costs), direct non-medical (i.e. community care, transportation, adaptation and informal care costs) and indirect (i.e. lost workdays and decreased productivity costs) costs. The most recent<sup>4</sup> economic evaluation estimated the direct costs of mental health care in England to be £21.3 billion (Centre for Mental Health 2010). In the same year, indirect and intangible costs were estimated to total £30.3 billion and £53.6 billion, respectively. Seven years prior, the estimated direct, indirect and intangible costs were £12.5 billion, £23.1 billion and £41.8 billion, representing a 36% increase in the total cost associated with mental health problems (The Sainsbury Centre for Mental Health 2003).

#### **Comparing the cost of mental health problems**

Due to differences in the allocation and calculation of costs, it is important to provide clear and comprehensive information on the care or services included as well as how standardised costs were identified in economic evaluations (Roberts et al. 2005). Knapp and Beecham (1990) suggest four rules for evaluating the costs of health and social care services (see Figure 1.3). Evaluations of costs should be comprehensive, incorporating all aspects of a service user's care. The Client Service Receipt Inventory (CSRI) was developed to provide a retrospective, comprehensive estimation of care costs for individuals who had moved from long-term inpatient care into the community

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<sup>4</sup> Financial year 2009/2010

1. Include all aspects of service user care
2. Sensitive to differences in service user, facility and location characteristics
3. Make like-with-like comparisons
4. Include measurements of effectiveness and service user outcomes

Note: From "Costing mental health services" by Knapp & Beecham, 2007

**Figure 1.3 Recommendations for the evaluation of health and social care costs**

(Beecham & Knapp 2001). Cost of care is derived through the collection of statutory, voluntary and informal care costs, service and informal care utilisation, income and related factors. Differences in service user, facility, location and other characteristics should be carefully examined as they may help provide vital information relating to findings. Any comparisons of cost should be made on a like-for-like basis. Finally, evaluations of costs should include assessments of service user outcomes or effectiveness of care.

After cost-related data are collected, they are transformed into monetary values. Beecham and colleagues (2001) assert that estimates of the costs associated with specific interventions should be based on 'long-run marginal opportunity costs'. This means that prices of treatments and services received should (a) focus on longer-timescales which better reflect intentions to develop community care, (b) consider potential changes in the cost of providing treatments and services as availability increases (e.g. economies of scale) and (c) reflect the societal cost instead of money spent (e.g. costs of informal carers and volunteers). In reporting costs of care and service user outcomes or other measures of effectiveness, it is important to distinguish

between clinical, statistical and economic significance since they require different interpretations (Roberts et al. 2005). Lastly, when comparing costs internationally, it is important to ensure costs are converted into a single currency and adjusted for each country's purchasing power and differences in the costs of service provision to ensure accuracy.

### **Deinstitutionalisation and the cost of longer term mental health care**

Part of the early appeal of deinstitutionalisation was the promise of a reduction in the cost of mental health care at a time when the number of psychiatric beds was reaching its zenith. Today, for the majority of mental health service users, the provision of community-based care has led to a reduction in the cost of treatment. However, the total cost of mental health care has not necessarily fallen with the implementation of deinstitutionalisation. There is evidence that the care required for individuals with a diagnosis of schizophrenia or schizoaffective disorder distorts the overall costs of community-based mental health services due to their complex nature and the high level of support they require.

Knapp and colleagues (2004) conducted a systematic review of the literature on international estimates of the cost of schizophrenia. Sixty-two studies from Europe, North America, Central America, Africa and the Caribbean published between 1975 and 2000 were analysed. Estimates for the direct costs of schizophrenia in Europe ranged from 1.4% (the Netherlands) to 2.8% (UK) of the total health budget. They concluded that the impact of schizophrenia on health care budgets is significant with a large proportion of inpatient budgets spent on care for individuals with schizophrenia. However, they point out that cost-of-illness studies are insensitive to costs associated with other illnesses and instead link total costs to a single illness. This methodology

lessens the strength of the findings since individuals with mental health problems are likely to suffer from co-morbid disorders, both mental and physical, which have the potential to significantly inflate the costs attributed to the mental health problem (World Health Organization 2001).

The EPSILON (European Psychiatric Services: Inputs Linked to Outcome Domains and Needs) study examined the costs of care among individuals with schizophrenia living in the community in Denmark, Italy, the Netherlands, Spain and the UK (Knapp et al. 2002). Researchers found higher service provision costs were associated with increased service user needs, decreased global functioning and greater severity of mental health problems. Individuals with these characteristics are largely in receipt of residential longer term care which may explain the higher costs.

In another European study, the direct costs (e.g. services and medication) of community care for service users with a diagnosis of schizophrenia living in Germany, the Netherlands, Spain, Sweden, Switzerland and the UK were examined over a 12 month period (Salize et al. 2009). Although the service users included in the study were found to be a homogeneous sample, variation in the costs associated with care was significant. The lowest costs were found in Grenada, Spain where the average annual cost of treating schizophrenia in the community was €2,958. The highest expenditure was found in Zürich, Switzerland where the average annual cost was €36,976. When the cost components were examined, the researchers found that the costs of medication were stable across countries. However, the costs associated with services were highly variable. Supported accommodation costs were the most expensive component of care. Costs were found to be more strongly associated with country and socio-demographic

characteristics (i.e. age, living situation and employment status) than with the severity of mental health problems.

The direct costs of community mental health care (e.g. outpatient treatment and supported accommodation) for service users with a diagnosis of schizophrenia recently discharged from hospital were 57% lower than the costs of care on a long-term hospital unit in Mannheim, Germany (Salize & Rössler 1996). However, the service users discharged from hospital were likely to need less support than inpatients due to less severe symptoms and higher levels of functioning. Therefore, one would expect the costs of care to be less among the community cohort. Similar to the findings of the EPSILON study, higher community care costs were associated with greater level of need due to social and rehabilitative problems.

In one of the most ambitious studies on the impact of deinstitutionalisation, the Team for the Assessment of Psychiatric Services (TAPS) carried out a longitudinal evaluation of the impact of the closure of two large North London asylums, including the evaluations of the community-based services established to provide continuing mental health care for those discharged (Knapp et al. 1990). Inpatients were discharged in eight cohorts between 1986 and 1993 and followed up over five years. The last cohort was comprised of the most poorly functioning individuals who required high levels of support. Seven hundred and eleven long-stay inpatients (751 discharges<sup>5</sup>) were assessed over the study period. Initial analyses found that the long-run marginal cost of care in the community (majority in receipt of residential care), was not greater and likely less than the hospital costs of service users moving within the first two years of the project – the higher functioning cohorts (Knapp et al. 1990). After including the data from the

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<sup>5</sup> Several inpatients fulfilled the inclusion criteria more than once with each discharge fully costed.



last cohort, the cost of community care was found to be significantly greater than hospital care (Beecham et al. 1997). The high costs associated with this group were accounted for by what were described as ‘wards in the community’, highly staffed communal residential houses. For all service users, length of stay, total time spent in hospital and proportion of life spent in hospital had significant positive correlations with service costs. Female and older service users were associated with lower care costs. The researchers concluded that community care should not be viewed as a less costly option (Beecham et al. 1997).

In 2011, Knapp and colleagues published a review of the economic literature focused on the deinstitutionalisation of mental health care in Italy, Germany and the UK –countries with a long history of deinstitutionalised care – in which they aimed to answer seven questions regarding the economic consequences of deinstitutionalised care (see Figure 1.4). The authors reported that the total cost of community care is greater than the cost of hospital care. However, among people with high levels of need, the cost of care is high regardless of the setting. When data was adjusted for the levels of service user needs, the cost of community-based care was found to be greater than the costs associated with hospital care. The authors note that as community care has evolved to provide better care for service users with high needs, this finding may no longer hold.

Knapp and colleagues concluded that the cost of providing longer term care is great regardless of the setting and inadequate levels of mental health spending are likely to result in poor service user outcomes. They caution that transferring service users from hospital to community settings will likely require an increase in mental health funding as individuals in hospital often have greater needs than those currently receiving care in the community (Knapp et al. 2011). However, once transferred, the literature suggests

Question A: Is the cost of care in the community today less than the cost of institutional care?

Question B: Are the costs of community and institutional care higher for people with more clinical, social or behavioural problems, that is, those with greater needs?

Question C: On a like-with-like basis – adjusting for users' needs – is the cost of care in the community lower than the cost of institutional care?

Question D: If community care is more costly than institutional care, is it nevertheless more cost-effective because better outcomes are achieved for users and families for which it is considered 'worth' paying extra?

Question E: How does the cost of care in the community for people currently in institutional care compare with the cost of care for people currently in the community?

Question F: How does the expected cost of care in the community for people currently in institutional care compare with the cost of their current hospital care?

Question G: As the balance of provision shifts from institutional to community care, what happens to average cost in each setting?

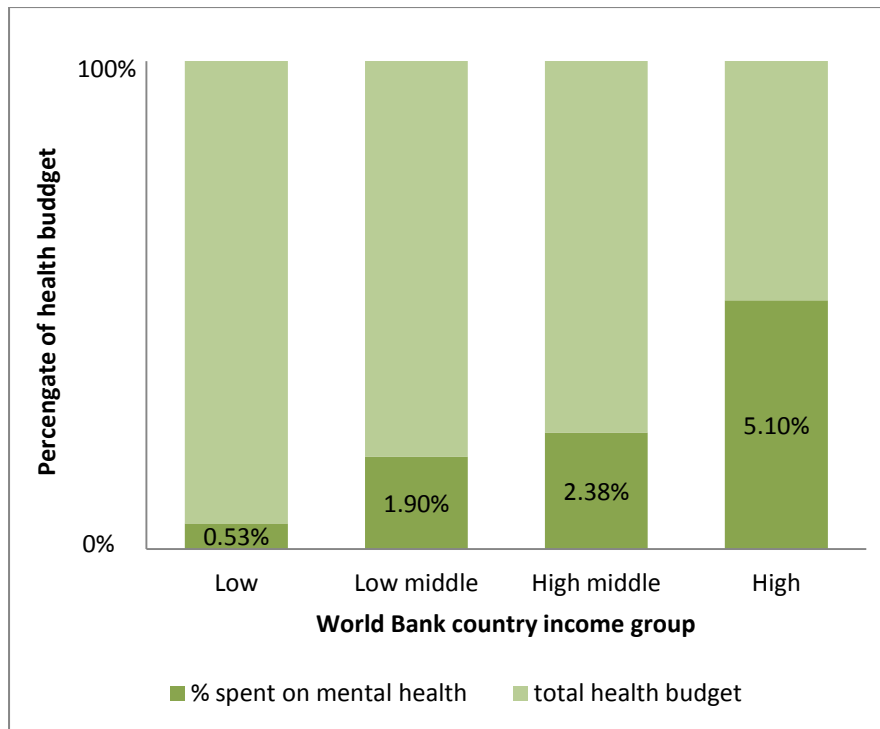
Note: From "The economic consequences of deinstitutionalisation of mental health services: Lessons from a systematic review of European experience" by Knapp et al, 2011

#### **Figure 1.4 Questions on the economic impact of deinstitutionalisation**

that the cost of care in the community is significantly lower than the cost of their inpatient care. Therefore, it is recommended that plans for deinstitutionalisation take a long-term perspective and allow for potential shifts in costs as more service users are transferred to the community.

### **1.3.3 Current expenditure on mental health**

The provision of high quality mental health services is reliant on adequate funding. However, despite the high prevalence of mental health problems and their associated burden around the world, 31% of 185 countries included in the WHO *Mental Health*



Note: From "Mental Health Atlas 2011" by World Health Organization, 2011, p. 27

**Figure 1.5 Median percentage of health budget allocated to mental health by country income group**

*Atlas 2005* did not have a specific mental health budget. Those countries that have dedicated budgets allocate far less than what is required to provide adequate mental health care (Saxena et al. 2007). Mental health spending is linked to national wealth, with low income countries spending a smaller proportion of their health budgets on mental health care (see Figure 1.5). In Europe, the median percentage of the health budget spent on mental health care is 5% (World Health Organization 2011). Among the ten countries of interest to this research, mental health expenditure ranges from 2.3% in Portugal to 10.1% in Germany (see Table 1.3; World Health Organization 2005). The low level of spending on mental health care is one factor associated with individuals with mental health problems going untreated. In Europe, an estimated 17.4% of individuals with a diagnosis of schizophrenia or other non-affective disorders

**Table 1.3 National mental health expenditure by country**

Country	% GDP on mental health	% of health budget allocated to mental health
Bulgaria	0.12	2.5
Czech Republic	0.25	3
Germany	0.82	10.14*
Greece	Unavailable	not available
Italy	0.34	5*
The Netherlands	0.58	7
Poland	0.15	3.5*
Portugal	0.33	2.3
Spain	0.27	5.89*
England	1.02	10 (UK)

\* From "Shifting care from hospital to the community in Europe: Economic challenges and opportunities" by Medeiros et al, 2008

Note: From "Mental Health Atlas 2005" by World Health Organization, 2005

do not receive treatment for their condition (Kohn et al. 2004). This treatment gap continues to rise among individuals suffering from bipolar disorder (39.9%), major depression (45.4%) and generalised anxiety (62.3%). These figures illustrate the need for increased mental health expenditure and improved availability of treatment.

Effective provision of community mental health care has been found to be highly contingent upon the availability and appropriate use of funds (Belcher 1988; Scott 1993; Aderibigbe 1997). In fact, the balanced care model, currently upheld by the WHO as the best practice in the provision of mental health care, includes recommendations on the implementation of the model based on a country's available resources (Thornicroft & Tansella 2003). In the current economic climate it is difficult, if not impossible, to allocate any further funds to mental health care. Many services will instead have to provide care under increasing financial strain. In order to understand how investment in

mental health care may impact on quality of care and service user outcomes, it is important to understand how quality of care is defined and assessed.

## ***1.4 The Measurement of Quality of Care***

### **1.4.1 Definitions of quality care**

There is no universally accepted definition of quality care. Quality is generally defined by Bluementhal (1996) as the degree to which appropriate care or services are chosen and adequately provided. Campbell and colleagues (2000) argue that quality of care should be measured by the accessibility and effectiveness of needed care. The definition developed by the Institute of Medicine (1990) in the USA is the most widely used in both policy and academic literature. It defines quality as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Institute of Medicine 1990, p. 21). This definition excludes the importance of non-health related outcomes such as social functioning, housing and employment. It also fails to indicate which stakeholder’s (e.g. clinician, service user, carer and politician) desired outcomes should set the benchmark. For the purpose of this research, I have defined quality of care in psychiatric and social care settings as the degree to which provision of mental health services corresponds to best available evidence and increases the probability of achieving both health- and non-health-related outcomes desired by key stakeholders (i.e. service users, mental health professionals, carers and advocates). This definition is in line with the principles of recovery-based practice which assert a holistic view of recovery including outcomes which are indirectly affected by mental health problems and require the engagement and empowerment of the service user in care discussions (Anthony 1993).

#### 1.4.2 The measurement of quality

Only when there is consensus regarding what services should look like and what is desired from them can decisions be made regarding how quality is measured. There are three general categories of quality assessment: (1) input, or structure, measurement, (2) process measurement and (3) outcome measurement (Schuster et al. 2005; Legido-Quigley et al. 2008). Each type examines specific components of care which can be used separately or combined depending on the conceptual approach used to define quality and the outcomes of interest.

Input measurement (also known as structure measurement) provides an assessment of the characteristics of the health care settings and the resources needed to provide care. In relation to mental health services, these assessments may include the living environment, accessibility to physical, mental and social care organisations and staffing levels. In order to ensure that services meet national standards, national legislation or guidelines regarding mental health care provision may be incorporated into assessments conducted by auditors and researchers. For example, in the UK, the Health Building Notes (Department of Health 2005) detail aspects of care required for specialist mental health services such as acute inpatient wards and community rehabilitation facilities. Similar guidelines are found in Germany (HeimMindBauV 2003) and the Netherlands (College Bouw Ziekenhuisvoorzieningen 2006). The WHO has also published international policy and planning guidelines to assist countries in the development of mental health services (Funk et al. 2010a; 2010b).

While input measurement evaluates the physical composition of mental health services, process measurement focuses on the provision of care. Treatments and interventions, assessments, continuity of care and therapeutic milieu are aspects of care which can be

measured in this category. Quality of care, as measured by process-focused assessments, is determined by the degree to which the care provided is both necessary and appropriate. Examples of process assessments used in research are the Ward Atmosphere Scale (WAS) and Community-Oriented Programs Environment Scale (COPEs) which assess treatment environments in hospital and community settings (Moos 1974). The Performance Assessment Tool for quality improvement in Hospitals (PATH, Veillard et al. 2005) was developed by the WHO Regional Office for Europe to assist hospitals in evaluating their performance and quality improvement strategies by measuring clinical effectiveness, efficiency, staff orientation, responsive governance, safety and patient-centredness.

Both input and process assessments are often measured against a gold standard which details components of appropriate care. However, these gold standards are not internationally uniform. Although the WHO has published its own recommendations for the care of individuals diagnosed with schizophrenia, several countries, including the UK, USA, Canada, Austria, the Netherlands, Germany and Norway, have developed their own national guidance (Gaebel & Falkai 1998; Buitelaar et al. 1998; Canadian Psychiatric Association 1999; National Institute for Clinical Excellence 2002; Katschnig et al. 2002; Statens Hestetilsyn 2003; Lehman et al. 2004a). This is often due to variety in available resources, levels of service provision and desired outcomes of care across countries.

Outcome measurements assess quality based on the effect of care on the service user and community. Outcome assessments may be completed by staff, service users or both. Many hundreds of outcome tools exist; for example, more widely standardised outcome

measures include the Health of the Nation Outcome Scale (HoNOS, Wing et al. 1998) and the Global Assessment of Functioning (GAF, Jones et al. 1995).

### **Service user participation in the assessment of quality of care**

Ideally, assessments of quality should include more than one type of measurement. Brook and colleagues (1996) argue that process measurement is more sensitive than outcomes measurement because poor outcomes are not observed in every instance of poor provision of care. However, relying on structural or process measurement alone discounts the perceived needs and expectations of the service user and may not necessarily result in improved outcomes. In order to better understand and, as a result, be better equipped to improve service delivery, an examination of all aspects of care and their related outcomes is ideal. However, comprehensive quality measurement is time-consuming and costly, making it more difficult to conduct. Therefore, it is important that discussions related to findings are sensitive to potential modifiers (e.g. methodology, validity of assessments, service user and staff characteristics).

The inclusion of service users' views and ratings in the assessment of the quality of mental health services is a relatively new phenomenon. Prior to the 1970s, the traditional, paternalistic view assumed that mental health service users were unable to make rational and appropriate decisions regarding their care. As a result, service users were largely excluded from active participation in discussions regarding their care. Instead, service user experiences of care were assessed through census data (Oliver et al. 1996) or clinical opinion (Brook et al. 1996). Today, individual nations (National Institute for Clinical Excellence 2002; Lehman et al. 2004b) as well as international organisations, like the WHO (Legido-Quigley et al. 2008), acknowledge the importance



of integrating service user perspectives into assessments of quality in all areas of medicine – including psychiatry.

Although service user participation in service assessment has gained popularity, it is still argued that self-report measures are inappropriate for use among populations with severe mental health problems – especially schizophrenia. Critics argue that the affect of schizophrenia on cognitive functioning results in a service user's inability to decide what is in his or her best interest (Rescher 1972; Oliver et al. 1996). However, the evidence regarding the accuracy of ratings is mixed. Atkinson and colleagues (1996) compared the perceived importance of and satisfaction with four life domains (health and functioning; socioeconomic; psychological/spiritual; family) as reported by service users diagnosed with a chronic mental illness: schizophrenia, bipolar disorder or depression. Although no significant differences were found in service users' perceptions of the importance of all domains, participants with schizophrenia had significantly higher satisfaction and composite scores (perceived importance and satisfaction) in every domain. The authors then used ratings from dialysis patients (taken from another study) in order to compare composite scores from chronic physical and mental illnesses. Dialysis patients had significantly higher scores in all domains when compared to service users with depression and bipolar disorder. No significant differences were found between service users with schizophrenia and dialysis patients except in the family domain where dialysis patients had a significantly higher composite score. The authors note that although clinical characteristics associated with schizophrenia such as reduced insight and anhedonia may explain the differences in ratings given by service users with bipolar disorder and depression from those reported by participants with schizophrenia, the scores reported by dialysis patients support the ratings of the patients with schizophrenia as there were no differences in socioeconomic status between the

two groups. The only difference between these two groups of chronic patients was the family domain of the Quality of Life Index. However, it is not surprising that patients with schizophrenia had lower scores on this domain as “the lack of ties to family (both of origin and procreation) is recognised as a problem area for many adult schizophrenic patients” (Atkinson et al. 1996, p. 103). Other research has shown that service users’ perception of the care they receive can play an important role in recovery by affecting the degree of engagement in care (Roter 1989; Gilson et al. 1994; Linhorst 1995; Oliver et al. 1996) and clinical outcomes (Simpson & House 2002; Bjorngaard et al. 2007).

The measurement of outcomes in individuals with chronic disorders, like schizophrenia, is unique. This is largely due to the fact that some may never achieve complete remission of their symptoms. However, the inability to make a full recovery does not necessarily reflect a poor experience of care or a lack of improvement in functioning (Legido-Quigley et al. 2008). Atkins and colleagues (1991) found that individuals receiving longer term care in a specialist rehabilitation facility made improvements in social functioning and quality of life.

#### 1.4.3 Evidence on the association between deinstitutionalisation and quality of longer term care

Evidence regarding the association between deinstitutionalisation and quality of care is largely limited to studies comparing service users’ outcomes in hospital and community-based care rather than evaluations of the associations between national systems of mental health care provision and outcomes. However, in the UK, the TAPS (Team for the Assessment of Psychiatric Services) project (described in section 1.3) evaluated the impact of deinstitutionalisation on clinical outcomes in 670 service users transferred from two psychiatric hospitals to community-based care from 1985 to 1993 (Leff & Trieman 2000). Although service users’ positive and negative symptoms and

social behaviour remained relatively unchanged five years after their transfer, service users saw significant improvements in their community and domestic skills. The size of service users' networks did not change following transfer. However, both the number of contacts with friends and individuals they described as confidantes increased at follow-up. The rate of readmission was relatively high (38%) with one-third of admissions lasting longer than 12 months (Leff et al. 2000). This may be linked to the high proportion (40%) of participants who experienced delusions or hallucinations throughout the study. However, individuals who moved on from their original placement generally moved to more independent settings, offering lower levels of support, at five year follow-up (1998). A small proportion (11%, n=72) of individuals in this study required high levels of support and were unable to move directly into standard community care (Leff et al. 2000). Instead, they were transferred to one of four high support facilities with high levels of staffing. After five years, researchers found a greater than 50% reduction in problem behaviours, specifically aggression, among this cohort and 40% had been successfully transferred to settings with lower levels of support.

In an evaluation of the impact of community services in Berlin, Germany, 128 mental health service users admitted to hospital for more than six months were interviewed and followed up either one year after discharge (n=65) or 18 months after baseline if they had never been discharged (n=63; Priebe et al. 2002). The majority of service users (74%, n=176) had a diagnosis of schizophrenia. Baseline differences between the two cohorts were significantly different for several characteristics. As expected, service users discharged to the community had less severe symptoms. They were also younger, had spent less time in hospital overall, and reported greater satisfaction with treatment. At follow-up, both cohorts showed significant improvement in symptoms. Although

service users discharged to the community reported a higher total number of needs and less satisfaction with life at baseline, at follow-up the group had significantly fewer total needs and greater life satisfaction when compared to the non-discharged group. Neither cohort showed significant reductions in the number of unmet needs at follow-up. No difference in treatment satisfaction was found at follow-up. However, high treatment satisfaction among those discharged at baseline prompted the authors to highlight the limited scope to result in significant improvement at follow-up (e.g. ceiling effect). As the authors do not describe the setting service users were discharged to it is unknown whether any service users were discharged to staffed community facilities or what affect this may have had on outcomes. Nonetheless, among less severely impaired service users, treatment in the community appeared to be more beneficial than hospital care.

Although the evidence suggests that community settings have no significant impact on service user symptoms, several studies have found improvement in functioning among this group. In a Finnish study, service users with a diagnosis of schizophrenia discharged from hospital between 1986 and 1994 were followed up three years after discharge to evaluate the impact of deinstitutionalisation on their outcomes (Honkonen et al. 2003). Three years following discharge, the majority of service users were in receipt of care from community mental health centres, alternative outpatient facilities (e.g. day hospitals, day centres and residential care homes) and hospitals. A minority of service users were cared for in primary care. Service users in receipt of community care who had not been readmitted to hospital at follow-up showed improved overall functioning. A similar study of Irish service users found significant improvement in satisfaction, self-care and social functioning one year after hospital discharge (McInerney et al. 2010). However, these change scores were no longer significant five

years post-discharge. The authors suggested that this could be due to difficulties in providing appropriate rehabilitation interventions within the community.

Improvement in quality of life has been reported in several studies of community-based care. Cullen and colleagues (1997) found service users receiving care in a 'ward in the community' showed significantly higher levels of quality of life and higher levels of satisfaction with care than those in traditional hospital rehabilitation wards. In another study evaluating quality of life among service users in a 'ward in the community', hospital wards and group homes (not 24-hour supported), service users in group homes were found to have higher self-reported well-being scores but poorer relationships with staff and other service users when compared to service users in other settings (Simpson et al. 1989). Both group home and ward in community service users had significantly more social contacts than those in hospital. When differences in support needs and severity of illness between groups were controlled for, service users in wards in the community were found to report the lowest ratings of their living situation. The authors advised that these results should be viewed with caution due to the small sample (N=34) and the relatively low participation rate of group home service users. In a larger study of 101 service users in the Netherlands, hospital settings were correlated with the lowest service user ratings of current life conditions while service users in community sheltered accommodation reported the highest ratings (Wiersma & van Busschbach 2001). Findings from the European Schizophrenia Cohort (EuroSC) study, which evaluated the outcomes of 1,208 service users with schizophrenia in France, Germany and the UK, suggest service users living in self-owned accommodation or supported housing have the highest levels of satisfaction with their current living situation when compared to service users in hospital, other settings or are homeless (Marwaha et al. 2008). A number of studies from Australia, Spain and the UK have found the majority

of patients with longer term mental health problems prefer living in community, rather than hospital settings (Leff & Trieman 2000; Trauer et al. 2001; Fakhoury et al. 2002; Rickard et al. 2002; Fakhoury et al. 2005).

Evidence from the literature suggests that although mental health service users in receipt of community-based care show no significant difference in symptoms compared to those cared for in hospital, community-based care is associated with improvement in other service user outcomes. Service users receiving care in the community are more likely to have better social relationships, higher self-reported ratings of life satisfaction, fewer numbers of needs and better overall functioning.

#### 1.4.4 Evidence on the association between mental health expenditure and quality of longer term care

Interest in economic evaluations in the field of mental health has only grown in recent years. As a result, evidence on this topic is extremely limited. Like the literature on the association between deinstitutionalisation and quality of care, most research on the costs associated with community and hospital-based care has focused on specific interventions or facilities rather than national levels of expenditure.

Roberts and colleagues (2005) conducted an international review of health economic analyses of 42 studies of community mental health care programmes published between 1979 and 2003. The majority of programmes focused on various forms of community-based care. The researchers found that assertive community treatment programmes showed the most convincing evidence of cost-effectiveness when compared to hospital-based care and some forms of community case management. However, trials of this model in countries with well-developed community mental health teams have failed to replicate these results (McCrone et al. 2009). Contradictory evidence regarding the cost-

effectiveness of case management and community psychiatric nurse programmes made it difficult for the authors to synthesize results. Only one study comparing long-stay, community-based mental health care and inpatient care was identified (Dickey et al. 1986). In this study, community-based care was associated with similar service user outcomes but at a lower operational cost. The small sample size (N=22) of this study limits its strength and generalisability.

The impact of expenditure levels on service user outcomes is difficult to assess due to differences in the nature and provision of care. We know that care for service users with more severe mental health problems is more expensive than the costs associated with less severe problems (Roberts et al. 2005; Knapp et al. 2011). This is due to greater functional impairment and increased level of need which necessitate higher levels of support. For those whose need warrants longer term, 24-hour care, costs are greatest. A review of the economic literature focused on the deinstitutionalisation of mental health care in Italy, Germany and the UK suggested that although potentially more expensive than hospital care, community-based services were associated with outcomes similar to or better than those resulting from hospital care (Knapp et al. 2011). This finding was especially robust for service users with less severe mental health problems; however, literature focusing on the impact of community care on service users with greater levels of need suggests that improvement in outcomes is also possible. However, improved outcomes among this group were linked to greater staffing intensity and, therefore, higher cost.

The cost-effectiveness of specialist community mental health accommodation in the UK was examined as part of the TAPS study (Knapp et al. 1999). Service users were transferred over eight years from hospital care to community services provided by the

NHS, the voluntary sector, an NHS/voluntary consortium, local authorities and the private sector. Costs included health and social care costs as well as other, formal service costs (e.g. criminal justice, employment agencies and education). The highest costs were associated with care provided by a consortium, followed by the NHS, voluntary sector, local authority and private sector. Higher cost of service provision was associated with better quality of care (as assessed by the level of restrictiveness imposed on service users) and significant improvement in service user symptomology and functioning at one year follow-up. Service user characteristics prior to discharge, the type of care provided and the type of service provider may have confounded these results; service users who were placed in NHS and consortium facilities had the greatest impairment while those transferred to local authority and private sector facilities had the least impairment. As a result, service users placed in NHS and consortium facilities – the most expensive care settings – may have been able to improve their outcomes more easily than service users with better levels of functioning at baseline. Differences in the type of care setting may also have influenced the results; the majority of consortium facilities were hostels and staffed group homes. These settings may be less restrictive in nature than residential/nursing homes, which accounted for the majority of private sector facilities, and therefore, had higher quality of care scores. It could also be argued that NHS and consortium facilities were better able to provide high quality care and interventions to improve service users' functional skills. However, one may expect that greater freedoms (i.e. higher quality of care) would be granted to service users with less impairment and greater functioning such as those receiving specialised care from local authority and private sector providers.

Predictors of the cost of care among the most difficult-to-place TAPS cohort were evaluated by McCrone and colleagues (2006). The authors found increased cost of care



was associated with poor self-care and domestic skills and a longer length of admission prior to hospital discharge. This finding is in line with literature which suggests that care is most expensive for those with high levels of need. However, in Knapp and colleagues' (2011) review of the impact of deinstitutionalisation, they found that service users with more aggressive behaviours and poor living skills had lower costs of care. This result implies that the most difficult to treat service users may be more likely to receive inappropriate care, a suggestion corroborated by research which found mental health inpatients displaying anti-social behaviour did not receive specific interventions to address this problem behaviour (Hodgins et al. 2009).

In another UK study, service user outcomes were reported for a small cohort (N=22) of service users placed in a 'ward in the community' or a psychiatric unit in a general hospital (Hyde et al. 1987). At baseline, service users transferred to the community exhibited less impairment. After two years, no significant difference in symptoms was found. However, service users in the community had significantly better domestic skills and spent more time on constructive activities defined as "eating, self-care, working, [and] conversation" (Hyde et al. 1987, p. 809). The direct and indirect costs associated with community care were significantly less than inpatient care. However, due to the small sample size and baseline differences between the groups, these findings have limited generalisability.

Evaluations of the relationship between the cost of mental health care and service user ratings are limited in the available literature. National ratings of treatment satisfaction and life satisfaction among European mental health service users were reported by the EPSILON (Ruggeri et al. 2003) and EuroSC (Marwaha et al. 2008) projects. Ruggeri and colleagues measured treatment satisfaction among service users with schizophrenia

receiving community mental health care in the Netherlands, Denmark, the UK, Spain and Italy using the Verona Service Satisfaction Scale (Ruggeri & Dall'Agnola 1993), while Marwaha and colleagues compared life satisfaction levels, as measured by Lehman's Quality of Life Index (QoLI; Lehman 1988) among service users receiving secondary mental health care in France, Germany and the UK. Italy, the country with the lowest relative mental health expenditure as measured by the percentage of the health budget spent on mental health (8%; World Health Organization 2005), reported the highest treatment satisfaction while, service users in the UK, which spends 10% of the health budget on mental health, reported the lowest treatment satisfaction (Ruggeri et al. 2003). Among EuroSC countries, no clear difference was found between mental health expenditure and self-reported life satisfaction. These findings, although mixed, suggest the possibility that increased expenditure may be linked to negative service user ratings of their care as there is evidence that service user satisfaction may be contingent upon expectations of care (Staniszewska & Ahmed 1999). Therefore, it is possible that service users in wealthier countries have much higher expectations of their treatment and care compared to service users in less wealthy countries.

The literature evaluating mental health expenditure suggests that increased facility-level expenditure is associated with care which better meets service users' needs and improved service user functioning. However, it is unclear whether or not greater spending causes this improvement in quality. Evidence regarding the impact of expenditure on service users' experiences of care suggests a reduction in treatment satisfaction as national mental health expenditure rises. The strength of this synthesis is weakened by methodological differences such as the severity of symptoms in the service users studied, the type of care assessed and the way in which the costs

associated with care are calculated and evaluated, in addition to the limited number of studies (see section 1.3).

### ***1.5 Summary***

The high prevalence and associated burden of disease of mental health problems make them an important target for health care reform around the world. However, current funding and service provision is generally inadequate with estimated treatment gaps ranging from 70% to 90% in developed and developing countries, respectively. As a result of this disparity, the WHO and leading mental health experts have begun to actively lobby for increased mental health spending and greater levels of deinstitutionalisation to improve quality of care and accessibility to services, although limited evidence for these recommendations exist.

In the last 30 years many European countries have begun to provide mental health care in community settings with mixed success. The numbers of conventional psychiatric beds have fallen and the majority of mental health service users are successfully cared for in the community. However, recently several experts have suggested that countries with a longer history of deinstitutionalisation are moving towards ‘reinstitutionalisation’ as evidenced by the rising numbers of beds in forensic settings, and there is some evidence of poor quality of care received by the most challenging mental health service users in psychiatric and social care facilities. Inadequate provision of care can have significant clinical and financial consequences as this small group requires a disproportionately large proportion of the mental health budget.

The literature demonstrates that individuals with more severe mental health problems can be successfully cared for in the community. Although their symptoms do not seem to be significantly improved by the transition from hospital to community-based care,

service users appear to show greater levels of functioning and improved social relationships and report greater life satisfaction in community settings. These gains mean community care is often more cost-effective than hospital-based care. Evidence of the effectiveness of deinstitutionalisation focuses on studies of the transition of service users to community-based care following discharge from mental hospitals and comparisons of community and hospital facilities. However, deinstitutionalisation requires the development and implementation of mental health legislation and policies, collaboration with relevant government departments (e.g. social care, education and criminal justice) and the commitment of both financial and human resources. Nonetheless, the impact of national levels of deinstitutionalisation on quality of care and service user outcomes has yet to be evaluated. This is likely due to the lack of a measure of deinstitutionalisation deemed relevant to a large number of countries. Current discussions regarding national deinstitutionalisation levels are based on subjective categorisations by experts which cannot be used for international comparisons due to a lack of consistency. Therefore, an appropriate tool must be developed before comparisons can be made.

Effective provision of community mental health care is contingent upon the availability and appropriate use of resources. Evidence regarding the cost of mental health care suggests that the provision of care for individuals with the greatest impairment is costly regardless of the treatment setting but that the cost of care in the community for current inpatients is significantly lower than their current hospital costs. However, expenditure appears to be positively associated with quality of care, especially in longer term care settings. Service user outcomes such as functioning, symptom severity and autonomy are also improved. Conversely, limited evidence suggests a possible negative association with treatment satisfaction. This may be due to increased expectations of

care among service users in wealthier nations. Like the evidence for the association between deinstitutionalisation and quality of care, research has yet to examine the relationship between national levels of mental health spending and the quality of care.

In the current economic climate it is unlikely, if not impossible, that governments will allocate any further funds towards mental health care. In fact, many services may instead be forced to provide care under increasing financial strain as budget cuts become a greater possibility. Therefore, it is important that we understand the relationship between expenditure and the quality of mental health services in order to ensure the provision of the best possible care. Several estimates of the costs associated with mental health problems have been published over the past decade which suggest that current levels of expenditure do not reflect the true cost of mental health problems. These estimates vary widely, partly due to the methodological differences, which makes it difficult to draw definite conclusions from them. Clearly written and transparent descriptions of the interventions and services evaluated, and use of a standard methodology for cost calculation and reporting currency, may help overcome some of these challenges. In comparing international evaluations of cost with quality of care and outcomes, it is important that widely available standardised measures of cost are used (e.g. national mental health budgets). As a result, the use of direct costs for this purpose is the most appropriate as the valuation of indirect and intangible costs can vary by culture.

In order to make suggestions on how to maximise the quality of longer term care, a deeper understanding of the components of longer term mental health care which improve service user outcomes is needed. This will not only help to improve the provision of care in countries where the availability of community care is lacking, but

also inform the provision of care for service users with the most severe symptoms and functional impairments who continue to require high levels of support in residential community facilities. In the next chapter I report the results of a critical synthesis of the international literature on key aspects of longer term care that promote service user recovery.

## Chapter 2

### **The Components of Effective Care**

#### ***2.1 Introduction***

The majority of mental health service users can be successfully treated in community settings. However, a small group of individuals, often with a diagnosis of schizophrenia or schizoaffective disorder, require highly supported, longer term mental health care provided in psychiatric or social care facilities. These conditions impact on their capacity to make informed choices for themselves and to actively participate in their care, putting individuals at risk of exploitation and abuse from others, including those who care for them. To ensure facilities provide appropriate treatment and care, many countries have set up their own systems for monitoring service provision. However, currently there are no internationally agreed quality standards for institutional care or a common method of quality assessment. This chapter provides a broad systematic review of the international literature relevant to longer term mental health care in psychiatric and social care facilities and identifies key components of care vital to service user recovery.

##### **2.1.1 Aims**

A systematic review of the literature published in peer reviewed journals since 1980 was conducted with the aims of:

1. identifying key components of institutional care for people with longer term mental health problems;
2. evaluating the effectiveness of these components; and
3. undertaking a critical interpretative synthesis of the evidence in order to identify the domains of institutional care that are key to service users' recovery.

The review was conducted as part of the Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care (DEMoBinc) project (Taylor et al. 2009).

## **2.2 Method**

### **2.2.1 Eligibility**

#### **Inclusion criteria**

Included papers examined factors associated with the quality of care received by adults of working age with longer term mental health problems living in psychiatric or social care facilities in hospital or the community. The review was limited to papers published since 1980 since much of the deinstitutionalisation across Europe has taken place in the last 30 years.

#### **Exclusion criteria**

Papers were excluded if the focus, setting or client group could not be extrapolated to the care in facilities for people with longer term mental health problems. Studies that reported on drug trials, examined patients' quality of life or satisfaction in isolation from their context in institutional care, or whose focus was too broad for its results to be useful for the aims of the review were excluded. Medication, although integral to the treatment of individuals with serious mental illness, was not included in this review as numerous guidelines (National Institute for Clinical Excellence 2002; Lehman et al. 2004a) exist which include recommendations on medications and monitoring their effects and side effects. Where a systematic review was included, no further detailed examination of each paper contained within it was undertaken. Nor were editorials, letters, books or book chapters included.



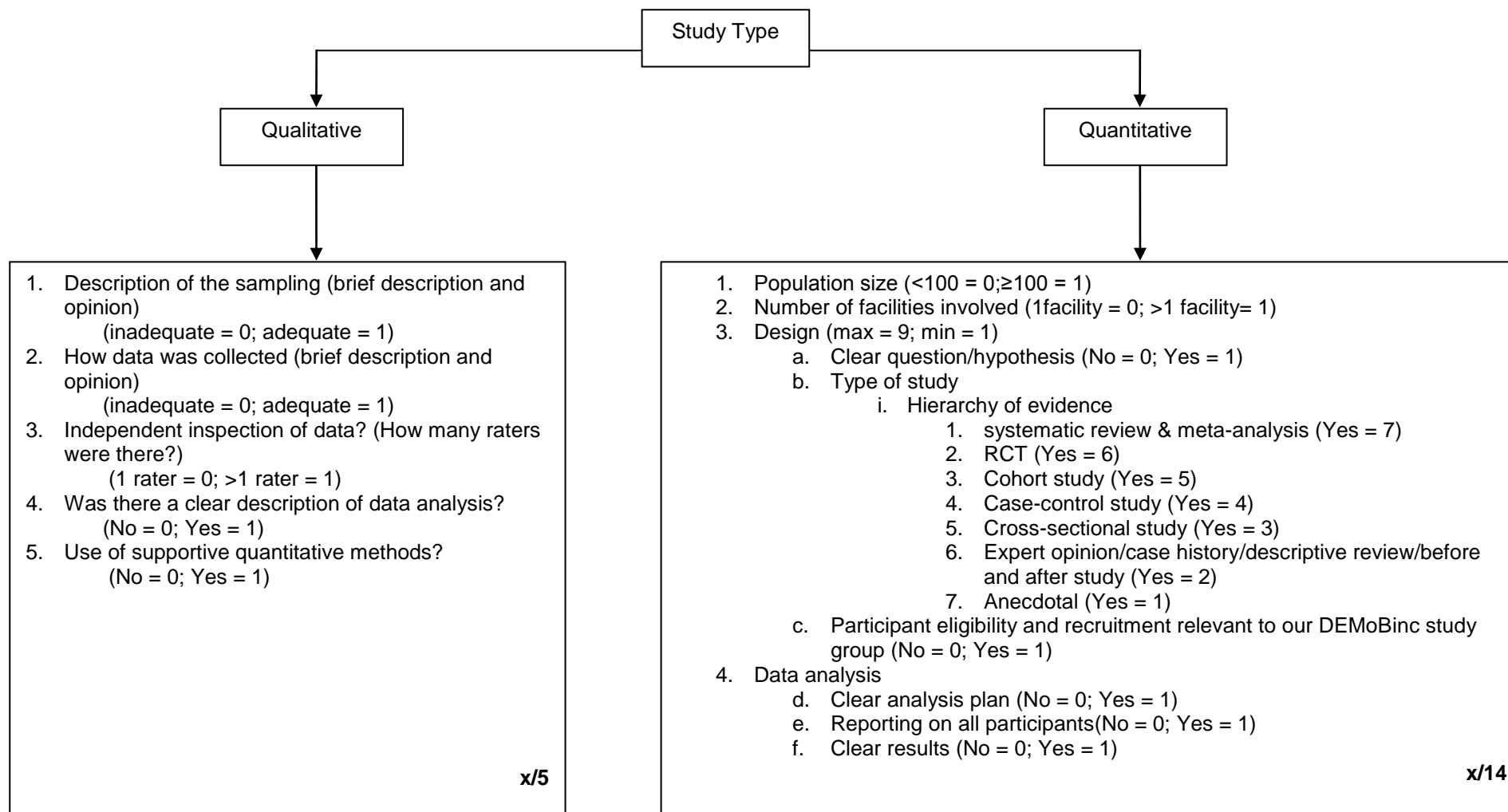
### 2.2.2 Search strategy

A wide range of search terms, including client group, settings, treatments and interventions, were adapted for each database and used to identify relevant articles.

Eleven electronic databases (Medline, Embase, PsycINFO, CINAHL, The Cochrane Library, Web of Knowledge, ASSIA, International Bibliography of the Social Sciences, Sociological Abstracts, Social Science Citation Index and Science Citation Index) were searched for papers published between the years 1980 and 2007. Author and paper searches were clarified, where necessary, using Google Scholar. First authors of included articles were contacted for additional published or unpublished material when appropriate. Principal investigators from each of the ten countries participating in the DEMoBinc study provided references or copies of relevant papers that had not been identified from the databases listed above. No relevant studies were found which had been missed by the initial search.

### 2.2.3 Assessment of methodological quality

The quality of papers was independently rated by two researchers using separate criteria for qualitative and quantitative research papers (Figure 2.1). These criteria were derived from recommended approaches (Guyatt et al. 1995; Mays & Pope 2000; University of Sheffield 2000; Medical Research Council 2000) and additional items specific to the aims of the review. Quantitative papers were assessed on: (1) population size; (2) number of facilities from which participants were recruited; (3) design (i.e. clarity of the research question or hypothesis, the type of methodology used (Medical Research Council 2000) and relevance of the participants to the aims of the review); and (4) data analysis (i.e. clarity of the analysis plan, reporting on all participants and clarity of the results). These criteria provided a maximum score of 14 points. Qualitative



**Figure 2.1 Quality assessment criteria for studies included in the systematic review of the key components of effective mental health care**

papers were assessed on: (1) sampling; (2) data collection; (3) data inspection; (4) data analysis; and (5) the use of supportive or corroborative quantitative methods. These criteria provided a maximum score of five points. Where a paper included both types of research method and data collection, two separate quality assessments were carried out.

#### 2.2.4 Domain allocation

Included papers were grouped by theme and domains of care associated with longer term mental health institutions were determined once all data were compiled. Domains were agreed upon by consensus of the DEMoBinc UK Steering Group<sup>6</sup>. Domain allocation of a randomly selected sample of 20 papers was carried out independently by a second researcher to ensure reliability. Nineteen of the 20 papers were matched.

#### 2.2.5 Analysis

The review was carried out systematically but includes a narrative component whereby the best available evidence in this field was synthesised to identify the key components of care. Conventional systematic reviews are often unable to provide a critical analysis of a complex body of literature. This is particularly the case in assessing evidence on the components of care that constitute an ‘ideal’ institution, thus a ‘critical interpretative synthesis’ approach was adopted to allow for the analysis of a broad and complex body of literature which includes both quantitative and qualitative methodologies (Dixon-Woods et al. 2006). Instead of analysing the literature using pre-determined outcomes, key concepts were defined after the synthesis of the findings, allowing for greater exploration of a broad array of outcomes and experiences.

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<sup>6</sup> The DEMoBinc UK Steering Group was composed of the chief investigator, study statistician and UK-based principal investigators and research associates.

## **2.3 Results**

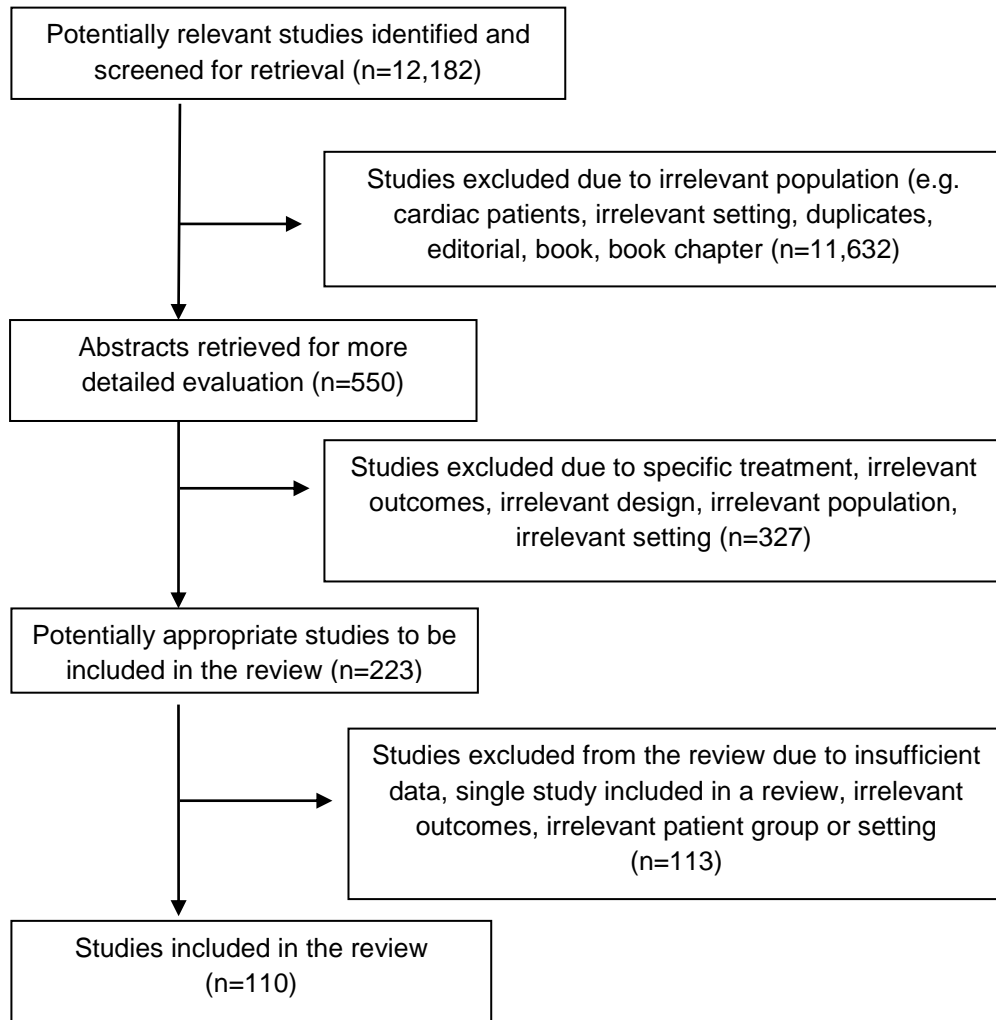
A total of 12,182 relevant articles were identified (see Figure 2.2). After further inspection of abstracts and papers, 12,072 articles were excluded due to duplications or exclusion criteria. One hundred and ten articles were included in the review.

### **2.3.1 Key domains of care**

Eight domains of institutional care were identified as key to service users' recovery: (1) living conditions; (2) treatments and interventions; (3) physical health; (4) restraint and seclusion; (5) staff training and support; (6) therapeutic relationship; (7) autonomy and service user involvement; and (8) clinical governance. Evidence was strongest for specific interventions for the treatment of schizophrenia (i.e. family psychoeducation, cognitive behavioural therapy [CBT] and vocational rehabilitation).

### **Characteristics of included studies**

The main characteristics of papers included within each domain are shown in Appendix A. Included papers came from 19 countries and were published between 1980 and 2007. The majority came from the USA (42%, n=46) and the UK (25%, n=27). Five were international multicentre studies (Roder et al. 2001; Rickard et al. 2002; Roder et al. 2002; McGorry et al. 2005; Rummel-Kluge et al. 2006). Fifty-six studies specifically included patients with schizophrenia but several did not describe participants' diagnoses. The types of facilities investigated included both hospital-based (e.g. wards) and community-based (e.g. boarding homes, nursing homes, supported housing) institutions. Most (70%, n=77) included papers used quantitative research methods. Of these, 24 were systematic reviews or meta-analyses and 19 were descriptive reviews. Three papers included qualitative



**Figure 2.2 Study flow diagram of evidence on the key components of effective mental health care**

methods while two included both qualitative and quantitative methods. Six papers were clinical guidelines.

The type of studies and number of papers for each domain is presented in Table 2.1. The majority of evidence was associated with the treatments and interventions domain (58 studies and meta-analyses) although the number of papers for specific treatments and interventions varied markedly (range 1-12). The living environment and restraint and seclusion domains had 18 papers each. Clinical governance, with two relevant papers, had the least available evidence.

### 2.3.2 Strength of the evidence

A broad systematic review of the components of institutional care was deliberately undertaken in order to inform a whole systems approach to the care of longer term mental illness. Evidence was strongest for specific interventions for the treatment of schizophrenia, especially CBT, family psychoeducation and supported employment. This is unsurprising as specific interventions lend themselves to randomised controlled trials and other, more robust methods of study than other aspects of care. Although all relevant studies were included in the review, the assessed quality of each study determined the weight given to its findings. This method is not without limitations. Several studies, mostly quantitative in design, obtained the maximum possible score. This does not necessarily infer that these studies were without limitation – it simply denotes that the study met the requirements laid out. Furthermore, well designed studies conducted in a single centre would not obtain full marks. However, the inclusion of the number of sites as a quality criterion seems reasonable since multi-centre studies provide greater evidence than single site studies as results are more generalisable. This is in keeping with the Medical Research Council's

**Table 2.1 Type and number of included studies for identified domains**

Domain	Systematic reviews and meta-analyses		Randomised controlled trials	Qualitative studies	Other studies	Clinical guidance
	Number of reviews	Total number of studies				
<b>Living Conditions</b>	2	58	-	-	15	1
<b>Interventions for the Treatment of Schizophrenia</b>						
CBT	2	39	2	-	-	2
Family Interventions and Psychoeducation	4	117	2	-	4	2
Vocational Therapy	3	46	-	-	3	2
Social Skills Training	3	33	-	-	2	2
Cognitive Remediation	2	24	1	-	-	-
Arts Therapies	3	11	-	-	-	-
Integrated Therapy	1	30	-	-	2	-
Treatment of Co-morbid Substance Misuse	-	-	-	-	1	2
Medication Management	-	-	-	-	-	2
Compliance Therapy	1	1	4	-	1	-
Occupational Therapy	-	-	1	-	1	-
Supportive Therapy	1	21	-	-	-	-
Coping Skills Training	-	-	2	-	-	-
<b>Physical Health</b>	-	-	-	-	7	2
<b>Restraint and Seclusion</b>	4	275	-	1	9	4
<b>Therapeutic Relationship</b>	1	7	-	1	12	-
<b>Service User Involvement and Autonomy</b>	1	13	1	1	3	-
<b>Staff Training and Support</b>	-	-	-	-	4	1
<b>Clinical Governance</b>	1	Not specified	-	-	1	-

(2000) accepted hierarchy of evidence.

There were few high quality studies conducted on other specific interventions (such as cognitive remediation, arts therapies, compliance therapy, relapse prevention, coping skills training), the living environment and staff training and support. Lower quality studies (with an average quality rating of less than 10) were found in relation to living environment, integrated therapy, physical health, restraint and seclusion, the therapeutic relationship and service user involvement. Fewer and poorer quality studies were found in relation to interventions for co-morbid substance misuse, occupational therapy, autonomy and clinical governance.

### 2.3.3 Living environment

The highest quality papers investigating the effect of living environment on service user outcomes found that mental health care should be provided in the least restrictive setting which ensures patient safety and allows for effective treatment (Lehman et al. 2004b). Community residential facilities provide a greater quality living environment when compared to hospital settings as care is often less regimented, more facilitative of service user autonomy and linked to greater levels of service user satisfaction (Kruzich & Kurzich 1985; Cullen et al. 1997; Trauer et al. 2001; Fakhoury et al. 2002; Rickard et al. 2002; Fakhoury et al. 2005). A positive social climate, characterised as cohesive, organised, comfortable and encouraging of residents' independence and involvement in decision making, was found to be associated with greater service user satisfaction with their living situations (Mares et al. 2002).



Although there is inconsistent evidence for the effect of the physical environment (i.e. access to sunlight, layout of communal areas, degree of institutional-like setting and furnishings; Dijkstra et al. 2006), the degree of privacy afforded to service users was found to mediate outcomes of mental health service users living in supported housing (Fakhoury et al. 2002) and in hospital (Corrigan 1990).

Culture appeared to be relevant to satisfaction with care in a study comparing community-based facilities in Andalucía, Spain and London, England (Rickard et al. 2002). Although English facilities were less restrictive and offered service users greater access to privacy, Spanish service users reported greater satisfaction with their individual progress, enjoyment of the company of other residents, acceptance of house rules and routine and benefits from their activities and medication.

#### 2.3.4 Interventions for the Treatment of Schizophrenia

As the majority of individuals receiving mental health care in hospital and community residential facilities have a diagnosis of schizophrenia, interventions included primarily focused on this population. Medication, although integral to the treatment of individuals with serious mental illness, was not included in this review as numerous guidelines (e.g. National Institute for Clinical Excellence 2002; Lehman et al. 2004b) exist which include recommendations on medications and monitoring medication effects and side effects.

The evidence for cognitive behaviour therapy (CBT), family interventions, including psychoeducation and supported employment has consistently been linked with improved service user outcomes. Research on CBT has shown it to be effective in reducing positive (Pilling et al. 2002b; Pfammatter et al. 2006) and negative (Turkington et al. 2006)

symptoms, reduce the chance of developing depressive symptoms and improving insight (Turkington et al. 2006). However, findings regarding relapse rates are inconclusive (Pilling et al. 2002b; Barrowclough et al. 2006; Turkington et al. 2006).

Family interventions, including psychoeducation, have been associated with a decreased risk of relapse (Pekkala & Merinder 2002; McFarlane et al. 2003; Pfammatter et al. 2006; Pitschel-Walz et al. 2006), improved functioning (Pekkala & Merinder 2002; McFarlane et al. 2003; Pfammatter et al. 2006) and increased medication adherence (Pilling et al. 2002b; Pharoah et al. 2006).

Supported employment has been shown to be more successful in improving service users' chances of competitive employment than other forms of vocational rehabilitation (Crowther et al. 2001; Twamley et al. 2003) while programmes that encourage direct entry into competitive employment and provide individualised workplace support have the strongest evidence (Bond et al. 1997; Bond et al. 2001; Crowther et al. 2001; Twamley et al. 2003).

Integrated therapies have been associated with positive outcomes (Lenroot et al. 2003; Mueser et al. 2006; Roder et al. 2006) and satisfaction (Mueser et al. 2006) among service users. Evidence supports the integration of mental health and substance misuse interventions into a single care package (Drake et al. 2004; Lehman et al. 2004b; Ziedonis et al. 2005). Patient-centred programmes and those that incorporate some form of motivational counselling and outreach to engage the individual are recommended (Drake et al. 2004; Mueser et al. 2006).

Studies examining cognitive remediation (Pilling et al. 2002a; Pfammatter et al. 2006; Wykes et al. 2007), social skills training (Bustillo et al. 2001; Roder et al. 2002; Pilling et al. 2002a; Pfammatter et al. 2006; Roder et al. 2006), arts therapies (Gold et al. 2005; Ruddy & Milnes 2005; Ruddy & Dent-Brown 2007), compliance therapy (Seltzer et al. 1980; Streicker et al. 1986; Eckman et al. 1990; Eckman et al. 1992; Kuipers et al. 1994; Kemp et al. 1998; McIntosh et al. 2006) and occupational therapy (Buchain et al. 2003; Oka et al. 2004) were few and provided insufficient evidence.

Supportive therapy, defined as any one-to-one intervention which aimed to improve or maintain the patient's functioning, was more likely to cause social impairment, treatment-related early termination, an episode of affective symptoms and poor medication compliance when compared to standard care and other psychological and psychosocial therapies in a Cochrane review (Buckley et al. 2007). However, the reviewers noted that the small number of relevant studies included had small sample sizes (mean: 84, range: 12-315) limits the strength of the findings. Studies examining therapeutic relationships have found them to be an important predictor of service user outcomes (Snyder et al. 1995).

### 2.3.5 Physical Health

Screening and treatment for physical health problems is an important aspect of care for individuals with severe mental health problems receiving longer term care as the client group tends to have less healthy lifestyles than the general population (e.g. poor diet, lack of physical exercise, smoking and substance misuse) leading to increased risk of mortality from respiratory disease, cardiovascular disease and cancer (Kilian et al. 2006; Osborn et al. 2006). Those with a diagnosis of schizophrenia are at greater risk for negative health

outcomes than individuals with other mental health diagnoses (Kilian et al. 2006; Osborn et al. 2006; Mitchell & Malone 2006). However, this group often received poor physical care (Tang et al. 2004; Bazemore et al. 2005). To improve preventative care, comprehensive medical and psychological assessments should be provided upon admission and at appropriate intervals, which will vary depending on symptoms, as standard. These assessments should include weight checks, advice on diet, exercise and smoking cessation, as well as screening for physical health problems (National Institute for Clinical Excellence 2002; Lehman et al. 2004b).

### 2.3.6 Restraint and Seclusion

Two reviews have concluded that there is insufficient evidence to determine the efficacy of restraint and seclusion (Bower et al. 2000; Nelstrop et al. 2006). However, it has been suggested that its use is inevitable in facilities serving individuals with more severe mental illness (Fisher 1994; Bower et al. 2000; Palazzolo et al. 2001; Nelstrop et al. 2006). Therefore, it is important that facilities provide staff with training and strict protocols to ensure these interventions are administered safely (National Institute for Clinical Excellence 2002; Lehman et al. 2004b; Addington et al. 2005; McGorry et al. 2005; Nelstrop et al. 2006).

The use of restraint and seclusion may be significantly reduced by a range of interventions, including expectations to reduce the use of restraint and seclusion, greater ratio of staff to service users (Kostecka & Zardecka 1999), staff training (Palazzolo et al. 2001; Khadivi et al. 2004; Mccue et al. 2004; Gaskin et al. 2007; Janssen et al. 2007) and clearly defined protocols (National Institute for Clinical Excellence 2002; Lehman et al. 2004b; Addington

et al. 2005). Involving service users in developing alternate ways of de-escalating tense situations and monitoring actions taken following use of restraint or seclusion were also found to be effective in reducing subsequent use of restraint and seclusion (Donat 2002; Donat 2003; Khadivi et al. 2004; Mccue et al. 2004).

### 2.3.7 Therapeutic Relationship

Many individuals with severe mental illness have limited relationships with other people. Therefore, the relationship between staff and service users plays an integral role in recovery – especially in long-term residential care (Allen et al. 1985; Clarkin et al. 1987; Gehrs & Goering 1994; Howgego et al. 2003; McCabe & Priebe 2004; Johansson & Eklund 2004). Evidence suggests that positive relationships are correlated with positive service user outcomes (Gehrs & Goering 1994; Howgego et al. 2003; McCabe & Priebe 2004) while negative relationships with high rates of critical comments from staff are associated with decreased service user satisfaction and negative outcomes (Snyder et al. 1995).

### 2.3.8 Autonomy and Service User Involvement

Provision of opportunities for autonomy and involvement in service delivery and evaluation has been shown to improve service user satisfaction, quality of life and social functioning. Studies have found service users can work effectively as service developers (Ahuja & Williams 2005), providers (Simpson & House 2002), trainers (Ahuja & Williams 2005) and evaluators (Linhorst & Eckert 2002). Including service users in service evaluation may facilitate a better understanding of service users' views and expectations, and increase their personal investment and involvement in service improvement (Linhorst & Eckert 2002). For clients who are more functionally and cognitively impaired such that participation in care discussions may not be possible, Frese and colleagues (2001) suggest that evidence-

based interventions should be used with more collaborative approaches implemented as the client's mental state and functioning improve.

### 2.3.9 Staff Training and Support

A review of strategies for the implementation of evidence-based practices in mental health settings cited lack of training as a key barrier (Corrigan et al. 2001). Training in effective psychosocial interventions and the philosophy of rehabilitation (Linhorst 1995) and recovery-orientated practice (Sowers 2005) is recommended for staff who work with this client group. Increased staff training and support may improve the quality of care provided and service user outcomes (Corrigan et al. 2001). Multidisciplinarity within teams is positively associated with service user functioning in activities of daily living (Alexander et al. 2005). An intervention to improve team leadership was found to improve team leaders' supervisory feedback which, in turn, resulted in an increase in service user satisfaction and quality of life (Corrigan et al. 2001).

### 2.3.10 Clinical Governance

In a systematic review which evaluated practice improvement methods for health care services conducted by Cape and Barkham (2002), they describe a model of practice improvement which is comprised of three main stages which operate in a continuous feedback loop: process guidance (such as education and training, evidence-based clinical guidelines and clinical supervision); process monitoring (through clinical audit, clinical supervision and quality improvement); and outcomes management (outcomes monitoring, quality improvement and benchmarking). These components of service improvement were shown to be effective in changing professional practice and improving health outcomes but staff had to commit to clinical audits and feedback. Practice improvement methods

focusing on more than one intervention were more effective than those comprising single interventions.

## ***2.4 Discussion***

The organisation and components of care for individuals with severe mental health problems in longer term hospital or community-based settings have historically been based on face validity and professional opinion rather than scientific evidence. This literature review intended to undertake a broad approach in order to maximise the relevance of the findings. Thus, I adopted a critical interpretative synthesis approach. The strength of this method is the way in which key concepts are defined after the synthesis of the findings, allowing for greater exploration of a broad array of outcomes and experiences. The eight domains of care identified through the literature are similar to the findings of a qualitative study of service users, carers, professionals, policy makers and other citizens in five European countries (van Weeghel et al. 2005).

This synthesis of the best available evidence indicates that the ideal longer term mental health facility is based in the community, operates a flexible regime, maintains the lowest density of residents possible given the resources available and maximises residents' privacy. Since the majority of service users in these settings have a diagnosis of schizophrenia, specific interventions with high efficacy (CBT, family interventions involving psychoeducation and integrated supported employment) are key to positive outcomes. They should be seen as priorities and delivered through programmes of complex interventions by specialist staff integrated within the same service. Restraint and seclusion should be avoided wherever possible and all staff should have adequate training in the use

of early de-escalation of potential violence. Adequate staff training in appropriate clinical skills and regular supervision should be provided. Positive therapeutic relationships between staff and service users should be developed through a collaborative, client-centred approach where treatments and interventions are discussed, negotiated and reviewed. There should be clear lines of clinical governance that ensure adherence to evidence-based guidelines and attention should be paid to service users' physical health through regular screening.

Although generalisations based on the literature should be done with sensitivity due to limitations in the number and quality of studies in certain domains, this review provides the first wide ranging review of components of care and the best available evidence relevant to components of institutional care for people with longer term mental health problems.

## ***2.5 Conclusions***

This synthesis of the literature has examined of the strength of the evidence for various components of institutional care for people with longer term mental health problems. An 'ideal' institution should be small and community based and maximise flexibility, privacy, engagement and positive therapeutic relationships. It should provide regular physical health screening and specific interventions (CBT, family interventions involving psychoeducation and supported employment) through integrated programmes for service users with a diagnosis of schizophrenia. Restraint and seclusion should be avoided whenever possible and staff should have adequate training in de-escalation techniques. Regular staff supervision should be provided with clear lines of clinical governance that ensure adherence to evidence-based guidelines.



## Chapter 3

# Development of the Quality Indicator for Rehabilitative Care

### ***3.1 Introduction***

Differences in the measurement of quality of care emerge due to a variety of factors such as cultural beliefs regarding mental health, socio-political beliefs regarding the responsibilities for care, available resources and level of deinstitutionalisation which shapes what is considered an appropriate level and composition of service provision. As a result, the way in which quality is defined and measured can vary by country, making it difficult to make cross-cultural comparisons. To ensure comparisons are appropriate and sensitive to differences, an internationally agreed tool is needed.

Recently, such a tool to assess the quality of care in longer term mental health facilities was developed through the DEMoBinc (Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care) project (Killaspy et al. 2009). The project was a pan-European collaboration of 11 centres in ten countries at different stages of deinstitutionalisation (Bulgaria, Czech Republic, Germany, Greece, Italy, the Netherlands, Poland, Portugal, Spain and the UK). The resulting tool, the Quality Indicator for Rehabilitative Care (QuIRC), was designed to reliably assess the living conditions, care and human rights of adults with longer term mental health problems whose levels of need necessitate treatment in psychiatric or social care facilities. In this section, I

will describe the development of the QuIRC, findings related to its psychometric properties and its implications for the assessment of quality.

### ***3.2 Toolkit preparation***

The initial stages in the development of the QuIRC focused on identifying the key components of institutional care for people with longer term mental health problems. Evidence was gathered from three sources: (1) a systematic review; (2) a Delphi exercise and (3) a synthesis of national and regional care standards. Evidence for the efficacy of care was gathered through a systematic review of the international literature published since 1980 to identify components of institutional care provided and to examine the evidence for the effectiveness and efficacy of these components as described in the previous chapter (Taylor et al. 2009).

Delphi exercises (an iterative postal/email focus group) were undertaken in each of the ten countries (Turton et al. 2009). These involved four stakeholder groups (mental health practitioners, service users, carers and advocates) in each country, consisting of 10 members (hence, 400 participants), who were asked their views on the Delphi question: “In your view, what most helps recovery for people with long-term mental health problems in institutional care?” Individual responses from each group were compiled by the research team and a list of all responses circulated to the group. All members were asked to rank the importance of each response on a scale from one, unimportant, to five, essential. The median score for each response was calculated by the research team and group members were contacted a third time and given a list of responses including the median score from the group along with their own score. Participants were asked to re-rate each response in

light of the median score. Final scores were evaluated to determine the degree of consensus among the group. Consensus was defined as a score within one point of the group median. Items with at least 80% consensus and a median score of four (very important) or five (essential) were grouped into domains using a “heuristic method reinforced by clinical judgement and experience” (Turton et al. 2009, p. 295). This process resulted in the identification of eleven domains of care deemed important to recovery: social policy and human rights; social inclusion; self-management and autonomy; therapeutic interventions; governance; staffing; staff attitudes; institutional environment; post-discharge care; caregivers; and physical health care.

In addition a review of current guidance on best practice in longer term mental health facilities was carried out by collating relevant national or regional care standards in each of the participating countries.

These three approaches led to the identification of six domains of care (living environment; therapeutic environment; treatments and interventions; self-management and autonomy; social policy, citizenship and advocacy; clinical governance) and three cross-cutting themes (social interface; human rights; recovery-based practice) for inclusion in the tool. As standardised assessment measures of the identified domains were largely unavailable, questions to assess these domains were developed and agreed by all research partners and members of an international expert panel (IEP)<sup>7</sup> for inclusion in the toolkit. The resulting

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<sup>7</sup> The IEP was composed of experts in the fields of rehabilitation and long term care for people with mental health problems, service users’ experiences, international mental health law, human rights, quality and care standards of inpatient and community based facilities for this service user group.

prototype contained 154 questions (280 items) and was designed for completion by a facility manager.

### ***3.3 Testing and refinement***

The toolkit was translated into local languages and piloted in face-to-face interviews with managers of two facilities in each country. Following refinement, it was assessed for inter-rater reliability in 202 institutions across the ten countries. Kappa coefficients and intra-class correlation coefficients (ICC) were used to assess the inter-rater reliability of categorical data and continuous data, respectively. Items were excluded from the toolkit where they were found to be unreliable (Kappa coefficient  $< 0.4$  or ICC  $< 0.7$ ), or where the distribution of data reflected a narrow range of responses impairing their sensitivity to identify differences in quality between facilities, or where they were difficult for the facility manager to complete. This process led to the exclusion of 25 items (see Figure 3.1). Eight items were merged with another item and the response structures of three items were amended. One additional item (Total number of staff employed by or visiting the facility) was added following testing. Thus, the revised tool contained 145 questions (223 items). It took, on average, 60 minutes to complete during a face-to-face interview.

Following completion of the toolkit, managers were asked to complete a feedback questionnaire on its relevance and usefulness. Responses were overwhelmingly positive. One hundred and eighty-nine (93.6%) managers believed the questions were 'relevant' or 'very relevant' to their facility while 88.1% (n=178) rated the toolkit as 'useful' or 'very useful' for internal audits.

Item	Reason for dropping item
Other doctor employed in the facility	Missing data*
Other doctor full-time equivalent	Missing data*
The facility provides a television for patients/residents	Narrow response range
The facility provides a radio for patients/residents	Narrow response range
Patients/residents can choose paintings or posters for their bedroom	Narrow response range
Patients/residents have their own key to their own lockable storage	Narrow response range
Lockable storage located in staff office	Too detailed
Lockable storage located in patient/resident's bedroom	Too detailed
Lockable storage located elsewhere	Too detailed
Where is lockable storage if elsewhere?	Too detailed
There is a single sex communal area	Narrow response range
There is single sex outside space	Narrow response range
Patients/residents allowed to have visitors in their room	Unable to agree on scoring
Access to public transport is within ten minutes of the facility	Narrow response range
How involved staff are in management of medication	Narrow response range
Helping patients/residents understand their mental health problems through one-to-one discussions	Narrow response range
Helping patients/residents understand their mental health problems through staff involvement in outside groups	Facility manager unable to answer/missing data*
Staff discussions with patient/resident facilitates their involvement in activities	Narrow response range
Allocated worker is involved in creating individualised care plans	Narrow response range
Other facility staff are involved in creating individualised care plans	Narrow response range
Deciding what to wear is generally decided by the resident themselves	Narrow response range
Deciding what to watch on TV is generally decided by the resident themselves	Narrow response range
Deciding what music to listen to is generally decided by the resident themselves	Narrow response range
Non-detained patients/residents are free to decide to have consensual sexual relationships outside the facility	Narrow response range
Proportion of patients/residents who have financial hardship because of the contribution they have to make for their own care	Facility manager unable to answer/missing data*

\*> 30% data missing

**Figure 3.1 Items excluded from the Quality Indicator for Rehabilitative Care during testing**

Data from the pilot was used to conduct an iterative exploratory factor analysis (EFA) to confirm the initial allocation of items to domains (2009). The EFA had three iterations to assess the validity of item domain allocations. In the first iteration, a Principal Components Analysis was carried out to assess the correlation of items to their allocated domain. Weakly correlated items, defined as a factor loading of less than 0.3, were only removed from the domain if they were strongly correlated with another domain. In the second iteration, items with poor correlation were once again removed only if they were strongly correlated with another domain. In the third and final iteration, any remaining item with a factor loading of less than 0.3 was removed. Only eight items failed to correlate with any domain following all three iterations. These were removed from the items contributing to domain scores but were retained as descriptive items. Sharing of items allocated to different domains was greater than 50% between the following domains: (1) social policy, citizenship and advocacy and human rights; (2) recovery-based practice and therapeutic environment; (3) recovery-based practice and self-management and autonomy; (4) human rights and self-management and autonomy; (5) social interface and treatments and interventions; (6) clinical governance and human rights; and (7) clinical governance and therapeutic environment. The initial description of social interface, human rights and recovery-based practice as cross-cutting themes was confirmed by their large overlap with domains.

The third EFA iteration examined the sampling adequacy and internal consistency of the six domains and three cross-cutting themes using Kaiser-Meyer-Olkin (KMO) statistics and Cronbach's alpha, respectively. The clinical governance and social policy, citizenship and advocacy domains contained three and six items, respectively, all of which loaded onto

**Table 3.1 Results of exploratory factor analysis to confirm initial allocation of items to Quality Indicator for Rehabilitative Care domains**

Domain	No. of items in initial allocation	No. of items after 3 <sup>rd</sup> EFA <sup>1</sup> iteration	Sampling adequacy (KMO statistic)	Internal consistency (Cronbach's $\alpha$ )
Clinical Governance	8	-	0.52	-
Human Rights	30	24	0.74	0.78
Living Environment	25	22	0.77	0.82
Recovery-based Practice	25	20	0.72	0.77
Self-management & Autonomy	32	28	0.80	0.86
Social Interface	19	10	0.67	0.65
Social Policy, Citizenship & Advocacy	8	-	0.61	-
Therapeutic Environment	42	36	0.70	0.76
Treatments and Interventions	34	28	0.74	0.70

<sup>1</sup>Exploratory factor analysis

other domains, and showed low sampling adequacy (KMO of 0.52 and 0.61, respectively). As a result, both domains were removed from the toolkit. The remaining seven domains showed good internal consistency with six of the domains having a Cronbach's  $\alpha$  less than or equal to 0.7. Less item sharing between domains was also achieved (see Table 3.1).

The toolkit was refined in response to the results of reliability testing and interviewee feedback and named the Quality Indicator for Rehabilitative Care (QuIRC). A complete description of the reliability and cross-validation of the toolkit has been published by Killaspy and colleagues (2009). The QuIRC consists of 223 items, 88 of which assess seven domains of care (living environment; therapeutic environment; treatments and interventions; self-management and autonomy; social inclusion; human rights; recovery-orientated practice). The quality score for each domain is presented as a percentage derived

from the ratings from 88 items. These scores are then compared to the average domain scores of similar facilities within the same country.

Following the development of the QuIRC it was translated into a web-based application to facilitate its use (<http://www.quirc.eu>). Facility managers are invited to create an account after answering several questions about their facility to ensure the QuIRC is appropriate for their setting. Following completion of the toolkit, managers are presented with the QuIRC domain scores for their facility as well as the average domain scores of similar facilities within their country. These are presented as a spider chart and table for ease of interpretation (see Figure 3.2).

### ***3.4 The relationship between QuIRC and service user ratings***

The QuIRC was developed for completion by facility managers. However, the literature regarding the measurement of quality of care highlights the importance of service user participation in the assessment process (see section 1.4). Although there is evidence to support the involvement of service users with a diagnosis of schizophrenia in the assessment of quality of care, I have already highlighted the substantial impairment in functioning that the subset of this population receiving longer term care in psychiatric and social care facilities exhibit (see section 1.1). This level of impairment can sometimes make it difficult to engage service users in the assessment process. In these circumstances, it is essential that assessment tools designed for completion by a member of staff are able to also reflect service users' experiences of care. Therefore, facility managers' QuIRC ratings were compared with service user ratings of their care.



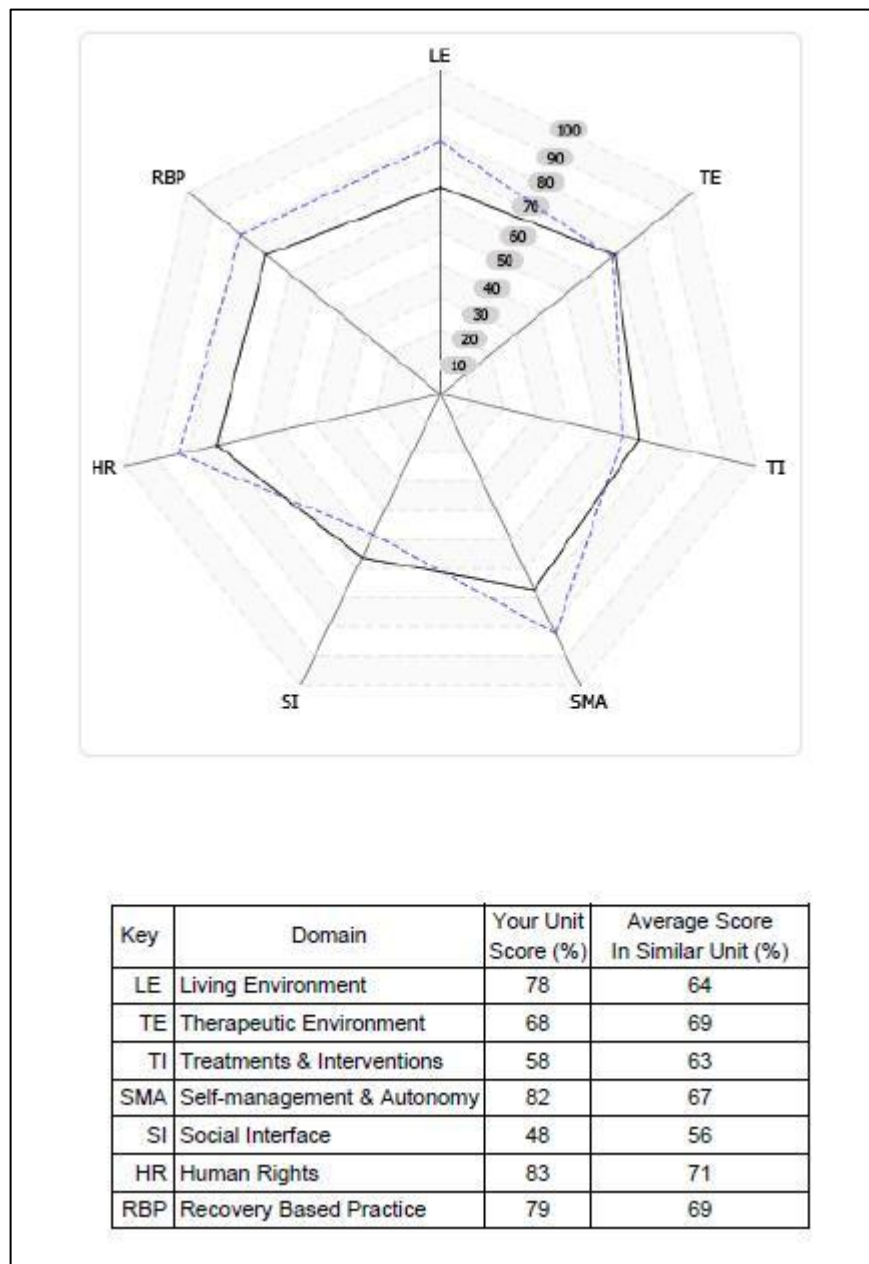
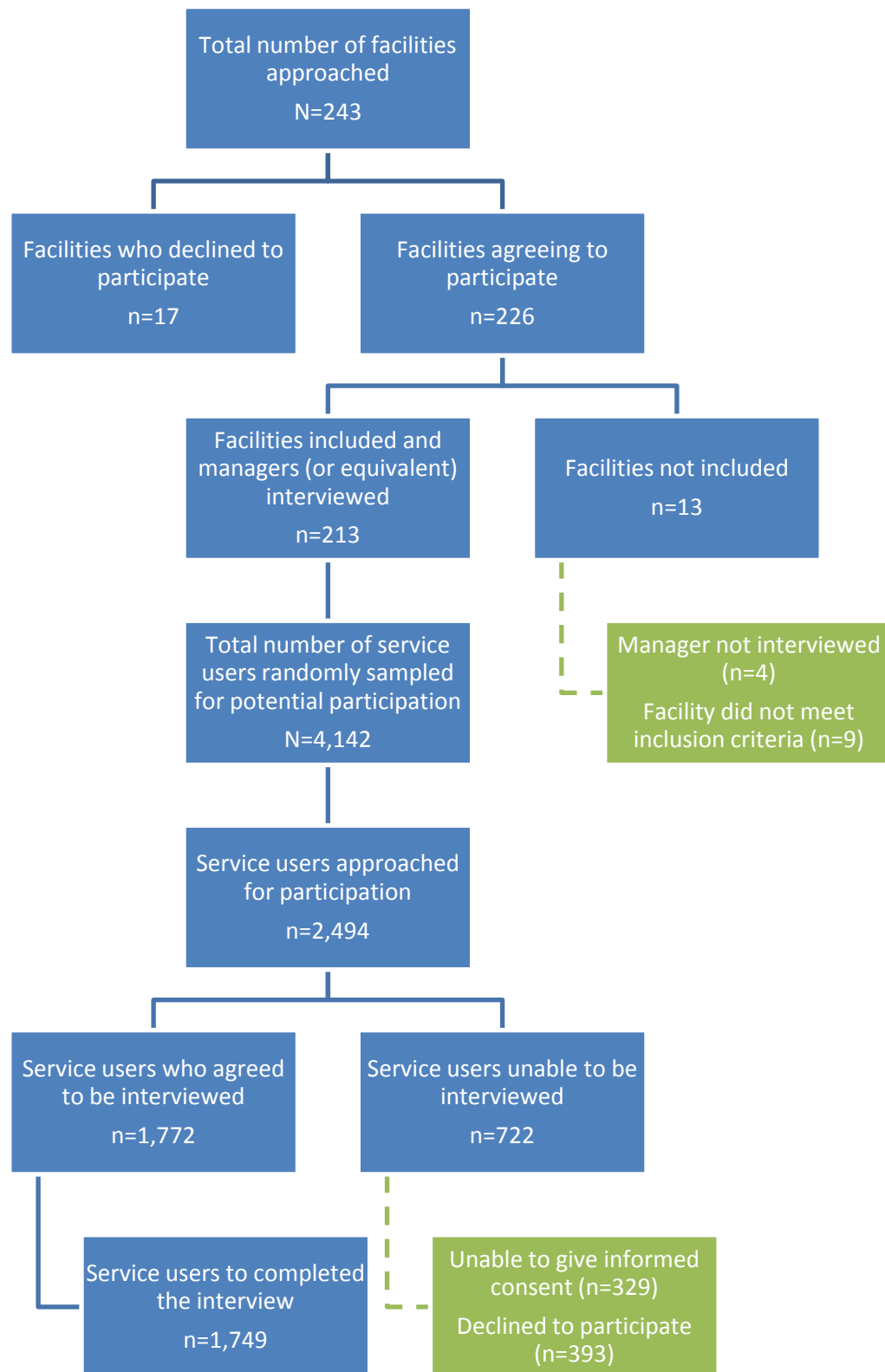
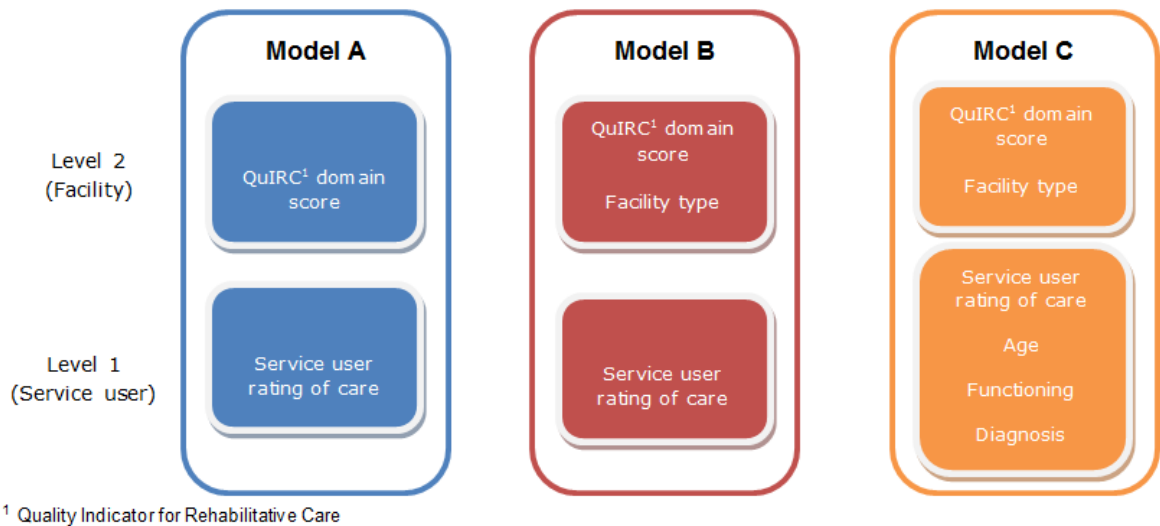


Figure 3.2 Example of Quality Indicator for Rehabilitative Care report diagram



**Figure 3.3** Flow chart showing participation of facilities, managers and service users in the assessment of the Quality Indicator for Rehabilitative Care



**Figure 3.4** Multilevel models used to investigate the relationship between the Quality Indicator for Rehabilitative Care domain scores and service user ratings of care

The QuIRC was used to assess the care provided in 213 facilities across the ten participating DEMoBinc countries (Killaspy et al. 2012). QuIRC ratings were cross-validated against service users' ratings of life satisfaction (Manchester Short Assessment of Quality of Life; Priebe et al. 1999), autonomy (Resident Choice Scale; Hatton et al. 2004), experience of care (Your Treatment and Care; Webb et al. 2000) and the therapeutic milieu (Good Milieu Index; Røssberg & Friis 2003). A total of 1750 service users were included in the analysis (see Figure 3.3). A detailed description of the sample is presented in Chapter 4.

The relationship between quality and service user ratings was assessed using multilevel models (see Figure 3.4). In Model A domain scores (level 2) were entered as independent,

fixed effect variables. An adjustment for the multiple service users per facility was made by including a random intercept term. Model A was adjusted to include a level 2 facility type variable (hospital or community) to create Model B. The interaction between domain score and facility type was also examined. In Model C three service user (level 1) variables, age, functioning (as assessed by the Global Assessment of Functioning; Jones et al. 1995) and diagnosis, were added to Model B. Age and functioning were allowed to vary randomly at the service user level (i.e. random slopes model). The interactions between domain score and facility type were insignificant in models A and B and were, therefore, excluded from the models.

The percentage of variation in service users' assessment measures explained by each QuIRC domain is shown in Table 3.2. Scores on the Human Rights, Recovery Based Practice, Self-management and Autonomy and Living Environment domains were significantly associated with service users' life satisfaction ratings, explaining three to ten per cent of the variance in Model A. When service user characteristics were included in the model (Model C), the per cent of variance explained increased by 30% in all four of these domains. Service user age was positively associated with satisfaction in all four models ( $p < 0.0001$ ). Service user functioning was also positively associated with satisfaction ( $p$ -values ranged from 0.004 to 0.02).

All QuIRC domains were significantly associated with service users' ratings of autonomy in Model A with the variation explained ranging from five to 55 per cent. Facility type was found to be highly related to this relationship adding between eight and 24 per cent to the percentage of facility-to-facility variation explained (Model B). Service user characteristics

**Table 3.2 Percentage of facility-to-facility variance in service users' assessment measures explained by Quality Indicator for Rehabilitative Care domains**

QuIRC domain	Model	Life satisfaction	Autonomy	Experience of care	Therapeutic milieu
Human Rights	A <sup>1</sup>	3.96	29.15	22.77	8.00
	B <sup>2</sup>	3.63	40.06	27.21	16.39
	C <sup>3</sup>	35.52	41.64	35.96	38.89
Living Environment	A <sup>1</sup>	10.89	35.15	26.75	15.38
	B <sup>2</sup>	9.05	35.65	25.81	16.95
	C <sup>3</sup>	40.15	34.84	28.11	31.33
Recovery-Based Practice	A <sup>1</sup>	3.79	29.86	28.31	14.11
	B <sup>2</sup>	2.87	38.24	31.50	19.63
	C <sup>3</sup>	31.98	37.29	31.80	40.18
Social Interface	A <sup>1</sup>	1.24	5.83	6.84	1.73
	B <sup>2</sup>	4.46	24.28	18.05	14.47
	C <sup>3</sup>	-	20.38	15.14	-
Self-Management and Autonomy	A <sup>1</sup>	10.26	54.98	35.34	22.12
	B <sup>2</sup>	8.47	56.01	34.65	24.94
	C <sup>3</sup>	40.33	55.68	37.97	42.48
Therapeutic Environment	A <sup>1</sup>	-0.28	16.63	19.35	3.44
	B <sup>2</sup>	3.23	32.39	27.81	12.95
	C <sup>3</sup>	-	29.92	28.27	33.40
Treatment and Interventions	A <sup>1</sup>	0.26	11.59	15.72	0.48
	B <sup>2</sup>	3.90	27.19	24.22	9.67
	C <sup>3</sup>	-	25.20	25.81	-

<sup>1</sup>Multilevel model evaluating relationship between Quality Indicator for Rehabilitative Care (QuIRC) domain score (independent variable, level 2) and service user rating of care (dependent variable, level 1)

<sup>2</sup>Multilevel model evaluating relationships between QuIRC domain score and facility type (independent variables, level 2) and service user rating of care (dependent variable, level 1)

<sup>3</sup>Multilevel model evaluating relationships between independent variables QuIRC domain score (level 2), facility type (level 2), service user age (level 1), service user functioning (level 1) and service user diagnosis (level 1) and service user rating of care (dependent variable, level 1)

did not significantly affect these findings. Age was negatively associated with autonomy ( $p < 0.0001$ ) while functioning showed a positive correlation with autonomy ( $p < 0.0001$ ).

Similarly all QuIRC domains were significantly related to service user ratings of their experience of care (Model A). Between six and 35 per cent of the variation was explained by this model. Including facility type (Model B) to the model increased the percentage of variation explained among all domains except self-management and autonomy and living environment. Age was negatively associated with experience of care ( $p$ -values ranged from 0.01 to 0.04) while a positive association was found between functioning ( $p < 0.0001$ ) and experience of care.

The therapeutic environment, human rights, recovery-based practice, self-management and autonomy and living environment domains were significantly associated with service users' ratings of the therapeutic milieu (Model A). Between three and 22 per cent of facility-to-facility variation was explained by the model. Including facility type increased the percentage of variance explained in all these domains (Model B). However, service user characteristics substantially increased this amount by 14 to 22 per cent. Service user age ( $p$ -values ranged from 0.004 to 0.02) and functioning ( $p < 0.0001$ ) were positively correlated with ratings of the therapeutic milieu.

### **3.5 Summary**

The QuIRC is the first internationally agreed tool for the assessment of quality of care in psychiatric and social care facilities for individuals with longer term mental health problems. It has been shown to have strong psychometric properties and is positively viewed by facility managers as a useful and relevant tool. Further analyses of the

relationships between QuIRC scores and service user experiences of care have shown that the QuIRC can confidently act as a proxy measure of service user experience with sensitivity to the impact of service user characteristics. This is important due to the difficulties in including this population in accreditation and auditing activities. As a result, the QuIRC has been incorporated into the Royal College of Psychiatrists' peer accreditation process for inpatient mental health rehabilitation facilities (AIMS-Rehab) in the UK and steps are being taken to secure its incorporation into routine quality assessment processes in Portugal. The Czech Psychiatric Association and a leading centre for mental health rehabilitation in the Netherlands plan to use the QuIRC for local and national audit of longer term facilities. Research partners in Greece and Bulgaria have begun discussions with key officials involved in setting national care standards to consider incorporating the QuIRC into their national assessment processes tool.

## Chapter 4

### **Aims and Hypotheses**

Chapter 1 revealed a gap in the evidence regarding the association between national mental health expenditure, community mental health service provision and quality of care. Most research in this area has focused on the relationship between the characteristics of individual facilities (e.g. facility type; budgets) and measures of quality. This focus may be attributable to the lack of internationally validated assessments for measuring quality. The development of the Quality Indicator for Rehabilitative Care (QuIRC; Chapter 3), an internationally agreed tool which assesses the quality of care in longer term mental health settings, allows for the comparison of facilities both within and across countries. The QuIRC, coupled with standardised assessments of service user outcomes, enables an international evaluation of the impact of national expenditure and deinstitutionalisation.

#### ***4.1 Aims and objectives***

This research aims to evaluate, in a European sample, the association between national mental health expenditure and levels of deinstitutionalisation in terms of (1) the quality of care provided by longer term psychiatric and social care facilities and (2) service user ratings of this care. Since service users who require longer term mental health care represent one of the most expensive groups, this investigation will allow a clearer understanding of how adjustments in mental health spend and investment in community mental health care impact on the quality of longer term mental health care.

In order to accomplish these aims, my objectives were:



To develop a quantitative assessment of deinstitutionalisation to enable an international comparison of national mental health service provision in ten European countries.

To investigate the relationship between national mental health expenditure and quality of care in longer term psychiatric and social care facilities in these countries.

To investigate the relationship between national mental health expenditure and outcomes for service users in longer term care facilities in these countries.

To investigate the relationship between national levels of deinstitutionalisation and quality of care in longer term psychiatric and social care facilities in these countries.

To investigate the relationship between national levels of deinstitutionalisation and outcomes for service users in longer term care facilities in these countries.

## ***4.2 Rationale for hypotheses***

### **4.2.1 The relationship between expenditure and quality of care**

The World Health Organization (WHO) has acknowledged the global underfunding of mental health care and has lobbied for countries to increase their mental health budgets (World Health Organization 2001; World Health Organization 2005; Prince et al. 2007).

These actions reflect a belief that increasing national expenditure will result in improved mental health care and service user outcomes. Increased expenditure in both hospital and community mental health facilities has been linked to better treatment environments and higher staffing levels, as well as improved service user community integration (Chapter 1).

Although research has also suggested an inverse relationship where decreased mental

health expenditure is associated with higher levels of quality of care, institutional settings with low associated expenditure are more likely to deliver low-quality care (section 1.3).

Research in this area has focused on comparisons of the costs of running individual facilities while neglecting to evaluate the association between national levels of mental health expenditure and quality of care. Although this relationship is complex, expert opinion suggests that adequate financial resources at a national level are essential to the provision of a minimum standard of care (World Health Organization 2001; World Health Organization 2005; Prince et al. 2007).

#### **The relationship between expenditure and service user outcomes**

There is current uncertainty as to the relationship between mental health expenditure and service user outcomes due to the limited evidence base. There is some evidence that increased cost of care is associated with decreased service user ratings of quality of life and satisfaction with care (Chapter 1). This is perhaps due to higher expectations of service users in countries with better funded mental health systems.

The Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care (DEMoBinc) project showed clear positive associations between the quality of longer term mental health care facilities, as measured by the QuIRC, and service user experiences of care and autonomy (Chapter 3), although the cross-sectional design of the research makes it difficult to comment on causality. It therefore appears that the relationship between expenditure and service user outcomes is complex and may be mediated by the context in which mental health care is delivered.

**4.2.2 The relationship between deinstitutionalisation and quality of care**  
Evaluations of the impact of deinstitutionalisation on the quality of longer term mental health care have primarily focused on comparisons of hospital and community care. Although evaluations of national levels of deinstitutionalisation have yet to be conducted, evidence suggests that community-based facilities are better able to provide less regimented care, allow for greater service user autonomy in their everyday lives and support service user privacy than hospital-based settings (Chapter 2). These characteristics were associated with higher quality of mental health care. Community mental health care was also found to be associated with improved service user community integration and general functioning (Chapter 1). The DEMoBinc project found that facilities which were based in the community, had fewer beds and had a specified maximum length of stay were associated with higher QuIRC domain scores (Killaspy et al. 2012). These findings suggest that deinstitutionalisation of care is associated with greater quality of care.

### **4.2.3 The relationship between deinstitutionalisation and service user outcomes**

Service user ratings of care are generally more positive in community settings when compared to hospital settings. Although community-based care is not associated with significant improvements in service user symptoms when compared to hospital-based care, service users in receipt of community-based care have shown reduced problem behaviours, improved domestic skills and stronger social relationships (Chapter 1). Furthermore, evidence suggests that the improved quality of the living environment in community-based facilities, where routines are less regimented, staff support service user autonomy and a greater degree of privacy is afforded, is linked to increased levels of service user satisfaction with care (Chapter 2). Self-reported ratings of quality of life have also been

found to be significantly related to care setting, with more positive ratings reported by service users receiving care in the community (Chapter 1).

#### 4.2.4 Potential confounding variables

Both country and facility-level factors may influence the associations between expenditure, deinstitutionalisation, quality of care and service user ratings of care. Community facilities have already been shown to be related to greater quality of care and more positive service user ratings. However, a confounding variable is stigma. It is widely accepted that the stigma associated with mental health problems prevents individuals from seeking treatment (Corrigan 2004) and impacts on self-reported satisfaction, with service users who report higher levels of perceived stigma being more likely to report decreased satisfaction (Staring et al. 2009). Stigma has also been felt to influence negatively policy decisions regarding funding and provision of care at the national level (Byrne 1999; Corrigan 2004; Saraceno et al. 2007), as well as staff expectations for recovery and therapeutic relationships (Byrne 1999). It follows that government prioritisation of mental health issues will influence national investment in community-based mental health care provision.

Development of a national mental health policy suggests a belief in the importance of providing mental health care. If a specific policy is adopted, it is more likely that financial resources will be allocated to its implementation. Therefore, countries with a longer history of having an explicit mental health policy may have higher mental health budgets and greater deinstitutionalisation of care. Although there is no specific evidence to support or reject this theory, it is a variable which should be evaluated.

Within mental health facilities, the ratio of staff-to-service-users may mediate the effect of both expenditure and the degree of deinstitutionalisation on quality and service user experience. Countries with relatively low levels of mental health expenditure and less deinstitutionalisation of services often have low numbers of mental health professionals which may limit the ability to provide effective treatments and interventions and promote positive therapeutic relationships (World Health Organization 2005). Very poorly resourced facilities with low staff-to-service-user ratios are also likely to have more institutional and dehumanising practices simply due to the potentially overwhelming demand on staff (Goffman 1961; Hill et al. 2006).

Countries with greater levels of deinstitutionalisation will have a greater variety of mental health services based on the level of support required by the service user. These countries may be more likely to have facilities with a maximum length of stay, at the end of which a service user would generally be expected to be ready to move on to a more independent setting. The availability of ‘move-on’ facilities in the community and a process of gradual transition with the ultimate goal of achieving independent living may be associated with increased staff and service user expectations for improvement in functioning. It may also facilitate greater quality of care, as staff will need to ensure that service users have all the necessary skills to manage with less support.

### ***4.3 Hypotheses***

Based on the available evidence and WHO recommendations, I aim to test the following hypotheses:

1. Mental health expenditure will be positively associated with the quality of longer term psychiatric and social care facilities.
2. Deinstitutionalisation will be positively associated with the quality of longer term psychiatric and social care facilities.
3. Mental health expenditure will be negatively associated with service user ratings of longer term care in psychiatric and social care facilities.
4. Deinstitutionalisation will be positively associated with service user ratings of longer term care in psychiatric and social care facilities.

## Chapter 5

# **Development of a Quantitative Tool to Assess Deinstitutionalisation at a Country Level**

### ***5.1 Introduction***

As has been described in Chapter 1, deinstitutionalisation in some parts of the world began in 1950s as an alternative way of providing mental health care. Instead of treatment based in psychiatric hospitals, the locus of care is based in the community. The implementation of deinstitutionalisation was initially described as a three-step process: (1) discharging psychiatric inpatients to community care; (2) diverting further admissions to community care; and (3) providing appropriate and comprehensive community mental health services (Bachrach 1976). Deinstitutionalisation has been upheld as the gold standard of modern mental health service provision throughout Europe for at least half a century. During this time its definition has expanded to include the integration of mental health care in to general health care services and establishment of mental health legislation, policy and budget (Saxena et al. 2007; Funk et al. 2010a; 2010b).

However, implementation strategies and the essential components of care in the community are not unanimously agreed (Novella 2010). Furthermore, although countries are described and measured by their progress towards deinstitutionalisation (Knapp et al. 2009), there are no formal criteria in existence with which to measure this progress (Novella 2010). The European Service Mapping Schedule has been used to describe the provision of mental health services (Johnson et al 2000). However, this assessment tool focuses on the

provision of care in specific catchment areas rather than across the whole of a country. There are currently no quantitative assessments which allow for the international comparison of deinstitutionalisation levels.

Research evaluating the deinstitutionalisation of mental health care has primarily focused on individual services and comparisons of hospital and community care. The lack of an objective assessment of the deinstitutionalisation of mental health care is a barrier to a deeper understanding of the impact of deinstitutionalisation on mental health service users and learning from the successes and failures of other countries in their attempts to provide care in the community for this group. In this chapter I describe the development of a quantitative assessment tool to determine the degree to which mental health care has been deinstitutionalised across European countries. I had the following objectives:

1. Identify universal markers of deinstitutionalisation;
2. Develop a draft assessment tool;
3. Test the basic psychometric properties of the tool; and
4. Refine the assessment tool.

## ***5.2 Method***

### **5.2.1 Identification of markers of deinstitutionalisation**

In order to develop a measure of deinstitutionalisation capable of appropriately comparing service provision across countries, a synthesis of common markers of deinstitutionalisation was required. National mental health legislation, policies, plans and programmes were collated through contacts in each of the ten European countries of interest to this thesis (Bulgaria, Czech Republic, Germany, Greece, Italy, the Netherlands, Poland, Portugal,



Spain and the UK). In Spain and Germany national documents did not exist. Instead, regional documents for Andalusia and Saxony were obtained for review as these were the regions that participated in the Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care (DEMoBinc) project. Standards of care relevant to the deinstitutionalisation of mental health services (e.g. limits on the number of beds in hospital facilities; presence of a defined mental health budget; availability of community mental health care) were recorded for each country. Following the review of national and regional documents from all countries, common standards were included as markers of deinstitutionalisation and grouped together by theme. Markers were corroborated with World Health Organization (WHO) guidance on the development of mental health legislation and policies (Funk et al. 2010a; 2010b). The list of markers was agreed in collaboration with my supervisors.

### 5.2.2 Development of the draft assessment tool

The identified markers of deinstitutionalisation were used as the foundation for the development of the draft assessment tool. Items were constructed so that they could be easily completed using publicly available data. Each item was given equal influence in the analyses as it was unclear which items, if any, may be more or less important to deinstitutionalisation. All items were allocated a minimum score of zero and a maximum score of one.

The draft was reviewed by my supervisors to ensure included questions and their response options were likely to be reflective of publicly available information. Following this process, the tool was circulated to an international expert panel comprised of mental health professionals and/or academics from each of the ten included countries, a member of the

charity European Federation of Associations of Families of People with Mental Illness (EUFAMI) and a member of the WHO Department of Mental Health and Substance Abuse for comment on the tool's content validity. Responses from the expert panel were discussed with my supervisors and an amended version was agreed.

The tool was then used to assess deinstitutionalisation levels in each of the ten countries. Assessments were completed by consensus of three raters<sup>8</sup> using the information provided in the WHO *Mental Health Atlas 2005*. Response options were amended as necessary to better match the information provided in the WHO report.

### 5.2.3 Data analysis

In order to ensure that the tool was sensitive enough to discern national differences in the provision of mental health care, the spread of responses for individual items cannot be too heavily skewed. Therefore, the frequency of responses for each item was evaluated. Binary items in which more than 90% of responses were scored in a single category were removed from the tool on the grounds they would be insufficiently discriminatory. For the remaining items (those with more than two possible responses), items were removed from the assessment if more than 80% of responses were reported in a single category. Any item in which at least 30% of data were missing was also excluded.

A second rating was carried out by the author alone using the WHO *Mental Health Atlas 2005* one year later. Test-retest reliability was measured using the Kappa coefficient for categorical data. Items for which Kappa did not reach moderate agreement (Kappa = 0.40) were dropped (Landis et al 1977). The remaining items were assessed for internal

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<sup>8</sup> The author (TS) and her supervisors (Helen Killaspy [HK] and Michael King [MK])

consistency. A Cronbach's  $\alpha$  of 0.70 or greater was considered indicative of good internal consistency.

A single score of national deinstitutionalisation was calculated as the sum of the scores for each item of the finalised assessment tool. Deinstitutionalisation scores and national rankings were evaluated by TS, HK and MK for face validity.

## **5.3 Results**

### **5.3.1 Markers of Deinstitutionalisation**

Although no internationally agreed definition of deinstitutionalisation exists, mental health legislation and policies across the ten countries share similar objectives which are based largely on Bacharach's (1976) components of deinstitutionalisation (Chapter 1). The most common markers of deinstitutionalisation are provided in Figure 5.1. These include components of national legislation and policies as well as WHO recommendations (Chapter 1).

#### **Discharge and diversion from psychiatric hospitals**

All countries included in this project support the discharge of service users from psychiatric hospitals. However, clear guidelines on the implementation of this objective are not always included in national mental health plans and programmes. As a result, countries have used their own timelines and strategies when changing the locus of provision of care from hospital to community-based services. The WHO recommends that individuals with the least amount of functional impairment be transferred first, followed by the gradual transfer of those with increased impairment (World Health Organization 2003b). Services users should be discharged to care settings appropriate to their support needs. Furthermore,

- Discharge service users from psychiatric hospitals to appropriate care in general hospitals or community facilities.
- Ensure the availability of community mental health services for all levels of need.
- Develop a plan for the integration of mental health care with physical health care.
- Ensure that acute care is available in general hospitals and/or community facilities.
- Ensure the availability of psychotropic medication in general hospitals and primary care facilities.
- Ensure the availability of mental health care in primary care facilities.
- Ensure general hospital and primary care staff trained in mental health.
- Encourage multidisciplinary teams of mental health professionals.
- Ensure mental health care is locally accessible.
- Adopt mental health legislation and policies.
- Ensure mental health legislation and policies are integrated into relevant legislation/policy.
- Foster collaboration between mental health services and other relevant government departments.
- Provide adequate and clearly defined financial resources for community-based mental health care.
- Ensure continuity of care between primary, secondary and tertiary mental health care.
- Establish a co-ordinating body to oversee important decisions.
- Encourage service user participation in discourse regarding mental health provision.
- Adopt a quality improvement (e.g. accreditation and monitoring) process.
- Provide mental health care by catchment area.

**Figure 5.1 Markers of deinstitutionalisation common to focus countries and World Health Organization recommendations**

individuals and their families should receive support prior to and immediately following discharge to ease the transition.

Individuals who would have previously been admitted to a psychiatric hospital should be diverted to another setting which is most appropriate for their needs (e.g. psychiatric unit in a general hospital or community-based mental health inpatient facility; crisis house; home support from a crisis team).

### **Development of community services**

Components of community care include the provision of mental health services in primary care settings, and secondary mental health care including inpatient and community facilities. Staff in primary care settings and general hospitals must be adequately trained to detect, diagnose and treat mental health problems. Furthermore, they must have access to the resources to provide appropriate treatment, including psychotropic medication. Secondary mental health services include inpatient mental health facilities (often within a local general hospital), alternatives to admission such as crisis houses and a range of community mental health teams to oversee care for an individual. In addition to standard community mental health teams, countries with greater deinstitutionalisation also have early intervention, assertive outreach and crisis treatment teams and supported accommodation.

Countries should provide services such as outpatient care, psychosocial interventions, specialist treatment (e.g. child and adolescent; elderly; refugee) and vocational rehabilitation and can be provided from across statutory and voluntary sectors. Service users should be able to access care locally. Therefore, community mental health facilities

must be widely available. The WHO recommends that community mental health facilities be made available *prior* to the discharge and diversion of service users from psychiatric hospitals (World Health Organization 2003b). Continuity of care between primary, secondary and tertiary mental health services should be of the utmost importance to ensure the receipt of adequate care and the best possible chance of recovery.

### **Organisation, funding and development of mental health services**

Deinstitutionalisation cannot be successful without sufficient service planning, organisation and funding. In order to properly implement deinstitutionalisation, mental health legislation and policies are needed. Equally important is the development of an implementation plan or programme which clearly defines the steps necessary to meet a country's mental health objectives. Great care must be taken to ensure that objectives are realistic and plans feasible in regard to available resources. Objectives should also be consistent with other relevant legislation and policies (e.g. social; education; employment).

Funding of mental health care must take into consideration the burden of illness and the resources needed to provide effective care which, in many countries, must include development of community services and its associated infrastructure. Budgets for mental health should be clearly stated and ring-fenced.

The organisation and provision of mental health services is best achieved through defined catchment areas which help ensure local access to treatment and continuity of care. Collaboration with other relevant government organisations (e.g. social services) is required to ensure consistency across sectors. Many countries also work in partnership with non-statutory providers to ensure the full complement of interventions is available. For example,

in the UK, the voluntary sector is a major provider of supported accommodation and vocational rehabilitation services. Accreditation and monitoring systems are needed to ensure quality care is delivered and many countries have such systems.

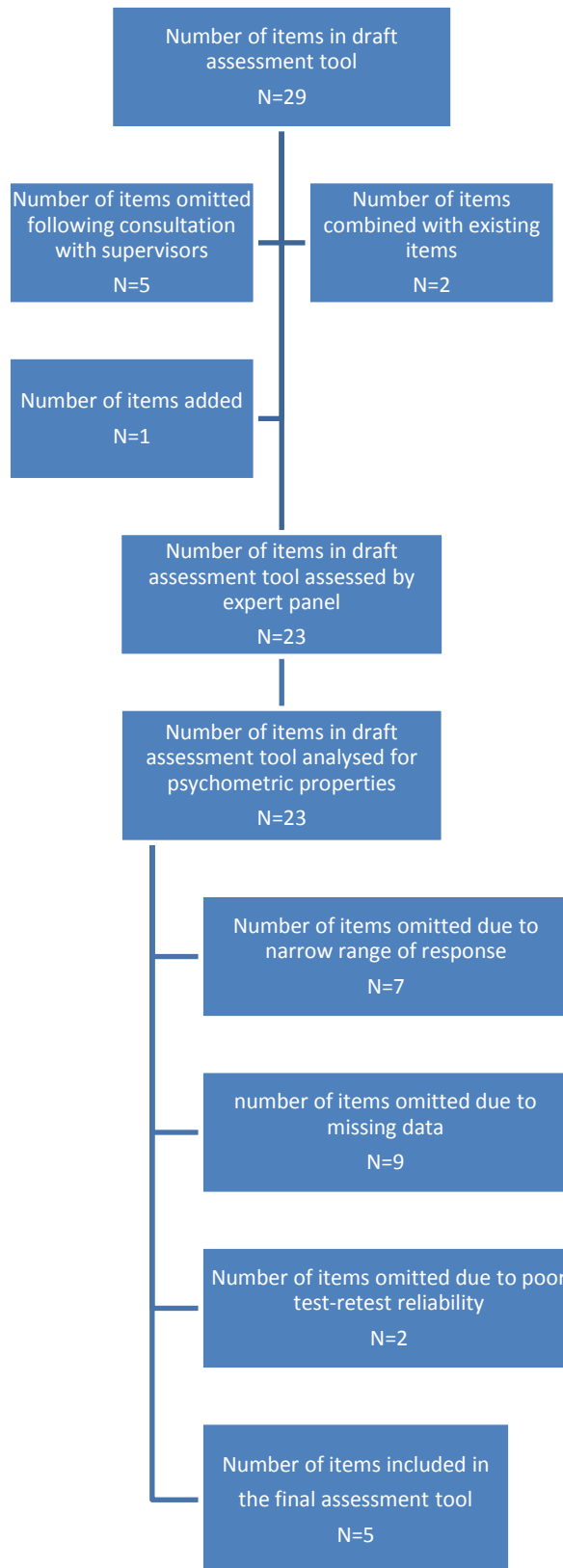
### 5.3.2 Development of the assessment

Questions were developed to address the markers of deinstitutionalisation identified through the review of national and regional mental health legislation, policies and programmes. The initial draft assessment tool comprised 29 items with categorical response structures (see Appendix B.1). Following consultation with my supervisors, five items were omitted. The item regarding the availability of psychotropic medication in general hospitals was excluded from the tool as availability of medication in primary care settings was thought to be most relevant to deinstitutionalised care. The distinction between psychosocial services and community mental health centres was believed to be too blurred. As a result, the items were merged. The presence of a local or national body which governs mental health care was seen to be similar to accreditation and service monitoring organisations and was, therefore, removed. Finally items regarding the participation of service users, carers and advocates in mental health care decisions and the adequacy of financial resources allocated to mental health were believed to be too subjective for adequate measurement. Two items were combined with other items. Items regarding the accreditation process and service monitoring were merged. Integration of mental health into general health legislation and policies were incorporated into existing questions regarding the introduction of mental health legislation and policies. One item regarding the adequacy of staffing levels was changed to instead request the number of mental health professionals (i.e. psychiatrists, psychologists, psychiatric nurses and social workers) per 100,000

inhabitants. Availability of community mental health centres/outpatient clinics was split to make two separate items, availability of community mental health centres and availability of ambulatory care/outpatient clinics. One item and several response options were amended to increase clarity. For example, the response options for the item “Describe access to mental health treatment in primary care within the country” were changed from information on the availability of care in urban and rural areas to a description of availability by the type of mental health problem (e.g. neurotic or psychotic disorders). The response option, ‘not mentioned’ was added to several items to allow for the collection of missing data. Following this process, the draft tool contained 23 items (see Figure 5.2).

The amended tool (see Appendix B.2) was distributed to the expert panel for review and comments. Several comments regarding the generalisability of the tool across the countries of interest were received. However, this was anticipated as the questions included in the tool were not necessarily reflective of practice across all ten countries. Furthermore, response options were supplemented by WHO recommendations for best practice. Therefore, no items were omitted or added to the assessment tool. The potential for subjectivity due to a lack of operational definitions was also commented upon. Additional information was provided within the tool following discussion with my supervisors, and a manual including operational definitions and descriptions of services was developed to accompany the tool. Consensus assessments were completed by three raters (TS, HK and MK) using the country profiles in the WHO *Mental Health Atlas 2005*.





**Figure 5.2** Number of items included in the deinstitutionalisation assessment tool during the refinement process

**Table 5.1 Items excluded from the deinstitutionalisation assessment tool**

Item	Reason for exclusion
Do primary care staff generally receive formal training in mental health (before or after certification)?	Narrow response range
Do general hospital staff generally receive formal training in mental health (before or after certification)?	Missing data
Is psychotropic medication available in general practices?	Narrow response range
Are mental health services provided using clearly defined catchment areas?	Missing data
Availability of day centres	Missing data
Availability of community mental health centres	Poor test-retest reliability
Availability of ambulatory/outpatient care	Missing data
Availability of home care	Missing data
Availability of rehabilitation (vocational, occupational)	Poor test-retest reliability
Availability of crisis teams	Missing data
Availability of specialized mental health services	Narrow response range
Is mental health legislation (laws) in place?	Narrow response range
Is a mental health policy (plan) in place?	Narrow response range
Does mental health policy include a commitment to continuity of care across primary, secondary and tertiary care settings?	Missing data
Do mental health documents include a commitment to the provision of care close to a service user's place of current/last residence?	Missing data
Have accreditation and service monitoring/auditing systems of mental health facilities been established?	Missing data
Is mental health policy/legislation integrated into other related policy/legislation (e.g. social services, education and employments, justice)?	Narrow response range
Does the government organization responsible for mental health services collaborate (work together) with other relevant government organizations (e.g. social services, education and employments, justice)?	Narrow response range

**Table 5.2 Test-retest reliability among deinstitutionalisation assessment tool items**

Item	Kappa	SE	Z
Closure of mental hospitals	0.80	0.14	5.54
Access to mental health treatment in primary care	0.80	0.17	4.78
Availability of community mental health centres	0.32	0.13	2.54
Availability of residential care/supported housing	0.46	0.1	4.54
Availability of rehabilitation (vocational, occupational)	0.33	0.23	1.42
Are financial resources for mental health care clearly defined with the national budget?	1.00	0.18	5.48
Total number of mental health staff per 100,000 inhabitants	1.00	0.18	5.48

### 5.3.3 Analysis

Seven items were removed from the assessment tool due to poor variability of responses (see Table 5.1). At least 90% of countries reported in the positive for all seven items. Nine items were excluded due to missing data. Seven items contained between 60 and 90 per cent missing data. Two items, the availability of day centres and the availability of ambulatory/outpatient care, had 40% and 30% missing data, respectively. Test-retest reliability among the remaining seven items ranged from fair to perfect agreement (see Table 5.2). Two items, availability of community mental health centres (Kappa = 0.32) and availability of vocational and occupational rehabilitation (Kappa = 0.33) were removed from the assessment as a result of poor reliability. The final version of the assessment tool, the Mental Health Deinstitutionalisation Measure (MHDM) consisted of five items which measured the availability of mental health care outside of mental hospitals and resources for the provision of mental health care (see Figure 5.3).

**1. Describe the closure of mental hospitals within the country.**

- It has not happened (no beds in general hospitals or community facilities).
- It is in early transition (more beds in mental hospitals than general hospitals and community facilities).
- It is in late transition (more beds in general hospitals and community facilities than mental hospitals).
- It has been completed (no mental hospitals).

**2. Describe access to mental health treatment in primary care within the country.**

- There is no access to mental health treatment.
- There is a general statement of availability.
- There is evidence of a clear programme for neurotic disorders.
- There is evidence of a clear programme for neurotic and psychotic disorders.

**3. Please describe the availability of community residential care/Supported housing.**

- Residential care is unavailable.
- There is limited availability (general statement of availability).
- There is evidence of a clear programme.

**4. Are financial resources for mental health care clearly defined within the national budget?**

- No/Not mentioned
- Yes

**5. Is the total number of mental health professionals (psychiatrists, psychiatric nurses, psychologists and social workers) per 100,000 inhabitants greater than 135 (median of all ten countries)?**

- No
- Yes

**Figure 5.3 Mental Health Deinstitutionalisation Measure items**

Binary items were coded as 0 and 1. The remaining three items were scored as 0, 0.33, 0.67 and 1 with larger scores representing greater deinstitutionalisation. The internal consistency of the MHDM was acceptable ( $\alpha = 0.70$ ). Therefore, a country's total deinstitutionalisation

**Table 5.3 Deinstitutionalisation scores for ten European countries**

Country	Deinstitutionalisation score
UK	4.67
Germany	4.33
The Netherlands	4.33
Italy	4.00
Portugal	3.67
Greece	2.67
Czech Republic	2.66
Bulgaria	1.99
Spain	1.66
Poland	0.99

score was calculated as the sum of scores for each item (range: 0-5). Higher scores represent increased deinstitutionalisation. Total deinstitutionalisation scores for all countries are presented in Table 5.3. The UK was found to have the highest level of deinstitutionalisation (total score = 4.67) while Poland had the lowest score (total score = 0.99).

These country ratings were agreed by TS, HK and MK to have adequate face validity.

#### **5.4 Discussion**

Deinstitutionalisation is currently viewed as the gold standard for the provision of mental health care (World Health Organization 2001; World Health Organization 2005). Although countries' progress towards deinstitutionalised care has been discussed and compared since

the late 1970s, no objective measure of deinstitutionalisation existed. The aim of this work was to develop a quantitative tool to assess the deinstitutionalisation of mental health care for use in my investigation of its association with the quality of care in longer term mental health facilities and service user ratings of care. The resulting tool consists of five questions which measure the degree to which a country has closed down mental hospitals, made mental health care available in primary care settings, provided community-based longer term mental health care and allocated financial resources towards mental health care, in addition to the level of staffing available to provide mental health care. The strength of the MHDM is the use of objective items to determine national progress towards deinstitutionalisation. This allows for cross-country comparisons which are more equitable and transparent than subjective ratings.

Obtaining national data on mental health care is not an easy task as information, such as the number of beds in hospital and community settings, number of psychiatric admissions and the types of community mental health services available, may not be uniformly collected across a country. The MHDM was designed to be compatible with publicly available information (specifically, the WHO *Mental Health Atlas 2005*) in order to circumvent this potential problem. The standardised reporting schedule used by the WHO was drafted by a single team, inclusion of operational definitions for mental health services (e.g. community mental health centres) and confirmation of information by government officials strengthens the consistency of the reported information.

Tests of inter-rater reliability, variability of responses, internal consistency and face validity of assessment items and total scores were conducted to evaluate the robustness of the tool.

Through these tests, inadequate items were excluded so that scores calculated using the final version of the tool could be relied upon to be an accurate indicator of national deinstitutionalisation. Due to the limited number of countries included in my sample, it was not appropriate to conduct extensive psychometric testing of the tool. Factor analysis, a common method included in psychometric testing used to evaluate the factorial validity of an assessment measure which includes items that may be potentially linked to more than one construct (Hardy & Bryman 2004), is suggested where there are sample sizes of five to ten subjects per item, with a suggested minimum sample of at least 100 (Costello & Osborne 2005). This was far beyond the scope of my objectives for this aspect of my research.

The draft version of the tool contained 23 items. Following testing for reliability, variability of responses and internal consistency, 18 items were omitted to form the tool. The exclusion of 78% of the original items may be perceived as significantly limiting the robustness of the tool. However, the majority (89%, n=16) of items omitted from the tool were largely excluded due to the narrowness of recorded responses or non-reporting within the WHO *Mental Health Atlas 2005*. Seven items were omitted due to a narrow response range. For all seven items nine of the ten countries assessed reported providing the mental health care, legislation or policy described. As a result, these items were excluded due to their inability to discriminate between more or less deinstitutionalised countries.

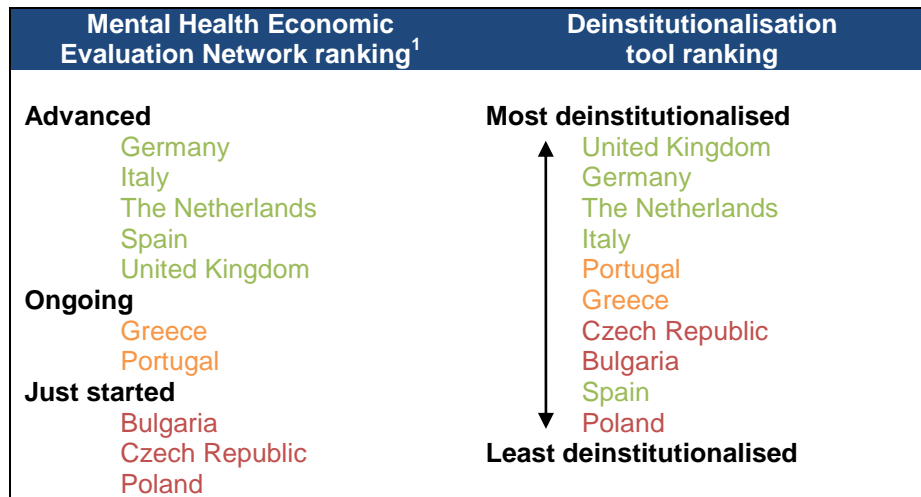
Nine items were omitted from the tool due to high levels of missing data. Information regarding the provision of care close to service users' last place of residence, mental health training for general hospital staff, variation in community mental health services, continuity

of care and national quality assessment processes was not uniformly available within the *Mental Health Atlas 2005* country reports. This lack of reporting may limit the tool's ability to differentiate between countries currently providing community-based care as the quality of deinstitutionalised mental health services cannot be assessed. Information on whether or not clinical staff in general hospitals receive training in mental health and continuity of mental health care may affect the quality of mental health care provided as service users transfer to less supported care. Availability of a variety of mental health care facilities can impact on a mental health system's ability to provide tailored mental health care based on service users' needs. Provision of care close to a service user's last place of residence may have a large impact on their social relationships and community integration, two aspects deemed integral to the provision of high quality mental health care.

Measurement of the face validity of the final assessment tool on the basis of three researchers may be questioned. However, all 23 original items were chosen as a reflection of national standards of care from ten European countries and WHO recommendations for the implementation of deinstitutionalisation. Furthermore, all items were assessed by an expert panel, comprised of partners from each of the countries evaluated with the tool, a member of the European mental health advocacy group EUFAMI and a member of the WHO Department of Mental Health and Substance Abuse, and agreed to be relevant to deinstitutionalisation and worded in a clear and consistent way.

Although the majority of items were omitted from the final version of the MHDM, the five included items reflect the definition of deinstitutionalisation provided in Chapter 1 and used within my thesis. Deinstitutionalisation is defined as the transition from hospital-based





<sup>1</sup>From: "Balance of care (deinstitutionalisation in Europe) Results from the Mental Health Economics European Network (MHEEN)" by Knapp et al 2009

**Figure 5.4 Comparison of Mental Health Economic Evaluation Network deinstitutionalisation rankings and the deinstitutionalisation assessment tool rankings**

mental health care to a system of care fully integrated into general medical care, strengthened by the establishment of mental health legislation, policies and budgets, with a range of mental health services provided in the community and based on the needs of service users to allow for greater service user autonomy.

The primary aim of the MHDM was to create a quantitative measure of the degree of deinstitutionalisation across ten European countries. Therefore, work developing the markers of deinstitutionalisation only synthesised mental health legislation and policies as well as details of mental health programmes from those countries and WHO recommendations. As the MHDM was tested on a purposive sample of European countries, it may be argued that this limits its generalisability. However, the countries included in this

research were chosen partly for their combined ability to reflect differentiation in hospital and community mental health service provision across Europe.

The final ranking of the ten countries, presented in Figure 5.4, is largely consistent with subjective ratings of deinstitutionalisation as reported by experts within those countries by the Mental Health Economic Evaluation Network (MHEEN; Knapp et al. 2009). The deinstitutionalisation score for Spain (equivalent to the MHEEN category ‘just started’), varies from the categorization reported by Knapp and colleagues (MHEEN category ‘advanced’). The reasons for a near reversal in the ranking of Spanish mental health care provision are the greater numbers of psychiatric beds in mental hospitals, limited availability of community residential care/supported housing, the lack of a mental health budget across the autonomous regions and low numbers of mental health care professionals.

## ***5.5 Conclusions***

Deinstitutionalisation is a term used to describe the shift in the locus of mental health care from hospital to community. However, implementation of the principles of deinstitutionalisation is varied and descriptions of the degree to which a country provides deinstitutionalised care have been rather subjective to date. The development of a novel quantitative tool for the measurement of national deinstitutionalisation has allowed for an objective assessment of the provision of mental health care and international comparison.

The MHDM is comprised of five items based on national standards of mental health care across the ten countries of interest to this thesis and WHO guidance on the deinstitutionalisation. A large proportion of the original items were excluded from the final

tool due to their inability to differentiate between more and less deinstitutionalised countries. The five final items were deemed to have adequate reliability, face validity and internal consistency.

The MHDM was developed specifically for use in the ten countries of interest to this thesis. Variety in the development of mental health care and other national characteristics suggest that it may be an appropriate measure for all European countries. Furthermore, the ranking of countries based on their progress toward deinstitutionalised care, as assessed by our tool, reflects the subjective rankings of mental health experts.

## Chapter 6

### **Method**

In this chapter I present the method used to investigate the hypotheses presented in Chapter 4.

#### **6.1 Sample**

The sample of longer term psychiatric and social care facilities, facility managers and service users assessed in this research were participants in the Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care (DEMoBinc) project.

##### 6.1.1 Setting

Hospital and community-based facilities for people with longer term mental health were identified through existing databases in each of the ten participating countries (Bulgaria, Czech Republic, Germany, Greece, Italy, the Netherlands, Poland, Portugal, Spain and the UK). Facilities were recruited based on geographic location, size and service user demographics. Inclusion criteria are presented in Figure 6.1. Eligible facilities included wards within a hospital as well as community-based facilities and facilities on hospital grounds. Facilities providing care exclusively to a specific sub-group of service users (e.g. older people, individuals with learning disabilities, forensic patients) were excluded.

- Group residential setting (i.e. communal facilities)
- Specialisation in mental health
- Designed for longer-term care (minimum of six months)
- Onsite clinical staff, ideally 24 hours per day
- Supports a minimum of five service users
- A minimum of five service users completed service user interviewed

**Figure 6.1 Inclusion criteria for hospital and community-based facilities**

## 6.1.2 Participants

### **Facility managers**

Managers of identified facilities were contacted by local DEMoBinc researchers, provided with a verbal and written explanation of the research project and asked for consent to participate in the study. When the manager of a facility was unavailable for interview, an alternative senior member of staff (e.g. the deputy manager) was approached.

### **Service users**

Service users were randomly selected from participating facilities for potential participation. Managers from each participating facility provided researchers with a list of all service users resident in the facility. Each service user was then allocated an identification number by the research team. For each facility, a random sequence of identification numbers was created using a random number generation computer programme. Service users were then approached by facility staff in sequential order for participation. Those who agreed to discuss the study with a researcher were provided with a participant information sheet. DEMoBinc researchers provided service users with a verbal

explanation of the study and sought consent. Service users were excluded only if they were not present at the time of recruitment, declined to participate, lacked mental capacity to provide informed consent or were unable to complete the interview.

At least five and no more than 13 service users were interviewed from each facility to ensure cluster sizes were uniform. Facilities where five service users could not be recruited were excluded from the study and a replacement facility was recruited. Service user recruitment and interviews took place in each facility over several days to maximise participation.

## **6.2 Assessment measures**

### **6.2.1 Staff interview**

#### **Quality Indicator for Rehabilitative Care**

Facility managers completed face-to-face interviews conducted by DEMoBinc researchers using the Quality Indicator for Rehabilitative Care (QuIRC) which was translated into the appropriate language. The QuIRC was developed to assess and review the living conditions, care and human rights of people with longer term mental health problems in psychiatric and social care facilities in European countries. Details of its development and testing are described in Chapter 3. The assessment tool includes 145 questions and uses a combination of question types (descriptive, single number response, Likert scales, ordered categories, list of related yes/no items and binary response). The tool was found to have high internal consistency (Cronbach's  $\alpha = 0.89$ ) and good inter-rater reliability (average ICC = 0.95). Quality scores for each of the seven domains assessed (human rights; living environment; recovery-based practice; self-management and autonomy; social interface;

therapeutic environment; treatments and interventions) are presented as a percentage derived from the ratings from 88 items.

The QuIRC takes approximately 60 minutes to complete. Before the interview, the facility manager was asked to complete a proforma to assist them in answering some QuIRC items (e.g. details of staffing, facility budget, service user diagnoses and prescribed medication) in order to reduce the length of face-to-face interviews.

### 6.2.2 Service user interview

Service users were interviewed using standardised instruments to measure autonomy, experience of care, life satisfaction and therapeutic milieu. Demographic information, including age, gender, diagnosis and date of admission, was also sought from the service user and corroborated using case notes. The interview lasted approximately 30 minutes.

#### **Autonomy**

The Resident Choice Scale (RCS) was developed by Hatton and colleagues (2004) to assess the degree of choice service users have within residential facilities. Initially developed for use among those with intellectual disabilities, the tool was slightly amended<sup>9</sup> for use with service users in longer term psychiatric and social care facilities for the DEMoBinc study. The 22 items from the RCS included in the interview were thought to be relevant in facilities across the participating countries. Responses are provided on a four-point scale, ranging from having no choice about something (1) to having complete freedom to make a choice (4). The total score is a sum of all response codes. The maximum score possible is 88 while the lowest possible score is 22. Higher scores indicate greater autonomy.

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<sup>9</sup> Four items were removed from the RCS: where evening meal eaten; who they live with; where they live; and time spent in bath or shower.

### **Experience of Care**

The Your Treatment and Care (YTC; Webb et al. 2000) questionnaire was used to assess service users' experiences of the care they receive. The YTC is a self-assessment measure which assesses service users' understanding and agreement with their treatment and care. The questionnaire was developed for service user focused monitoring and is widely used in service user audits of hospital and community mental health facilities in the UK. It has also been used in the USA and Australia (Webb et al. 2000).

The assessment measure consists of 25 items. Responses to the items are 'yes', 'no' and 'not sure'. Total scores are calculated as the total number of 'yes' responses. Therefore, total scores ranged from zero to 25. Higher scores indicate a more positive experience of care.

### **Life Satisfaction**

Life satisfaction was assessed using the Manchester Short Assessment of Quality of Life (MANSA; Priebe et al. 1999), a standardised scale which has been translated and used internationally (Hansson & Bjorkman 2005; Sytema et al. 2007; Iren Akbiyik et al. 2008; Priebe et al. 2009). The scale consists of 16 items. Satisfaction is rated using a seven-point scale ranging from 'couldn't be worse' (coded as 1) to 'couldn't be better' (coded as 7). The MANSA is a widely used research tool and has high reliability and validity (Priebe et al. 1999). Service users' life satisfaction scores were calculated as the mean score for the 16 items.



### **Therapeutic Milieu**

The Good Milieu Index (GMI) is comprised of five, five-point Likert scale questions designed for service user self-report (Røssberg & Friis 2003). The questions aim to assess satisfaction with the facility, feelings towards staff and other service users, the degree to which the facility increases service users' confidence and the degree to which the facility supports service users to test their own abilities. Responses range from no agreement with the statement (coded as 1) to total agreement (coded as 5). Total scores are calculated as the sum of scores for each question (range: 5-25). Higher scores indicate a more positive atmosphere.

#### **6.2.3 Level of deinstitutionalisation**

The degree of deinstitutionalisation in each country was determined using the novel measure, described in Chapter 5, which quantitatively assesses markers of deinstitutionalisation common to standards of care across the ten European countries included in the DEMoBinc project and World Health Organization (WHO) recommendations for mental health legislation and policy. The measure consists of five items which address the closure of mental hospitals, the availability of mental health care in primary care settings, the availability of residential care/supported housing, presence of a national mental health budget and the number of mental health professionals working in the country. Each item is equally weighted with a maximum score of one. The total deinstitutionalisation score (range: 0-5) is calculated as the sum of scores from each item. Higher scores indicate greater deinstitutionalisation of mental health care within the country.

#### 6.2.4 National mental health care expenditure

In order to evaluate the associations between the quality and cost of mental health care, national mental health expenditure data were sought for each participating country. The data used came from two sources, the WHO and the Mental Health Economics European Network (MHEEN). Data on the percentage of the health budget spent on mental health (percentage expenditure) were collected from the WHO *Mental Health Atlas 2005* which was compiled through the published literature from 1996 to 2004. However, data on mental health expenditure were unavailable for Germany, Greece, Italy, Poland and Spain. Data for these countries, except Greece, were obtained from work conducted by the MHEEN group (Medeiros et al. 2008). As Spanish data were reported by region, the average percentage of the health budget spent on mental health across all regions was used as the national statistic. Data were collected by local MHEEN collaborators and based on best available information such as government reports and journal articles. For these reasons these data can only be considered as best estimates based on the available information. No information on expenditure was available for Greece, which was excluded from all analyses of mental health expenditure.

A second measure of national expenditure, per capita expenditure in international dollars (Int\$) on mental health (per capita expenditure), was included to corroborate findings and potentially provide a clearer understanding of the amount of money needed to improve quality of care and service user experience. Per capita mental health expenditure is not a statistic reported by the WHO; therefore, data on the 2004 per capita expenditure on health, as reported in the *WHO Mental Health Atlas 2005*, were multiplied by the percentage

**Table 6.1 Per capita and percentage mental health care expenditure in ten European countries**

Country	Per capita government expenditure on mental health care in international dollars	Percentage of health budget spent on mental health care
Bulgaria	7.58	2.50%
Czech Republic	42.90 <sup>‡</sup>	3.80%*
Germany	285.95 <sup>‡</sup>	10.14%*
Greece	not available	not available
Italy	110.20 <sup>‡</sup>	5%*
The Netherlands	182.84	7%
Poland	22.02 <sup>‡</sup>	3.50%*
Portugal	37.21	2.30%
Spain	94.65 <sup>‡</sup>	5.89%*
United Kingdom	198.90	10%

Note: Data from "Mental Health Atlas 2005" by World Health Organization, 2005 except where denoted

\* Note: Data from "Shifting care from hospital to the community in Europe: Economic challenges and opportunities", Medeiros, 2008

<sup>‡</sup> Note: Statistic calculated using information from WHO and Medeiros (2008)

expenditure (see Table 6.1). Again, Greek data were excluded from the analyses as percentage expenditure data were unavailable.

### 6.2.5 Potential confounding variables

Facility type (hospital or community), full-time equivalent (FTE) staff to service user ratio, presence of a maximum length of stay and country variables (degree of stigma and number of years since the introduction of mental health policy) were included as potential confounding variables in the analyses examining associations between mental health expenditure and deinstitutionalisation on quality of care and service user ratings. These variables were included a priori, based on the findings of studies previously conducted among the client group and treatment settings and professional opinion (Chapter 4). As the DEMoBinc European dataset was used in this thesis, facility variables included in the

analyses were confined to those collected as part of the DEMoBinc project. Furthermore, potential confounding country-level variables were limited to publicly available data.

### **Facility variables**

All facility variables were collected as part of the DEMoBinc project. Facility type was coded as either a hospital unit (coded as 0) or a community-based facility (coded as 1). The latter included facilities on hospital grounds as their characteristics were more similar to community facilities than hospital units (Killaspy et al. 2011). The FTE staff to service user ratio was coded as less than (coded as 0) or equal to or greater than (coded as 1) the mean ratio of all participating facilities<sup>10</sup>. Facilities with a maximum length of stay were coded as 1. Data on the maximum length of stay were only included in evaluations of the associations between deinstitutionalisation, quality of care and service user ratings as the variable was not thought to be linked to mental health expenditure based on the available evidence.

### **Country variables**

Two variables were included as country-level variables: stigma associated with schizophrenia and years since the introduction of mental health policies. Ratings of stigma associated with schizophrenia, as measured by the Discrimination and Stigma Scale (DISC), reported by Thornicroft and colleagues (2009) were used. The DISC evaluates experienced discrimination using 32 items scored on a seven-point Likert scale ranging from experiencing a strong advantage (coded as +3) to a strong disadvantage (coded as -3)

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<sup>10</sup> Staff included in this calculation were identified as having direct involvement in service user clinical care. Unqualified support workers, defined as staff without a professional qualification (e.g. health care assistants or auxiliary nurses) were included in the calculation. Volunteers, students, and anyone not involved in direct clinical care (e.g. cleaners, cooks, administrators and security personnel) were excluded.

due to diagnosis of schizophrenia. The total score is calculated as the sum of ratings for each item. The range of the scale runs from 0-32. Higher scores are indicative of greater negative discrimination. Mean national experienced negative discrimination scores among individuals with a diagnosis of schizophrenia receiving treatment in any setting for the countries of interest were obtained from the authors. Among the countries of interest, scores ranged from 3.44 in Spain to 5.92 in Portugal. Data were unavailable for the Czech Republic as the country was not included in the study that developed the DISC (Thornicroft et al. 2009). As a result, Czech data were excluded from all analyses in this thesis.

The number of years to 2011 since the introduction of national mental health policies was taken from the WHO *Mental Health Atlas 2005* which reported the year mental health policies were introduced in all countries of interest.

### **6.3 Data collection and data management**

The sample size used for the DEMoBinc project was based on the sample needed to have sufficient power to identify QuIRC domains that independently predicted better service user experiences of care. Multilevel models were used to analyse the associations between service user ratings (level 1, dependent variables) and facility QuIRC domain scores (level 2, independent variables). A minimum of 203 facilities were required to test for 10 predictors of a medium effect size ( $R^2 = 0.35$ ) with 90% power at a 1.25% significance level (Dunlap et al 2004).

Data were collected between January and November 2009 across the ten participating countries. Researchers in all countries entered data into separate but common databases - one for QuIRC assessment data and one for service user data. Double data entry on 10% of

the data from each country was completed by a second researcher. Double entry of the entire dataset was required if initial double entry exceeded an error rate of 5%. Completed databases were then merged into facility (QuIRC) and service user master databases and cleaned prior to analysis. Any missing QuIRC data was assumed to be missing at random. Data on national mental health expenditure, levels of deinstitutionalisation, stigma and the number of years since the introduction of mental health policies were added to the master databases. Data were analysed using STATA release 12.

### 6.3.1 Data analysis

#### **Multilevel modelling**

Multilevel models were used to examine the relationships between dependent and independent variables as they allow for effects of data clustering to be taken into consideration when examining the variation between outcomes (Luke 2004). The multilevel equation, which is an extension of a regression equation, evaluates the relationship between a dependent variable and one or more independent variables. The simplest regression equation is:

$$Y = \beta_0 + \beta_1 X_1 + e_1$$

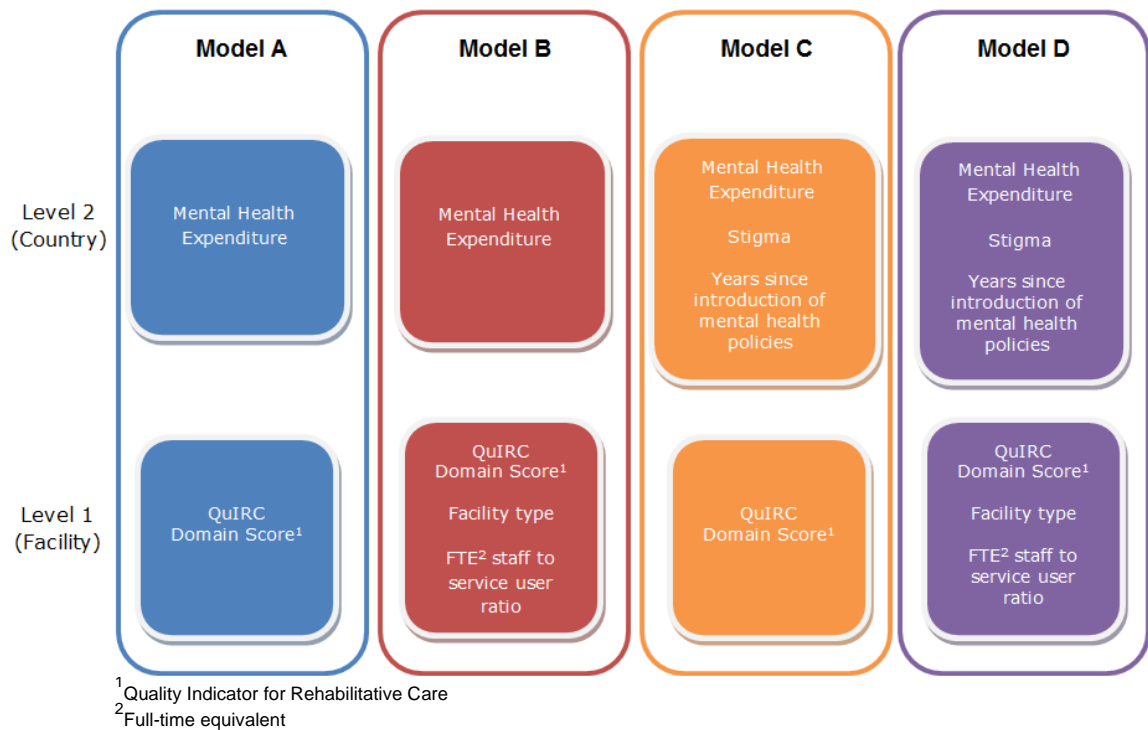
This equation maps a line of best fit through the approximate centre of a plot of values. The independent and dependent variables are represented by  $X_1$  and  $Y$ , respectively. The intercept is represented by  $\beta_0$ . The slope of the line is represented by  $\beta_1$  and  $e_1$  denotes the variance between the mapped value and the real data. Ordinary regression models are limited, however, in that they are unable to detect differences which are attributed to the clustering of data. However, in health research much of the data collected are inherently

clustered. For example, patient outcomes may be related to the hospital in which they receive treatment. In order to account for potential differences across clusters, multilevel equations include a second variable to explain additional variance. The basic multilevel equation is nearly identical to the simple regression equation:

$$Y = \beta_0 + \beta_1 X_{ij} + u_{0j} + e_{0ij}$$

Again the dependent variable is represented by  $Y$ ,  $\beta_0$  is the intercept and  $\beta_1$  denotes the line's slope.  $X_{ij}$  provides the value of the independent variable (e.g. medication dosage) for patient  $i$  in hospital  $j$ . The two variables representing variance denote the departure of the average outcome of patients in hospital  $j$  from the average of all hospitals ( $u_{0j}$ ) and the departure of the outcome of patient  $i$  in hospital  $j$  from the average outcome of all patients ( $e_{0ij}$ ).

In this study, clustering may occur at three levels: the service user, facility and country. It is likely that observations are interdependent across levels (i.e. facilities may be more similar to other facilities within the same country than those in other countries and service user ratings may be more similar within a facility than across facilities), making multilevel modelling an appropriate method for analysis. Country- and facility-level variables were modelled using fixed effects due to the low number of these highest level groups, countries, and the fact that the countries and facilities were not randomly chosen.



**Figure 6.2 Multilevel models of the association between mental health expenditure and quality of longer term care**

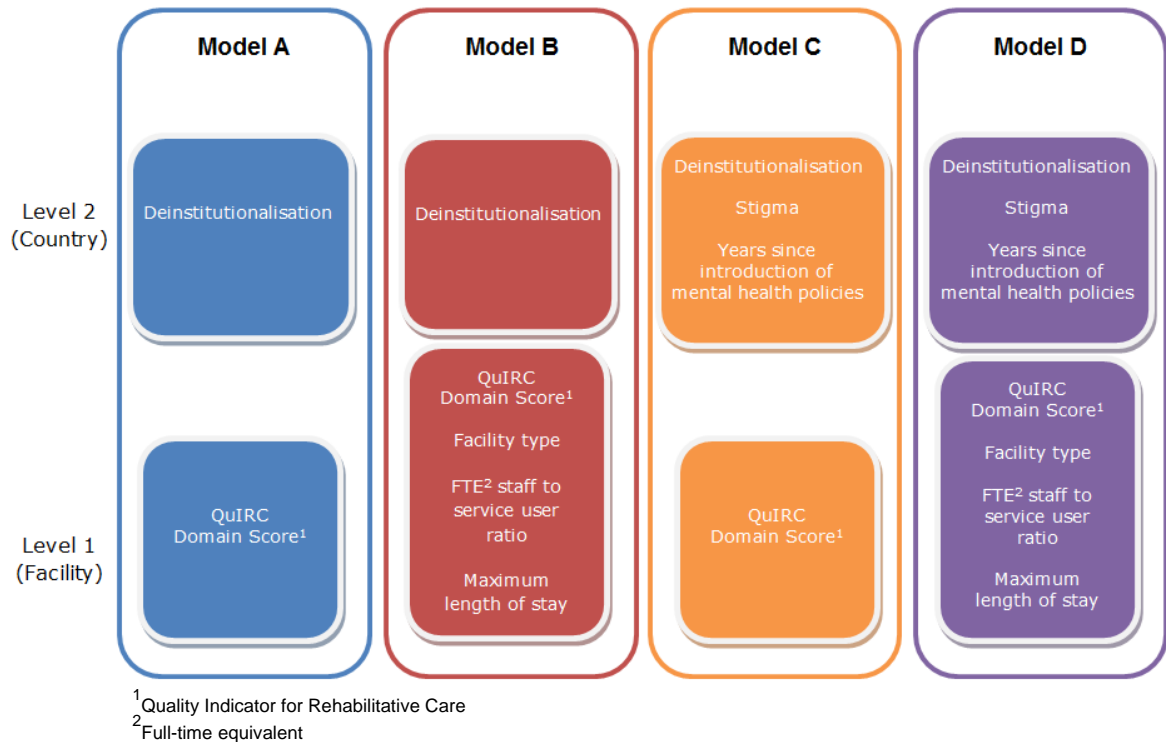
### **Investigating the association between mental health care expenditure and quality of care**

In order to investigate the association between quality of mental health care and expenditure (hypothesis 1), four two-level models were developed (see Figure 6.2). In Model A, the seven QuIRC domains (human rights; living environment; recovery-based practice; self-management & autonomy; social interface; therapeutic environment; treatments and interventions) were included separately as dependent variables at the facility level (level 1). National mental health expenditure, measured as the percentage of the health budget spent on mental health (percentage expenditure) or per capita total mental health expenditure (per capita expenditure), was included as an independent variable at the



country level (level 2). In Model B, the independent variables facility type (hospital = 0; community = 1) and FTE staff to service user ratio (below sample mean = 0; above sample mean = 1) were added to the model as level 1 fixed effects. In Model C, the degree of national stigma associated with schizophrenia and the number of years since the introduction of mental health policies were added as fixed effect, independent variables to level 2 in Model A. In Model D, both facility and country independent variables were added to Model A as fixed effects. All models were subjected to a visual inspection to ensure that the variables were normally distributed and the variance of the error terms ( $e_{0ij}$ ) was constant (homoscedasticity). As no mental health budget data were available for Greece and stigma scores were unavailable for the Czech Republic, both countries were excluded from all models.

The results of each set of models were then evaluated to determine the model of best fit. It is widely accepted that the best model “provides an adequate account of the data while using a minimum number of parameters [independent variables]” (Wagenmakers & Farrell 2004, p. 192). Models of best fit for each dependent variable were determined by its Akaike’s information criterion (AIC; Akaike 1987) value. The AIC is a popular method of determining which of the available models best approximates the true model. This method assumes the existence of a true model which is not included in the available models. The AIC value represents the difference between the most parsimonious model and the model which has been developed. The greater the difference between the models, the worse the fit. Therefore, the model with the lowest AIC value is deemed the best fitting model.



**Figure 6.3 Multilevel models of the association between deinstitutionalisation and quality of longer term care**

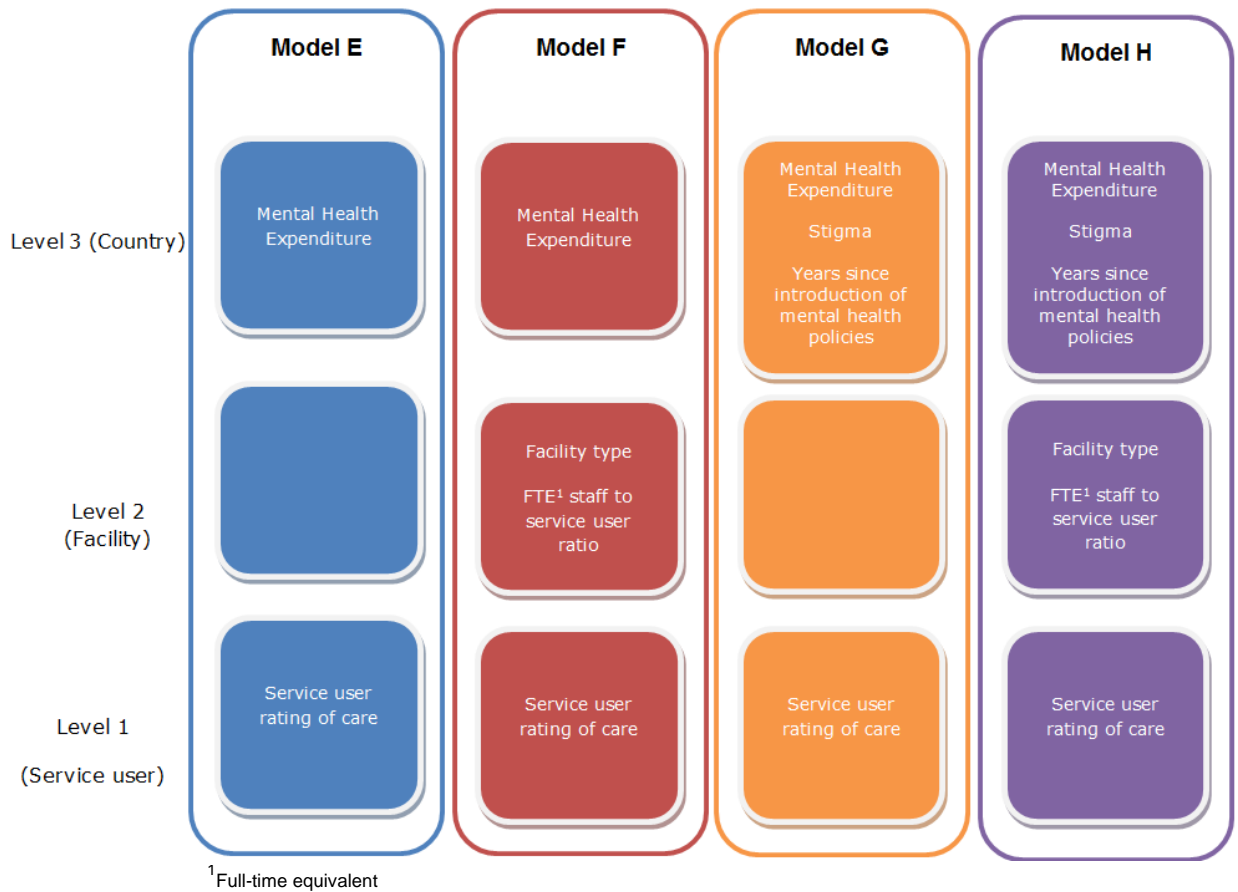
### **Investigating the association between deinstitutionalisation and quality of care**

In order to examine the association between quality of mental health care, and deinstitutionalisation (hypothesis 2), four two-level models were developed (see Figure 6.3). In Model A, QuIRC domain scores (human rights; living environment; recovery-based practice; self-management & autonomy; social interface; therapeutic environment; treatments and interventions) were included separately as dependent variables at the facility level (level 1). Deinstitutionalisation score was included as an independent variable at the country level (level 2). In Model B, the independent variables facility type, FTE staff to service user ratio and presence of a maximum length of stay (no = 0; yes = 1) were added to the model as level 1 fixed effects. In Model C, the degree of national stigma and the

number of years since the introduction of mental health policies were added as fixed effect, independent variables to level 2 in Model A. In Model D, both facility and country independent variables were added to Model A as fixed effects. As stigma data were unavailable for the Czech Republic, it was excluded from all models. Models of best fit were selected using AIC values.

### **Investigating the association between mental health care expenditure and service user ratings**

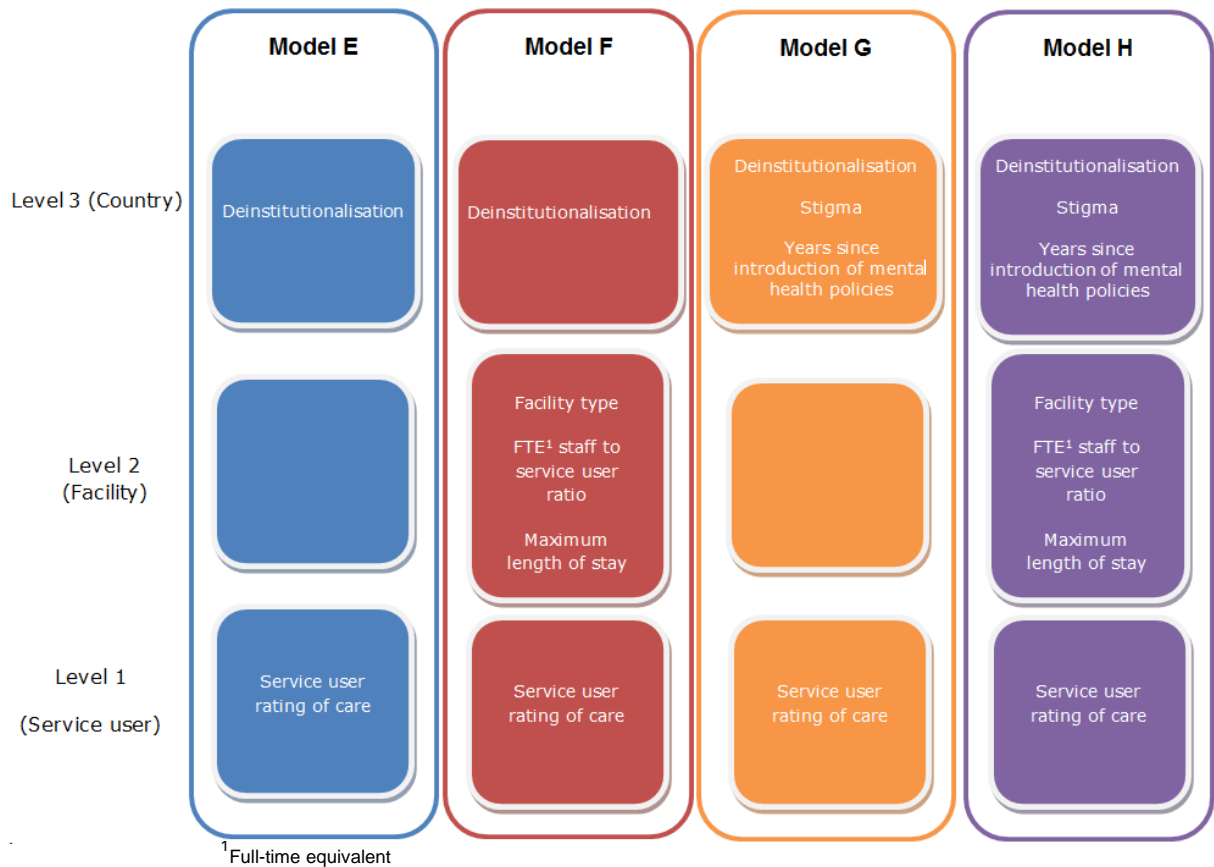
In order to examine the association between mental health expenditure and service user ratings (hypothesis 3), four, three-level models were developed (see Figure 6.4). In Model E, service user ratings of autonomy (RCS), experience of care (YTC), life satisfaction (MANSA) and therapeutic milieu (GMI) were included as dependent variables at the service user level (level 1). Mental health expenditure was included as a fixed effect at the country level (level 3). In Model F, the independent variables facility type and staff-to-service user ratio were added to the model as facility level (level 2) fixed effects. In Model G, the degree of national stigma and the number of years since the introduction of mental health policies were added to Model E as level 3 fixed effect, independent variables. In Model H, both facility and country independent variables were added to Model E as fixed effects. Data from Greece and the Czech Republic were excluded from all models due to missing data. Models of best fit were determined using AIC values.



**Figure 6.4** Multilevel models of the association between mental health expenditure and service user ratings of care

### Investigating the association between deinstitutionalisation and service user ratings

Four, three-level models were developed to examine the association between deinstitutionalisation and service user ratings (hypothesis 4; see Figure 6.5). In Model E, the service user ratings of autonomy (RCS), experience of care (YTC), life satisfaction (MANSA) and therapeutic milieu (GMI) were included as dependent variables at the service user level (level 1). Deinstitutionalisation score was included as a fixed effect at the country level (level 3). In Model F, the independent variables facility type, FTE staff to service user ratio and presence of a maximum length of stay were added to the model as



**Figure 6.5 Multilevel models of the association between deinstitutionalisation and service user ratings of care**

facility level (level 2) fixed effects. In Model G, the degree of national stigma and years since development of mental health policy were added to Model E as level 3 fixed effect, independent variables. In Model H, both facility and country independent variables were added to Model F as fixed effects. As stigma scores were unavailable for the Czech Republic, it was excluded from all models. Models of best fit were then selected using AIC values.

## Chapter 7

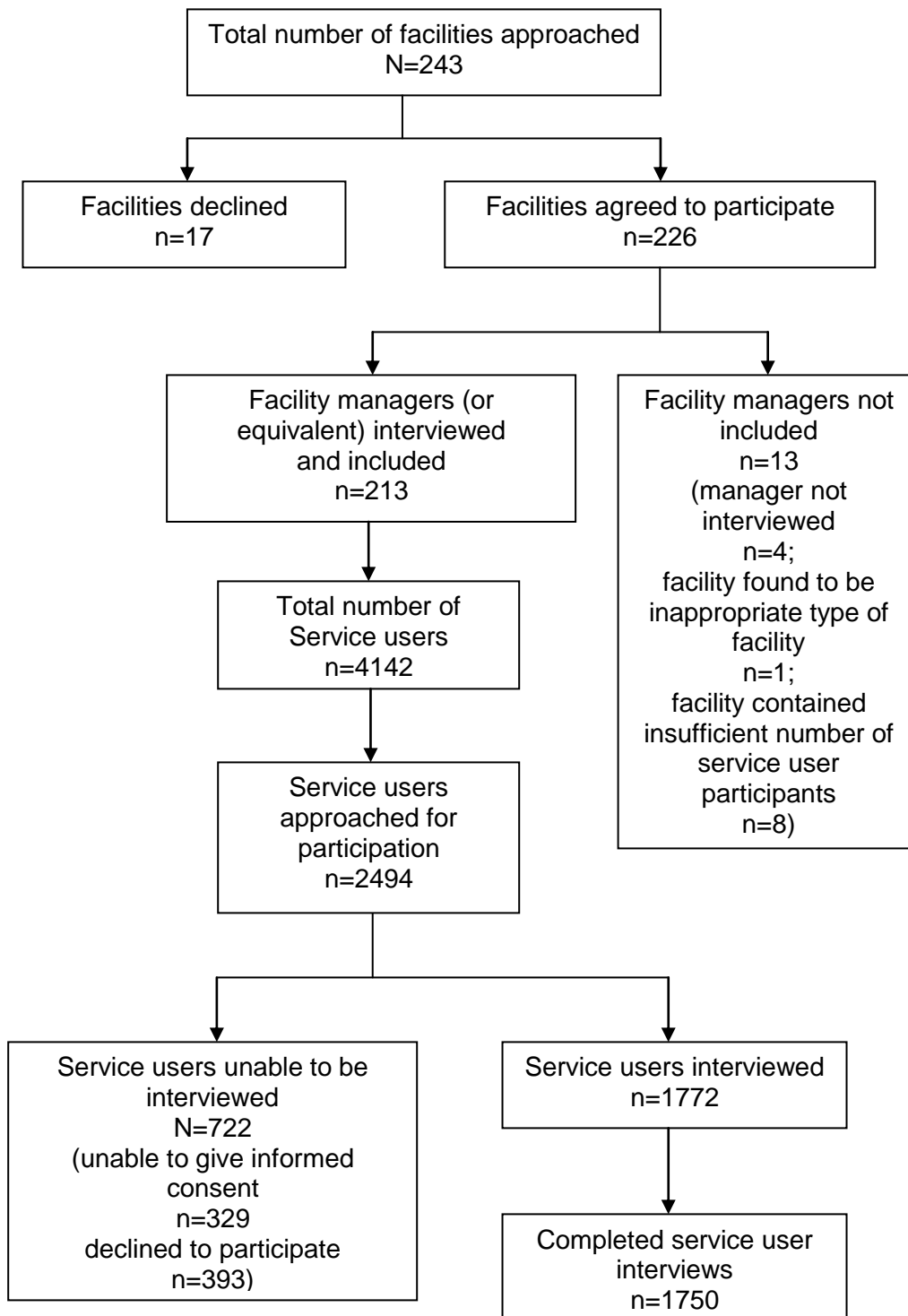
### Results

#### *7.1 Descriptive information*

Two hundred and thirteen managers of psychiatric and social care facilities and 1,750 service users resident in those facilities were interviewed as part of the Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care (DEMoBinc) project (see Figure 7.1). As Czech data were excluded from all analyses due to its missing stigma score, descriptive information is provided for the 192 facilities and 1,579 service users from the nine remaining European countries (Bulgaria; Germany; Greece; Italy; the Netherlands; Poland; Portugal; Spain and the UK).

##### 7.1.1 Facility characteristics

The majority of facilities were community-based (71.0%) and located in urban areas (51%; see Table 7.1). No hospital facilities were included in Germany or Greece and longer term hospital facilities do not exist in Italy; therefore, only community facilities were included in these three countries. The mean number of beds per facility was 25 (SD = 20) with a mean of 23 (SD = 20) beds occupied at the time of recruitment. In Bulgaria six facilities had more than 80 beds with the largest containing 120 beds. The mean number of staff per facility was 19 (SD = 11). The mean total staff FTE per service user was 0.57 (SD = 0.54). The majority (77.7%) of facilities did not have a specified maximum length of stay.



**Figure 7.1 Participant flow chart**

**Table 7.1 Facility characteristics**

Variable (N=193)	Mean (SD)	
Total beds	25 (20)	
Beds occupied	23 (20)	
Male service users (n=192)	14 (16)	
Female service users (n=192)	9 (13)	
Service users detained involuntarily	3 (8)	
Total facility and visiting staff	19 (11)	
Full-time equivalent staff to service user ratio (n=192)	0.57 (0.54)	
Variable (N=193)	n	%
<i>Type of facility</i>		
Community	137	71.0
Hospital	56	29.0
<i>Location of facility</i>		
Urban area	103	53.4
Suburban area	55	28.5
Rural area	35	18.3
<i>Maximum length of stay</i>		
Yes	43	22.3
No	150	77.7

However, this varied by country. For example, most facilities in the UK (n = 17, 85.0%) stated a maximum length of stay.

### 7.1.2 Service user characteristics

The majority of service users interviewed were male (n = 999, 63.3%) and lived in community facilities (n = 1064, 67.4%; see Table 7.2). The mean age of participants was 46 years (SD = 12.6) and the mean duration of their current admission was 4.5 years (range = 0.08-50.1 years). Seventy-four per cent (n = 1173) of participants had a diagnosis of



**Table 7.2 Service user characteristics**

	n	Mean (range)
Age in years	1578	46 (18-87)
Duration of admission in years	1519	4.5 (0.08-50.1)
	Frequency	Percent
<i>Facility type (N=1579)</i>		
Community	1064	67.4
Hospital	515	32.6
<i>Gender (N=1579)</i>		
Female	580	36.7
Male	999	63.3
<i>Employment (N=1579)</i>		
Paid employment	49	3.1
Sheltered employment	171	10.8
Training/education	26	1.7
Unemployed	546	34.6
Retired	752	47.6
Other	35	2.2
<i>Diagnosis (N=1579)</i>		
Schizophrenia or other psychosis	1173	74.3
Non-psychosis	166	10.5
Not specified	240	15.2

schizophrenia or other psychosis. Most participants described themselves as retired or unemployed (n = 1298, 82.2%).

### 7.1.3 Country variables

Mean facility quality scores as assessed by the Quality Indicator for Rehabilitative Care (QuIRC) are reported by QuIRC domain and country in Table 7.3.

**Table 7.3 Country-level variables by country**

	All countries	Bulgaria	Germany	Greece	Italy	The Netherlands	Poland	Portugal	Spain	UK
Number of Facilities (N)	193	20	21	22	29	21	20	20	20	20
Quality Indicator for Rehabilitative Care (QuIRC) domain scores (%)										
Human Rights (SD)	56.9 (13.0)	52.4 (14.4)	65.7 (5.7)	52.9 (11.7)	48.1 (9.6)	70.8 (6.4)	53.0 (10.4)	48.7 (11.4)	53.7 (9.1)	69.6 (9.2)
Living Environment (SD)	60.6 (15.3)	54.1 (18.1)	73.8 (7.9)	58.0 (7.6)	64.8 (9.6)	70.1 (14.0)	49.0 (12.9)	59.2 (15.6)	46.5 (16.8)	67.0 (10.7)
Recovery-based Practice (SD)	52.7 (12.7)	45.5 (15.9)	62.4 (8.8)	56.0 (11.7)	48.4 (8.1)	51.7 (8.6)	46.1 (10.3)	44.2 (13.4)	55.4 (8.8)	66.0 (9.7)
Self-management and Autonomy (SD)	56.2 (15.4)	44.9 (19.2)	71.9 (8.3)	59.9 (11.2)	53.2 (9.1)	66.0 (9.8)	44.1 (9.6)	49.6 (16.5)	46.9 (10.3)	68.7 (11.0)
Social Interface (SD)	48.4 (14.9)	45.8 (17.7)	40.3 (11.5)	47.3 (11.2)	50.0 (11.9)	47.0 (9.4)	40.1 (14.0)	52.0 (19.3)	59.5 (16.4)	53.9 (12.7)
Therapeutic Environment (SD)	52.1 (9.6)	45.6 (12.2)	51.8 (7.2)	52.1 (8.6)	52.6 (6.8)	51.6 (4.9)	47.5 (8.6)	47.8 (10.5)	55.7 (8.0)	64.6 (6.0)
Treatments & Interventions (SD)	50.7 (9.1)	48.5 (11.4)	51.6 (8.5)	47.4 (6.4)	50.6 (6.7)	52.7 (7.1)	46.2 (7.7)	46.5 (10.1)	54.0 (9.5)	59.5 (8.0)
Percentage expenditure (n=171)	5.8 (SD=3.1)	2.5	10.1	.	5	7	3.5	2.3	5.9	10
Per capita expenditure (n=171)	117.42 (SD=98.19)	7.58	285.95	.	110.20	182.84	22.02	37.21	94.65	198.90
Deinstitutionalisation	3.15 (SD=1.35)	1.99	4.33	2.67	4.00	4.33	0.99	3.67	1.66	4.67
Stigma	4.9 (SD=0.8)	5.5	4.7	4.4	5.2	5.5	4.1	5.9	3.4	5.1
Years since the introduction of mental health policy	19 (SD=9)	7	36	28	17	12	16	16	28	13

The UK had the highest scores for the recovery-based practice (66.0%, SD = 9.7), therapeutic environment (64.6%, SD = 6.0) and treatments and interventions (59.5%, SD = 8.0) domains. Germany scored the highest for living environment (73.8%, SD = 7.9) and self-management and autonomy (71.9%, SD = 8.3) domains. The human rights domain score was highest in the Netherlands (70.8%, SD = 6.4). Spain had the highest social interface domain score (59.5%, SD = 16.4). The variation of country mean domain scores from sample means is presented in Figure 7.2.

On average, countries spent 5.8% (SD = 3.1) of their national health budget on mental health care with expenditure ranging from 2.3% (Portugal) to 10.14% (Germany). Germany spent the most international dollars (Int\$) per capita on mental health (285.95 Int\$). Bulgaria spent the least per capita on mental health care (7.58 Int\$). Across all countries, a mean of 117.42 Int\$ per capita (SD = 98.19) was allocated to mental health.

The mean deinstitutionalisation score was 3.15 (SD = 1.35). Scores ranged from 0.99 in Poland to 4.67 in the UK. The mean item stigma score for all countries was 4.9 (SD = 0.8). The highest level of stigma associated with schizophrenia was reported in Portugal (5.9) while the lowest degree of stigma was found in Spain (3.4). Mental health policy was first introduced, on average, 19 years ago (SD = 9).

Mean service user ratings of autonomy, life satisfaction, experience of care and therapeutic milieu are presented in Table 7.4. The mean autonomy score across all nine countries was 60.2 (SD = 12.3). Service users reported the highest levels of autonomy in the Netherlands

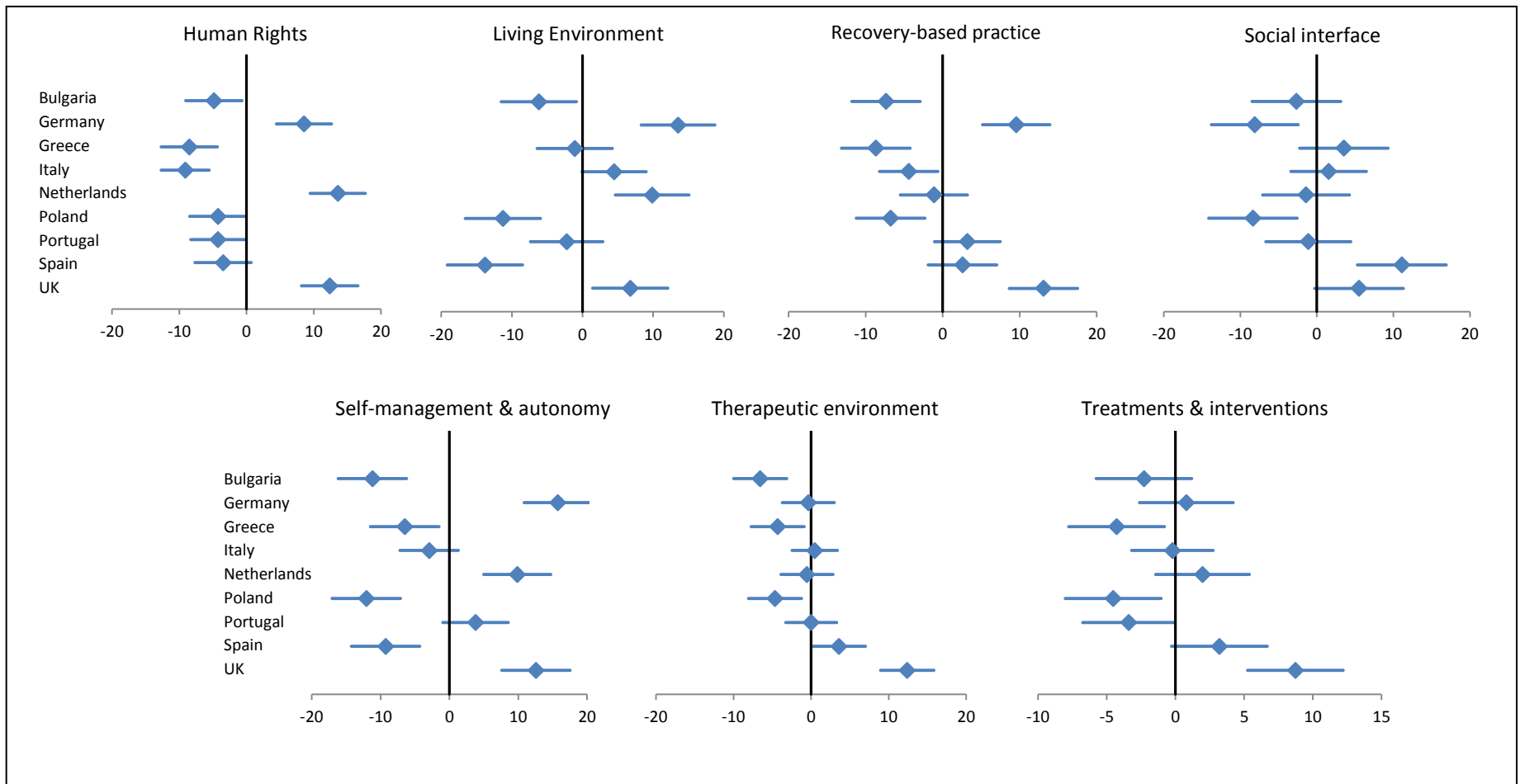
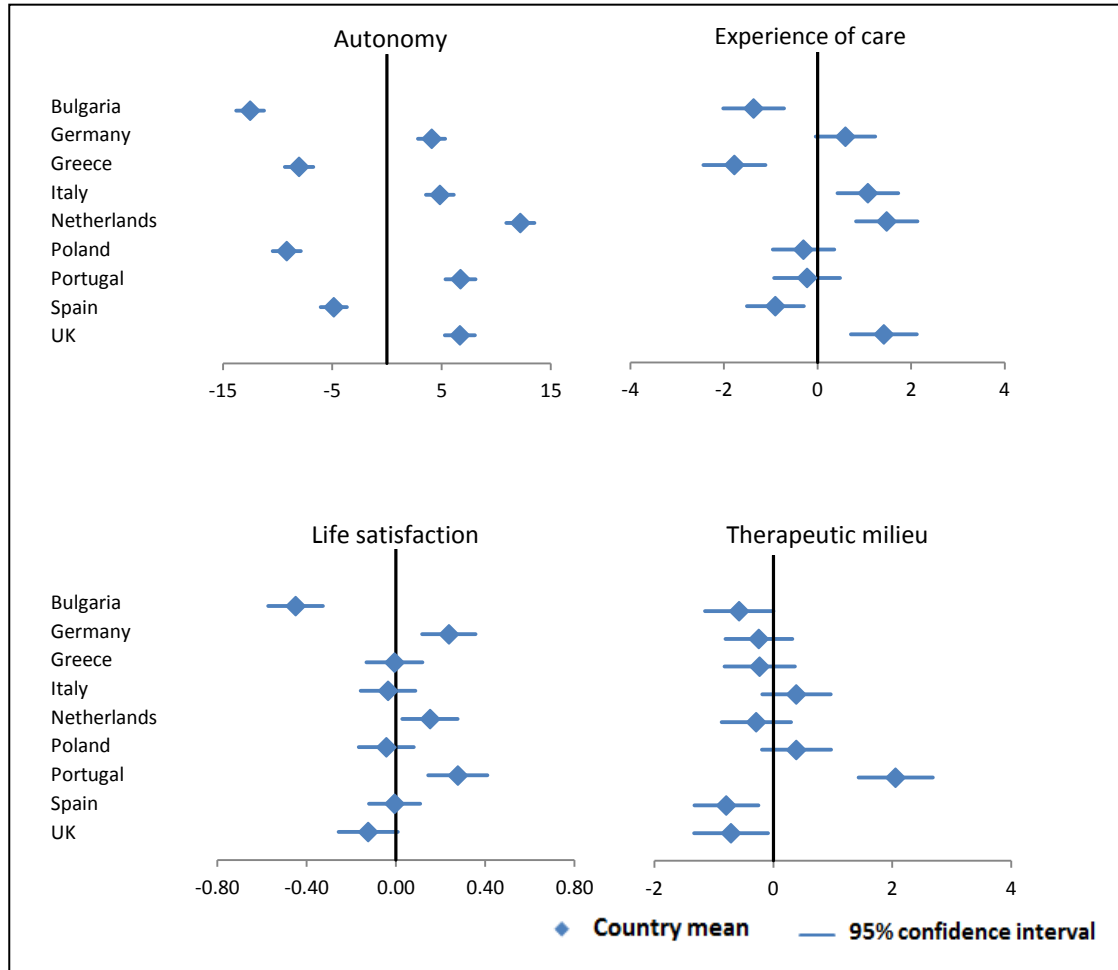


Figure 7.2 Forest plots demonstrating variation in country means from the sample means for Quality Indicator for Rehabilitative Care domain scores

**Table 7.4 Service user ratings of care by country**

Country	Number of facilities (N)	Autonomy (SD)	Experience of care (SD)	Life satisfaction (SD)	Therapeutic milieu (SD)
All countries	1579	60.2 (12.3)	17.5 (4.8)	4.6 (0.9)	17.6 (4.2)
Bulgaria	180	47.9 (9.7)	16.1 (4.6)	4.5 (0.9)	17.1 (4.0)
Germany	189	64.5 (7.5)	18.1 (4.1)	4.9 (0.9)	17.4 (4.1)
Greece	150	67.2 (11.1)	17.3 (4.2)	4.9 (1.0)	19.7 (3.9)
Italy	179	65.3 (7.2)	18.6 (4.5)	4.6 (0.7)	18 (4.1)
The Netherlands	175	72.7 (7.5)	19.0 (4.6)	4.8 (0.9)	17.3 (4.1)
Poland	176	51.3 (7.5)	17.2 (5.2)	4.6 (0.8)	18 (4.1)
Portugal	170	52.4 (11.9)	15.7 (4.8)	4.6 (0.9)	17.4 (4.3)
Spain	210	55.6 (10.9)	16.6 (4.8)	4.6 (0.9)	16.8 (4.4)
UK	150	67.1 (8.23)	18.9 (5.4)	4.5 (0.9)	16.9 (4.4)

(mean = 72.7, SD = 7.5). Autonomy was lowest in Bulgaria (mean = 47.9, SD = 9.7). Life satisfaction was generally positive with a sample mean of 4.6 (SD = 0.9). Country means ranged from 4.5 (SD = 0.9) in Bulgaria and the UK to 4.9 in Greece (SD = 1.0) and Germany (SD = 0.9). Experience of care was also positive with respondents reporting their ability to make decisions regarding their care most of the time (mean = 17.5, SD = 4.8). Portuguese service users reported the lowest scores for this measure (mean = 15.7, SD = 4.8) while Dutch respondents reported the highest scores (mean = 19.0, SD = 4.6). The mean therapeutic milieu score was 17.6 (SD = 4.2). Country means ranged from 16.8 (SD = 4.4) in Spain to 19.7 (SD = 3.9) in Greece. Variations in country means for service user ratings of care from the sample means are presented in Figure 7.3.



**Figure 7.3 Forest plots demonstrating variation in country means from the sample means for service user ratings of care**

## 7.2 Multilevel analysis

### 7.2.1 Association between mental health expenditure and quality of longer term care

This analysis aimed to test hypothesis 1 (the quality of institutional care will increase with increased expenditure). National expenditure, as measured by the percentage of the health budget spent on mental health (percentage expenditure) and the per capita mental health spend (per capita expenditure), was significantly associated with all QuIRC domains except social interface, where no models reached significance. A 1% increase in the percentage of

the health budget spent on mental health was associated with an increase in domain score ranging from 1.08 to 3.38 percentage points. In all models clustering, measured by intra-class correlation (ICC), was weak, indicating no significant clustering effect by country.

Hypothesis 1 was therefore supported for six of the seven domains of care. Further details regarding each quality of care domain are discussed below.

### **Human Rights**

Percentage expenditure was found to be significantly associated with human rights scores when examined without adjustment (coef = 2.51,  $t = 4.08$ ,  $p \leq 0.001$ ; see Table 7.5). This means that a 1% increase in mental health expenditure was associated with a 2.51 percentage point increase in human rights domain score. The per capita expenditure model of best fit, Model C, included national variables of stigma and mental health policy (see Table 7.6)<sup>11</sup>. In this model, increasing per capita mental health expenditure by 10 Int\$ was significantly associated with a 1.2 percentage point increase in human rights score (coef = 0.12,  $t = 6.05$ ,  $p \leq 0.001$ ).

### **Living Environment**

Model D was the model of best fit for both percentage and per capita expenditure models. Expenditure was significantly associated with living environment domain scores when adjusted for facility and country characteristics. A 1% increase in percentage expenditure was associated with a 1.77 percentage point increase in living environment score (coef = 1.87,  $t = 4.21$ ,  $p \leq 0.001$ ) while a 10 Int\$ increased in per capita expenditure was associated with a 0.7 percentage point increase in domain score (coef = 0.07,  $t = 4.60$ ,  $p \leq 0.001$ ).

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<sup>11</sup> Presented as the effect of a 1 Int\$ per capita increase in mental health expenditure on QuIRC domain

**Table 7.5 Main effects of a one per cent increase in percentage mental health expenditure on quality of care**

Dependent variable	Model of best fit	Coefficient	SE	t	95% CI		ICC (country)
Human rights	A	2.51	0.62	4.08***	1.30	3.72	0.17
Living environment	D	1.87	0.45	4.21***	1.00	2.75	0.00
Recovery-based practice	A	2.53	0.29	8.82***	1.96	3.09	0.00
Self-management and autonomy	C	3.42	0.38	9.07***	2.68	4.16	0.00
Social interface	B	0.06	0.69	0.08	-1.29	1.40	0.09
Therapeutic environment	B	1.43	0.39	3.64***	0.66	2.21	0.09
Treatments and interventions	B	1.08	0.27	4.02***	0.56	1.61	0.005

\*  $P < 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$

**Table 7.6 Main effects of a 1 Int\$ per capita increase in mental health expenditure on quality of care**

Dependent variable	Model of best fit	Coefficient	SE	t	95% CI		ICC (country)
Human rights	C	0.12	0.02	6.05***	0.08	0.15	0.08
Living environment	D	0.07	0.02	4.60***	0.04	0.10	0.00
Recovery-based practice	A	0.07	0.02	4.45***	0.04	0.10	0.09
Self-management and autonomy	C	0.12	0.01	9.17***	0.10	0.15	0.00
Social interface	B	-0.001	0.02	-0.07	-0.04	0.04	0.09
Therapeutic environment	B	0.04	0.01	2.56**	0.01	0.07	0.14
Treatments and interventions	B	0.03	0.01	3.17**	0.01	0.05	0.02

\*  $P < 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$



### **Recovery-based Practice**

The least complex model (Model A) was found to be the model of best fit for both expenditure values. Percentage expenditure was significantly associated with the recovery-based practice with a 1% increase in expenditure associated with a domain score increase of 2.53 percentage points (coef = 2.53,  $t = 8.82$ ,  $p \leq 0.001$ ). A significant association was also found with domain scores increasing 0.7 percentage points for an increase in expenditure of 10 Int\$ (coef = 0.07,  $t = 4.45$ ,  $p \leq 0.001$ ).

### **Self-management and Autonomy**

Percentage expenditure was positively associated with domain score when adjusted for country characteristics (Model C; coef = 3.38,  $t = 8.74$ ,  $p \leq 0.001$ ). Per capita mental health expenditure was also positively associated with self-management and autonomy score when adjusted for country characteristics (coef = 0.12,  $t = 9.17$ ,  $p \leq 0.001$ ).

### **Social Interface**

Neither percentage nor per capita expenditure was found to be significantly associated with social interface domain score in models of best fit. Type of facility was the only variable significantly associated with social interface. Hospital-based facilities were associated with an increase of 5.80 percentage points in the domain score in the percentage expenditure model of best fit (Model B; coef = -5.80,  $t = -2.23$ ,  $p = 0.03$ ). A similar association was found in the per capita expenditure model of best fit, where hospital-based facilities were associated with an increase of 5.72 percentage points (Model B; coef = -5.72,  $t = -2.21$ ,  $p = 0.03$ ).

### **Therapeutic Environment**

Both measures of expenditure were significantly associated with therapeutic environment score in models of best fit. Percentage expenditure was positively associated with domain score when adjusted for facility characteristics (Model B; coef = 1.43,  $t = 3.64$ ,  $p \leq 0.001$ ). A similar association was found in models including per capita expenditure (Model B; coef = 0.04,  $t = 2.56$ ,  $p = 0.01$ ).

### **Treatments and Interventions**

Expenditure was significantly associated with the treatment and interventions domain score. Percentage expenditure was positively associated with treatments and interventions score when adjusted for facility characteristics (Model B; coef = 1.08,  $t = 4.02$ ,  $p \leq 0.001$ ). The model including both facility and country characteristics (Model D) was the best fitting model for the association between per capita expenditure and the treatments and interventions domain score. Increased expenditure was also significantly associated with increased quality in this domain (coef = 0.03,  $t = 3.17$ ,  $p = 0.002$ ).

#### **7.2.1 Association between deinstitutionalisation and quality of longer term care**

This analysis aimed to test hypothesis 2 (the quality of institutional care will be positively correlated with the degree of deinstitutionalisation). Increased deinstitutionalisation of mental health service provision was significantly associated with higher QuIRC domain scores for human rights, living environment, recovery-based practice, self-management and autonomy, therapeutic environment and treatments and interventions in models of best fit (see Table 7.7). Deinstitutionalisation was significantly associated with quality across these

**Table 7.7 Main effects of a one point increase in deinstitutionalisation score on quality of care**

Dependent variable	Model of best fit	Coefficient	SE	t	95% CI		ICC (country)
Human rights	A	3.90	1.22	3.19***	1.50	6.29	0.22
Living environment	B	4.71	0.57	8.34***	3.61	5.82	0.00
Recovery-based practice	D	2.83	0.94	3.00**	0.98	4.68	0.05
Self-management and autonomy	D	4.96	1.0	4.78***	2.93	7.00	0.05
Social interface	B	0.22	0.88	0.24	-1.51	1.94	0.04
Therapeutic environment	D	1.99	0.49	4.08***	1.03	2.94	0.00
Treatments and interventions	D	1.93	0.51	3.77***	0.92	2.93	0.00

\*  $P < 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$

domains in models of best fit. The main effect ranged from 2.01 to 4.91 percentage points for each increased point on the Mental Health Deinstitutionalisation Measure (MHDM). Deinstitutionalisation had no significant association with social interface domain scores. Only the human rights domain had significant clustering by country (ICC = 0.22).

Hypothesis 2 was therefore supported for six of the seven domains of quality of care investigated.

### **Human Rights**

A one point increase in deinstitutionalisation was associated with a 3.90 percentage point increase in human rights domain score in the model of best fit (Model A; coef = 3.90, t =

3.19,  $p = 0.001$ ; see Table 7.7). High levels of clustering were found in the model (ICC = 0.22) indicating similarity of facility human rights domain scores within countries.

### **Living Environment**

National level of deinstitutionalisation showed a significant positive association with living environment domain score in the model of best fit when adjusted for facility characteristics (Model B; coef = 4.71,  $t = 8.34$ ,  $p \leq 0.001$ ; see Table 7.7). A one point increase in MHDM score was associated with a 4.71 percentage point increase in living environment score.

### **Recovery-based Practice**

The national levels of the deinstitutionalisation of mental health care were significantly associated with recovery-based practice scores when adjusted for country characteristics (Model C; coef = 2.83,  $t = 3.00$ ,  $p = 0.005$ ), with the domain score increasing by 2.83 percentage points per one point increase in MHDM score.

### **Self-management and Autonomy**

Deinstitutionalisation level was significantly associated with the self-management and autonomy domain scores when adjusted for facility and country characteristics (Model D; coef = 4.96,  $t = 4.78$ ,  $p \leq 0.001$ ; see Table 7.7). A one point increase in MHDM score was associated with an increase in domain score of 4.96 percentage points.

### **Social Interface**

National level of deinstitutionalisation did not significantly predict social interface score in the model of best fit. Hospital-based facilities were associated with an increased domain score of 5.61% in the model of best fit (Model F; coef = -5.61,  $t = -2.42$ ,  $p = 0.02$ ).

### **Therapeutic Environment**

An increase in MHDM score of one point was associated with an increase in therapeutic environment score of 1.99 percentage points when adjusted for facility and country characteristics (Model D; coef = 1.99,  $t = 4.08$ ,  $p \leq 0.001$ ; see Table 7.7).

### **Treatments and Interventions**

Increased deinstitutionalisation level was significantly associated with an increase in the treatments and interventions domain score in the model of best fit (Model D; coef = 1.93,  $t = 0.51$ ,  $p \leq 0.001$ ). An increase in MHDM score of one point was associated with an increase of 1.93 percentage points in domain score.

#### **7.2.2 Association between mental health expenditure and service user ratings of care**

This analysis aimed to test hypothesis 3 (service user ratings of care will be negatively associated with mental health expenditure). Models using percentage and per capita expenditure resulted in similar associations. Expenditure was positively associated with service user ratings of autonomy and experience of care but not life satisfaction or therapeutic milieu (see Table 7.8 and Table 7.9). Increased mental health expenditure had the greatest effect on service user autonomy scores. These models also had significant clustering at both the country and facility levels for both national mental health percentage expenditure (country ICC=0.25, facility ICC=0.30) and per capita expenditure (country ICC=0.20, facility ICC=0.32). This indicates significant similarity in autonomy ratings by country and facility. Clustering among the other models was weak.

Expenditure was not associated with life satisfaction. Increased expenditure was negatively associated with service user ratings of therapeutic milieu. However, the coefficient was small and did not reach significance.

Hypothesis 3 was therefore not supported as significant associations were positive.

### **Autonomy**

Expenditure was significantly associated with autonomy when measured as percentage and per capita expenditure. For both values, the model adjusted for facility characteristics (Model F) was determined to be the model of best fit. An increase in spending of 1% of the health budget on mental health was associated with an increase in service-user-rated autonomy score of 1.97 points (coef = 1.97,  $t = 3.00$ ,  $p = 0.003$ ). An increase in per capita mental health spending of 10 Int\$ was associated with an increase of 0.7 points (coef = 0.07,  $t = 3.76$ ,  $p \leq 0.001$ ). Both models of best fit had significant clustering at both country and facility levels.

### **Experience of care**

Service user experience of care was significantly associated with expenditure in models of best fit. A 1% increase in mental health expenditure was associated with a 0.29 point increase in service user ratings (Model E; coef = 0.29,  $t = 2.99$ ,  $p = 0.003$ ). Per capita expenditure was also positively associated with service user experience of care when adjusted for facility and country characteristics (Model H; coef = 0.01,  $t = 4.62$ ,  $p \leq 0.001$ ).

**Table 7.8 Main effects of a one per cent increase in percentage of mental health expenditure on service user ratings of care**

Independent Variable	Model of best fit	Coefficient	SE	t	95% CI		ICC (country)	ICC (facility)
Autonomy	F	1.97	0.66	3.00**	0.68	3.27	0.25	0.30
Experience of care	E	0.29	0.10	2.99**	0.10	0.47	0.02	0.12
Life satisfaction	G	0.01	0.02	0.77	-0.02	0.05	0.01	0.07
Therapeutic milieu	F	-0.08	0.05	-1.39	-0.18	0.03	0.00	0.07

\*  $p < 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$

**Table 7.9 Main effects of a 1 Int\$ per capita increase in mental health expenditure on service user ratings of care**

Independent Variable	Model of best fit	Coefficient	SE	t	95% CI		ICC (country)	ICC (facility)
Autonomy	F	0.07	0.02	3.76***	0.03	0.10	0.20	0.32
Experience of care	H	0.01	0.003	4.62***	0.01	0.02	0.00	0.11
Life Satisfaction	E	0.001	0.001	2.63**	0.000	0.002	0.02	0.06
Therapeutic Milieu	F	-0.002	0.002	-1.14	-0.005	0.001	0.00	0.07

\*  $p < 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$

### **Life Satisfaction**

National mental health percentage expenditure was not associated with service user ratings of life satisfaction in models of best fit. Only the number of years elapsed since the introduction of mental health policies was significantly associated with life satisfaction ratings in the model (Model G; coef = 0.02,  $t = 2.27$ ,  $p = 0.02$ ). However, per capita expenditure was significantly associated with life satisfaction in the unadjusted model (Model E; coef = 0.001,  $t = 2.63$ ,  $p = 0.01$ ). An increase of 10 Int\$ was associated with an increase in life satisfaction scores of one hundredth of a point.

### **Therapeutic Milieu**

Therapeutic milieu was negatively associated with percentage expenditure or per capita mental health expenditure in models of best fit adjusted for facility characteristics (Model F). However, the result failed to reach significance in either model. Facility type was significantly associated with increased service user ratings of therapeutic milieu in percentage expenditure (Model F; coef = 0.75,  $t = 2.39$ ,  $p = 0.02$ ) and per capita expenditure (Model F; coef = 0.71,  $t = 2.29$ ,  $p = 0.02$ ) models of best fit. Service users in facilities based in hospital had therapeutic milieu scores 0.75 and 0.71 points higher than service users in the community in percentage and per capita expenditure models, respectively.



**Table 7.10 Main effects of a one point increase in deinstitutionalisation score on service user ratings of care**

Dependent Variable	Model of best fit	Coefficient	SE	t	95% CI		ICC (country)	ICC (facility)
Autonomy	F	4.51	1.29	3.49***	1.98	7.05	0.21	0.31
Experience of care	H	1.10	0.26	4.26***	0.06	0.61	0.00	0.12
Life satisfaction	G	0.05	0.05	0.98	-0.05	0.11	0.08	0.21
Therapeutic milieu	F	-0.09	0.18	-0.49	-0.45	0.27	0.02	0.07

\*  $P < 0.05$ ; \*\*  $p \leq 0.01$ ; \*\*\*  $p \leq 0.001$

### 7.2.3 Association between deinstitutionalisation and service user ratings of care

The final analysis tested hypothesis 4 (service user ratings of care will be positively associated with deinstitutionalisation). A significant positive relationship was found between national levels of deinstitutionalisation and service user autonomy and experience of care in models of best fit (see Table 7.10). Similar to models examining the effect of mental health expenditure on service user experience of care, significant clustering of autonomy scores were found at both the country (ICC = 0.21) and facility (ICC = 0.31) levels. The model of autonomy included two outliers which were removed.

#### **Autonomy**

Increased deinstitutionalisation of mental health care was significantly associated with greater autonomy when adjusted for facility characteristics (Model F; coef = 4.51,  $t = 3.49$ ,  $p \leq 0.001$ ; see Table 7.10). An increase of one point in MHDM score was associated with a 4.51 point increase in autonomy score. Country (ICC = 0.21) and facility (ICC = 0.31) level

clustering were significant, indicating similarity in autonomy scores within countries and facilities.

### **Life Satisfaction**

Deinstitutionalisation was not significantly associated with service user reported life satisfaction in the model of best fit which adjusted for country characteristics (Model G; see Table 7.10). The number of years elapsed since the introduction of mental health policies was significantly associated with life satisfaction ratings in the model (coef = 0.02,  $t = 2.36$ ,  $p = 0.02$ ). However, the coefficient was small.

### **Experience of care**

Deinstitutionalisation total scores were positively associated with service user experience of care in the model of best fit (Model H; coef = 1.10,  $t = 4.26$ ,  $p \leq 0.001$ ; see Table 7.10). An increase of one point on the MHDM was associated with a 1.10 percentage point increase in service user ratings of experience of care.

### **Therapeutic milieu**

Deinstitutionalisation was not significantly associated with therapeutic milieu in the model of best fit which adjusted for facility characteristics (Model F; see Table 7.10). Facility type was significantly associated with increased service user ratings of therapeutic milieu in the model (Model F; coef = 0.76,  $t = 2.34$ ,  $p = 0.02$ ). Therefore, service users in hospital had therapeutic milieu scores 0.76 points higher than service users in the community.

### ***7.3 Application of results***

**7.3.1 The effect of mental health expenditure on quality of care**

Increased national mental health expenditure was significantly associated with quality of longer term care for six of the seven QuIRC domains. To better understand the effect of national investment in mental health care on quality of longer term care, it is important to examine projected domain scores at specific levels of expenditure. Changes to national percentage mental health expenditure were used in projections as the coefficients associated with per capita expenditure were so small as to make them difficult to interpret. Although the WHO supports an increase in national mental health spending, a specific target has not been suggested. Average national expenditure on mental health across the eight countries included was 5.8% of the total health budget with a range of 2.3% to 10.14%. A projection of the increase in QuIRC domain scores affected by changing national mental health expenditure to 5% and 10% was carried out. Where countries already spent greater than 5% or 10%, their domain scores were adjusted to reflect their projected domain scores at the indicated level of spending. Findings are presented in Table 7.11 and Figure 7.4. QuIRC domain scores can currently only be interpreted as indicative of the quality of a facility relative to other similar facilities since no studies investigating the association between QuIRC scores and longitudinal outcomes for service users have been published. Therefore, projected QuIRC scores in this hypothetical process were defined as clinically significant if the increase in national mental health expenditure moved the country above the mean QuIRC score.

**Table 7.11 Projected national mean Quality Indicator for Rehabilitative Care domain scores based on a change in mental health percentage expenditure**

Mean QuIRC <sup>1</sup> domain score	Bulgaria	Germany	Italy	The Netherlands	Poland	Portugal	Spain	UK
2005 % health budget spent on mental health	2.50	10.1	5.00	7.00	3.50	2.30	5.89	10.0
Human rights (mean = 57.4)								
2005 expenditure	52.4	65.7	48.1	70.8	53.0	48.7	53.7	69.6
5% expenditure	58.7	52.8	48.1	65.8	56.8	55.5	51.5	57.1
10% expenditure	71.2	65.3	60.7	78.3	69.3	68.0	64.0	69.6
Living environment (mean = 60.6)								
2005 expenditure	54.1	73.8	64.8	70.1	49	59.2	46.5	67
5% expenditure	58.8	64.2	64.8	66.4	51.8	64.2	44.8	57.7
10% expenditure	68.1	73.5	74.2	75.7	61.2	73.6	54.2	67.0
Recovery-based practice (mean = 52.3)								
2005 expenditure	45.5	62.4	48.4	51.7	46.1	44.2	55.4	66.0
5% expenditure	51.8	49.4	48.4	46.6	49.9	51.0	53.1	53.4
10% expenditure	64.5	62.0	61.1	59.3	62.5	63.7	65.8	66.0
Self-management and autonomy (mean = 55.7)								
2005 expenditure	44.9	71.9	53.2	66	44.1	49.6	46.9	68.7
5% expenditure	53.5	54.3	53.2	59.2	49.2	58.8	43.9	51.6
10% expenditure	70.6	71.4	70.3	76.3	66.3	75.9	61.0	68.7
Social interface (mean = 48.4)								
2005 expenditure	45.8	40.3	50.0	47.0	40.1	52	59.5	53.9
5% expenditure	46.0	40.0	50.0	46.9	40.2	52.2	59.4	53.6
10% expenditure	46.3	40.3	50.3	47.2	40.5	52.5	59.7	53.9
Therapeutic environment (mean = 52.2)								
2005 expenditure	45.6	51.8	52.6	51.6	47.5	47.8	55.7	64.6
5% expenditure	49.2	44.4	52.6	48.7	49.6	51.7	54.4	57.5
10% expenditure	56.3	51.6	59.8	55.9	56.8	58.8	61.6	64.6
Treatments and interventions (mean = 50.7)								
2005 expenditure	48.5	51.6	50.6	52.7	46.2	46.5	54.0	59.5
5% expenditure	51.2	46.0	50.6	50.5	47.8	49.4	53.0	54.1
10% expenditure	56.6	51.4	56.0	55.9	53.2	54.8	58.4	59.5

<sup>1</sup> Quality Indicator for Rehabilitative Care

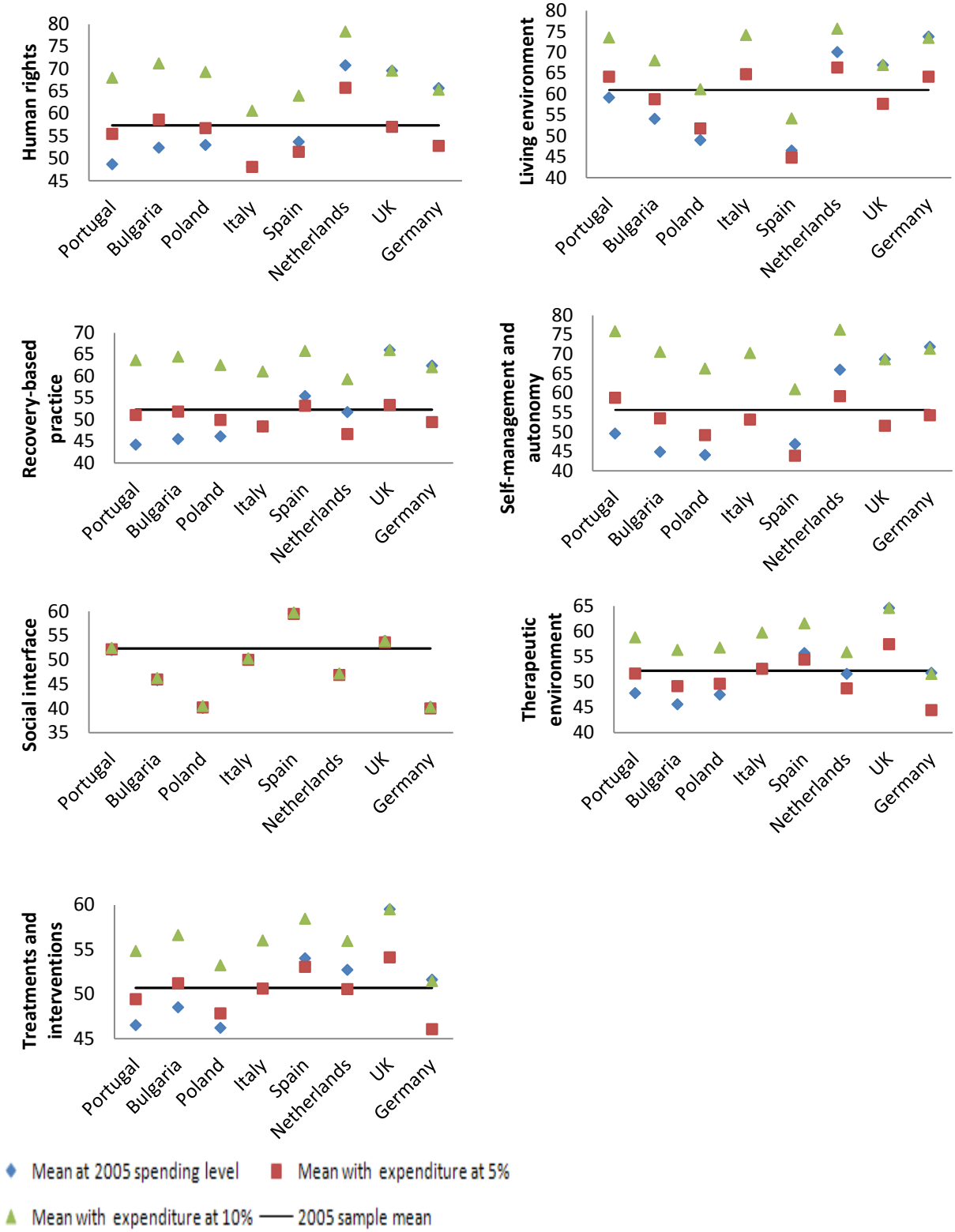


Figure 7.4 The impact of a change in mental health percentage expenditure on projected national mean Quality Indicator for Rehabilitative Care domain scores

As can be seen in Figure 7.4, an increase in percentage expenditure to 10% was associated with a projected clinically significant improvement in six of the seven QuIRC domains for Portugal, the country with the lowest level of mental health expenditure. In Germany, where more than 10% of the health budget is spent on mental health, a reduction to 5% percentage expenditure was associated with a projected overall negative effect on quality of care. Human rights, recovery-based practice, self-management and autonomy and treatments and interventions domain scores all fell below the sample mean. There was no clinically significant impact on living environment, social interface or therapeutic environment domains. Changes in percentage expenditure had no clinically significant impact on projected social interface scores for any country.

### 7.3.2 The effect of deinstitutionalisation on quality of care

Deinstitutionalisation levels were found to have statistically significant associations with five QuIRC domains (living environment, recovery-based practice, self-management and autonomy, therapeutic environment and treatments and interventions). In order to examine the potential impact of changes in the total deinstitutionalisation score, the mean deinstitutionalisation score across all countries (3.15) and the highest score from among the nine countries (4.67) were chosen as the levels on which to base projected QuIRC scores.

Again, clinical significance was defined as a change in score that moved a country above or below the mean 2005 domain score for the sample.

Poland, the country with the lowest level of deinstitutionalisation, saw projected mean scores for six QuIRC domains improve significantly when the deinstitutionalisation score

**Table 7.12 Projected national mean Quality Indicator for Rehabilitative Care domain scores based on a change in deinstitutionalisation score**

Mean QuIRC <sup>1</sup> domain score	Bulgaria	Germany	Greece	Italy	The Netherlands	Poland	Portugal	Spain	UK
Deinstitutionalisation (DI) total score	1.99	4.33	2.67	4	4.33	0.99	3.67	1.66	4.67
Human rights (2005 mean = 56.9)									
2005 DI score	52.4	65.7	52.9	48.1	70.8	53	48.7	53.7	69.6
DI score of 3.15	56.9	61.1	54.8	44.8	66.2	61.4	46.7	59.5	63.7
DI score of 4.67	62.9	67.0	60.7	50.7	72.1	67.4	52.6	65.4	69.6
Living environment (2005 mean = 60.6)									
2005 DI score	54.1	73.8	58	64.8	70.1	49	59.2	46.5	67
DI score of 3.15	59.6	68.2	60.3	60.8	64.5	59.2	56.8	53.5	59.8
DI score of 4.67	66.7	75.4	67.4	68.0	71.7	66.3	63.9	60.7	67.0
Recovery-based practice (2005 mean = 52.37)									
2005 DI score	45.5	62.4	56	48.4	51.7	46.1	44.2	55.4	66
DI score of 3.15	48.8	59.1	57.4	46.0	48.4	52.2	42.7	59.6	61.7
DI score of 4.67	53.1	63.4	61.7	50.3	52.7	56.5	47.0	63.9	66.0
Self-management and autonomy (2005 mean = 55.7)									
2005 DI score	44.9	71.9	59.9	53.2	66	44.1	49.6	46.9	68.7
DI score of 3.15	50.7	66.0	62.3	49.0	60.1	54.8	47.0	54.3	61.2
DI score of 4.67	58.2	73.6	69.8	56.5	67.7	62.4	54.6	61.8	68.7
Social interface (2005 mean = 52.3)									
2005 DI score	45.8	40.3	47.3	50	47	40.1	52	59.5	53.9
DI score of 3.15	46.1	40.0	47.4	49.8	46.7	40.6	51.9	59.8	53.6
DI score of 4.67	46.4	40.4	47.7	50.1	47.1	40.9	52.2	60.2	53.9
Therapeutic environment (2005 mean = 52.2)									
2005 DI score	45.6	51.8	52.1	52.6	51.6	47.5	47.8	55.7	64.6
DI score of 3.15	47.9	49.5	53.1	50.9	49.3	51.8	46.8	58.7	61.6
DI score of 4.67	50.9	52.5	56.1	53.9	52.3	54.8	49.8	61.7	64.6
Treatments and interventions (2005 mean = 50.7)									
2005 DI score	48.5	51.6	47.4	50.6	52.7	46.2	46.5	54	59.5
DI score of 3.15	50.7	49.3	48.3	49.0	50.4	50.4	45.5	56.9	56.6
DI score of 4.67	53.7	52.3	51.3	51.9	53.4	53.3	48.4	59.8	59.5

<sup>1</sup> Quality Indicator for Rehabilitative Care

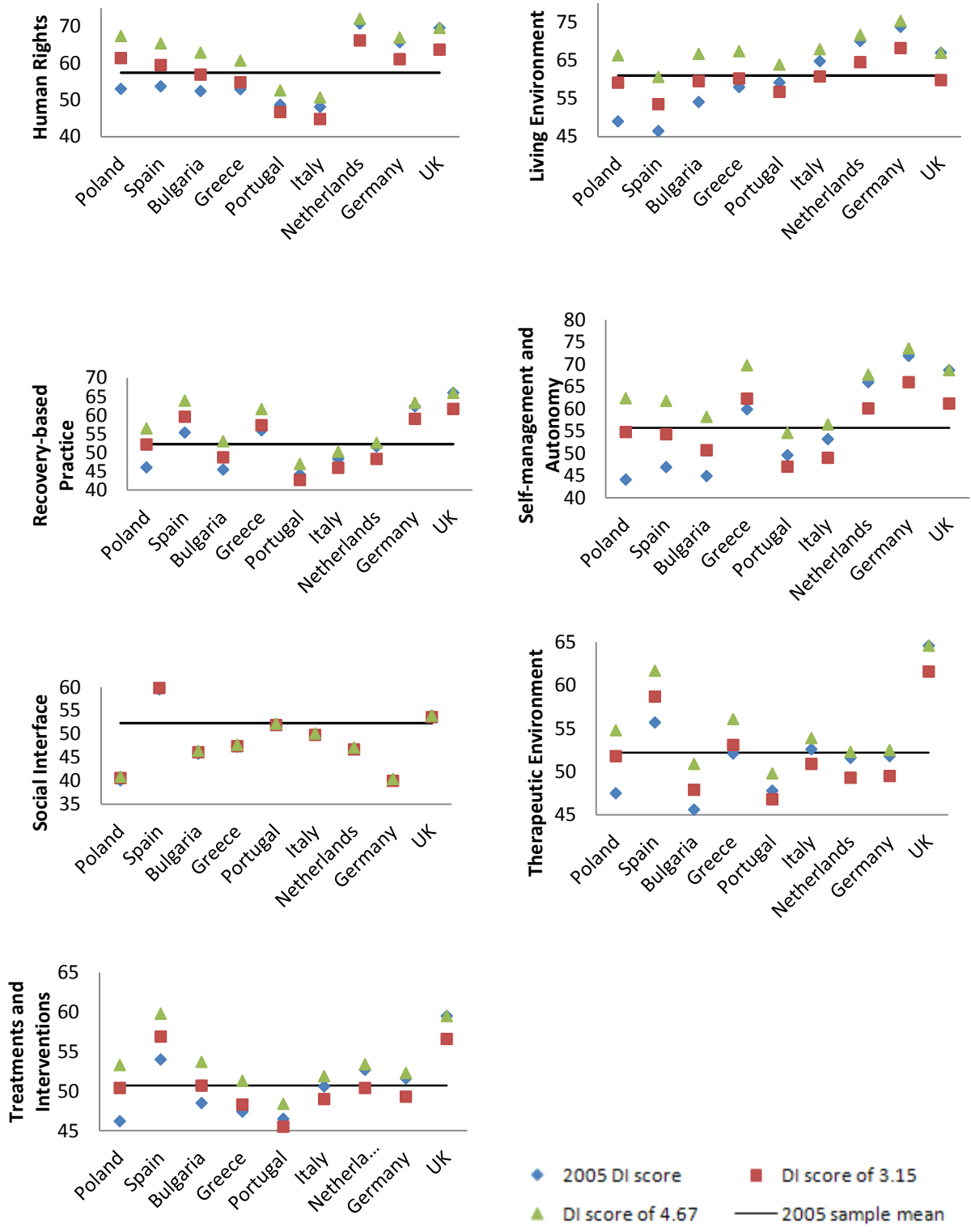


Figure 7.5 The impact of a change in deinstitutionalisation score on projected national mean Quality Indicator for Rehabilitative Care domain scores



was raised to 4.67 (see Table 7.12 and Figure 7.5). Only the projected social interface domain score was unaffected by change in deinstitutionalisation level. This was true for all countries.

In the UK, the country with the highest deinstitutionalisation score, a decrease in score to 3.15 was associated with a clinically significant reduction in the projected domain score for living environment. Projected scores for the other six domains were not significant, remaining above the sample mean.

### 7.3.3 The effect of expenditure on service user experience of care

Increased percentage expenditure was found to be associated with a statistically significant improvement in projected service user ratings of autonomy and experience of care. No statistically significant associations between percentage expenditure and projected service user ratings of life satisfaction or therapeutic milieu were found. Similar findings emerged when the impact of increasing expenditure to five and 10% was evaluated (see Table 7.13 and Figure 7.6). An increase in national percentage mental health expenditure to 10% resulted in a clinically significant increase in projected ratings of autonomy and experience of care. Projected service user ratings of life satisfaction improved significantly when percentage expenditure was set to 10% even though no statistically significant association was found. A reduction in expenditure had a significant impact on projected German ratings of autonomy and experience of care with scores falling below the mean. For all countries increased expenditure was associated with decreased ratings of therapeutic milieu.

**Table 7.13 Projected national mean service user ratings based on a change in national mental health percentage expenditure**

Service user ratings of care	Bulgaria	Germany	Italy	The Netherlands	Poland	Portugal	Spain	UK
2005 % health budget spent on mental health	2.5	10.1	5.0	7.0	3.5	2.3	5.9	10.0
Autonomy (2005 mean = 60.2)								
2005 expenditure	47.9	64.5	65.3	72.7	51.3	52.4	55.6	67.1
5% expenditure	52.8	54.4	65.3	68.8	54.3	57.7	53.8	57.3
10% expenditure	62.7	64.2	75.2	78.6	64.1	67.6	63.7	67.1
Experience of care (2005 mean = 17.5)								
2005 expenditure	16.1	18.1	18.6	19.0	17.2	15.7	16.6	18.9
5% expenditure	16.8	16.6	18.6	18.4	17.6	16.5	16.3	17.5
10% expenditure	18.3	18.1	20.1	19.9	19.1	17.9	17.8	18.9
Life satisfaction (2005 mean = 4.6)								
2005 expenditure	4.5	4.9	4.6	4.8	4.6	4.6	4.6	4.5
5% expenditure	4.5	4.8	4.6	4.8	4.6	4.6	4.6	4.5
10% expenditure	4.6	4.9	4.7	4.8	4.7	4.7	4.6	4.5
Therapeutic milieu (2005 mean = 17.6)								
2005 expenditure level	17.1	17.4	18.0	17.3	18.0	17.4	16.8	16.9
5% expenditure	16.9	17.8	18.0	17.5	17.9	17.2	16.9	17.3
10% expenditure	16.5	17.4	17.6	17.1	17.5	16.8	16.5	16.9

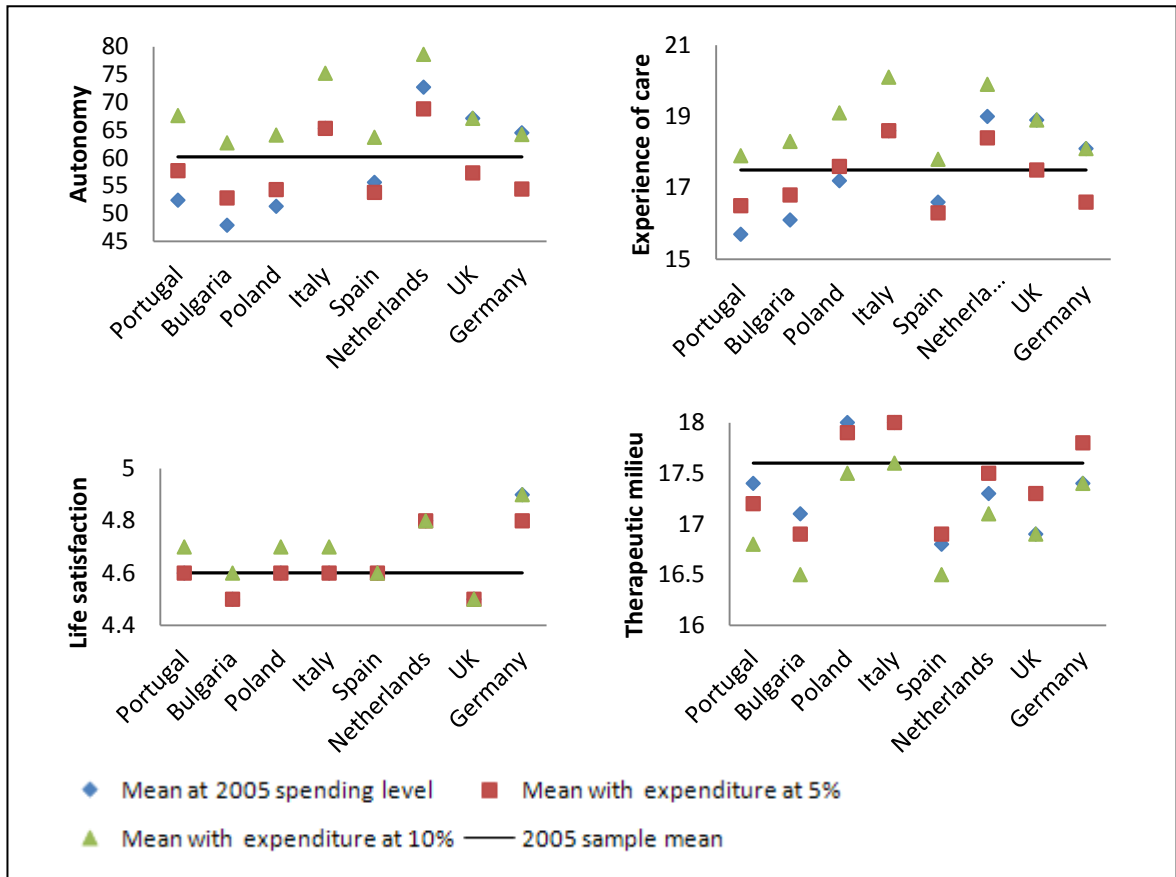


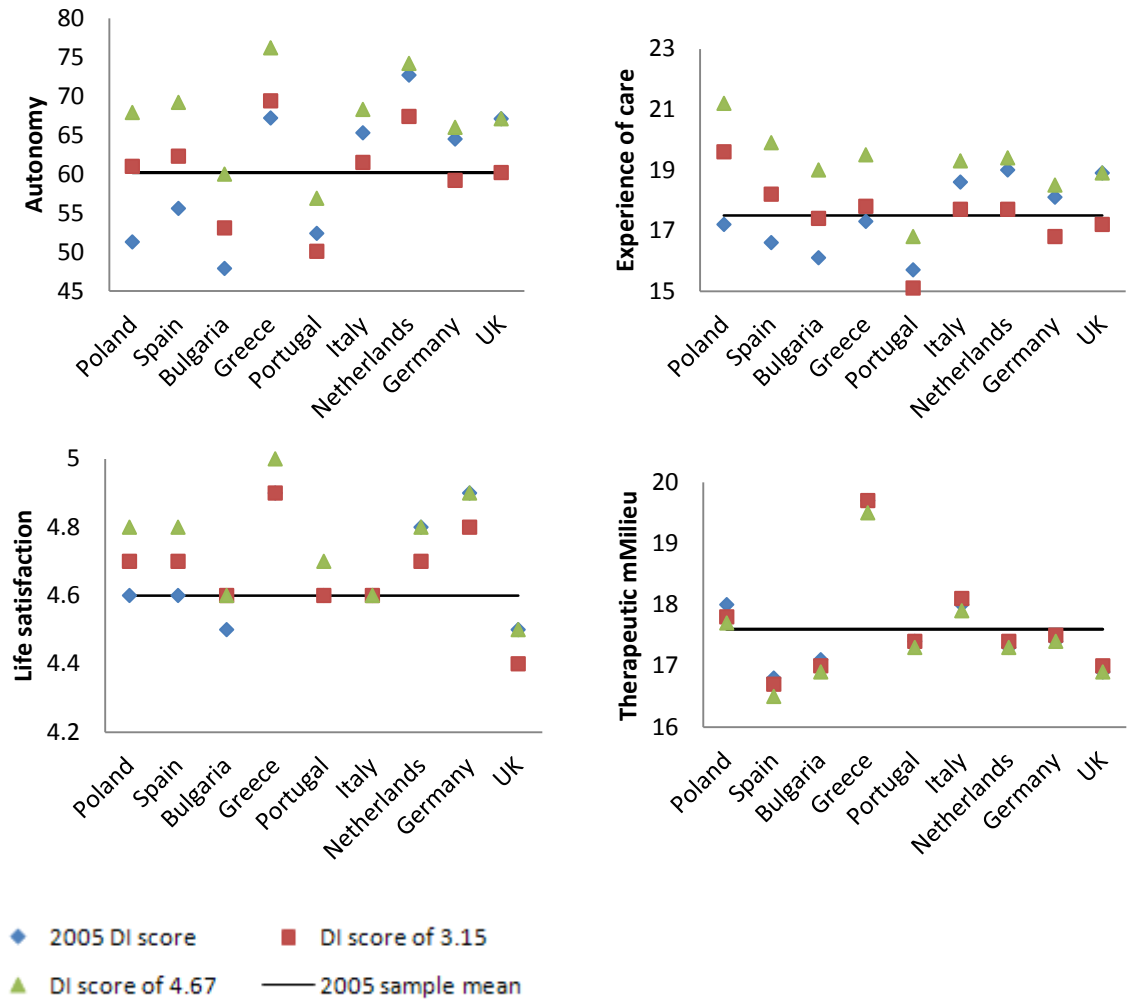
Figure 7.6 The impact of a change in national mental health percentage expenditure on projected national mean service user ratings of care

**Table 7.14 Projected national mean service user ratings of care based on a change in deinstitutionalisation score**

Mean service user ratings of care	Bulgaria	Germany	Greece	Italy	The Netherlands	Poland	Portugal	Spain	UK
Deinstitutionalisation (DI) total score	1.99	4.33	2.67	4.00	4.33	0.99	3.67	1.66	4.67
Autonomy (2005 mean = 60.2)									
2005 DI score	47.9	64.5	67.2	65.3	72.7	51.3	52.4	55.6	67.1
DI score of 3.15	53.1	59.2	69.4	61.5	67.4	61.0	50.1	62.3	60.2
DI score of 4.67	60.0	66.0	76.2	68.3	74.2	67.9	56.9	69.2	67.1
Experience of care (2005 mean = 17.5)									
2005 DI score	16.1	18.1	17.3	18.6	19	17.2	15.7	16.6	18.9
DI score of 3.15	17.4	16.8	17.8	17.7	17.7	19.6	15.1	18.2	17.2
DI score of 4.67	19.0	18.5	19.5	19.3	19.4	21.2	16.8	19.9	18.9
Life satisfaction (2005 mean = 4.6)									
2005 DI score	4.5	4.9	4.9	4.6	4.8	4.6	4.6	4.6	4.5
DI score of 3.15	4.6	4.8	4.9	4.6	4.7	4.7	4.6	4.7	4.4
DI score of 4.67	4.6	4.9	5.0	4.6	4.8	4.8	4.7	4.8	4.5
Therapeutic milieu (2005 mean = 17.6)									
2005 DI score	17.1	17.4	19.7	18.0	17.3	18.0	17.4	16.8	16.9
DI score of 3.15	17.0	17.5	19.7	18.1	17.4	17.8	17.4	16.7	17.0
DI score of 4.67	16.9	17.4	19.5	17.9	17.3	17.7	17.3	16.5	16.9

#### ***7.4 The effect of deinstitutionalisation on service user experience of care***

Associations between service user ratings of autonomy and experience of care and national levels of deinstitutionalisation were statistically significant in models of best fit while deinstitutionalisation was not significantly associated with ratings of life satisfaction or therapeutic milieu. In Poland, the country with the least deinstitutionalised mental health services, an increase in deinstitutionalisation score to 3.17 (the mean deinstitutionalisation score for the sample) resulted in projected service user ratings of autonomy, experience of care and life satisfaction moving above the sample means (see Table 7.14 and Figure 7.7). A reduction in the deinstitutionalisation of mental health care in the UK led to a clinically



**Figure 7.7** The impact of a change in deinstitutionalisation score on projected national mean service user ratings of care

significant reduction in projected service user ratings of autonomy, experience of care and life satisfaction as its mean national ratings fell below the sample means. However the reduction in deinstitutionalisation did not affect service user ratings of the therapeutic milieu. Although deinstitutionalisation was not statistically associated with service user ratings of life satisfaction, countries with deinstitutionalisation scores less than 3.15 saw

clinically significant improvement in their projected mean life satisfaction ratings when deinstitutionalisation scores rose to 3.15 (the sample mean).

### **7.5 Summary**

National mental health expenditure and deinstitutionalisation were associated with several aspects of quality of care in longer term mental health facilities. Specifically, national mental health expenditure was significantly associated with the human rights, living environment, recovery-based practice, self-management and autonomy, therapeutic environment and treatments and interventions QuIRC domain scores (see Table 7.15). Increased mental health expenditure to 10% of the health budget was associated with clinically significant projected improvements in all domain scores, except social interface for almost all countries, especially those countries currently spending less than 5% of their health budget on mental health care. Mental health expenditure was not found to be statistically or clinically associated with the social interface QuIRC domain score. Among these countries, the type of facility was significantly associated with social interface domain scores. Hospital-based facilities had the highest scores for the domain.

Deinstitutionalisation was similarly associated with QuIRC domain scores for human rights, living environment, recovery-based practice, self-management and autonomy, therapeutic environment and treatments and interventions (see Table 7.15). It was suggested that a high deinstitutionalisation score (greater than 4.5) is required for the majority of countries to see a clinically significant improvement in quality of care. The social interface domain score was not associated with a country's level of

**Table 7.15 Coefficients of significant associations between independent variables and Quality Indicator for Rehabilitative Care domain scores in models of best fit**

Independent variable	Quality Indicator for Rehabilitative Care (QuIRC) domains						
	Human rights	Living environment	Recovery-based practice	Social interface	Self-management & autonomy	Therapeutic environment	Treatments & interventions
Model of best fit <sup>1</sup>	A	D	A	B	C	B	B
Percentage expenditure	2.51	1.87	2.53	ns	3.42	1.43	1.08
Facility: community-based <sup>2</sup>		12.23		-5.80		-3.56	ns
Facility: staffing intensity <sup>3</sup>		ns		ns		ns	ns
Country: mental health policy <sup>4</sup>		ns			Ns		
Country: stigma		8.42			6.48		
Model of best fit <sup>1</sup>	C	D	A	B	C	B	B
Per capita expenditure	0.12	0.07	0.07	ns	0.12	0.04	0.03
Facility: community-based <sup>2</sup>		12.16		-5.72		-3.52	ns
Facility: staffing intensity <sup>3</sup>		ns		ns		3.76	3.69
Country: mental health policy <sup>4</sup>	-0.54	ns			Ns		
Country: stigma	ns	6.08			Ns		
Model of best fit <sup>1</sup>	A	B	D	B	D	D	D
Deinstitutionalisation	3.90	4.71	2.83	ns	4.96	1.99	1.93
Facility: community-based <sup>2</sup>		13.18	ns	-5.61	6.03	ns	ns
Facility: staffing intensity <sup>3</sup>		-5.09	ns	ns	Ns	ns	ns
Facility: max length of stay <sup>5</sup>		ns	6.47	9.88	Ns	9.90	7.28
Country: mental health policy <sup>4</sup>			ns		0.44	ns	ns
Country: stigma			ns		Ns	-3.05	-3.24

This table provides coefficients for significant ( $p < 0.05$ ) associations between independent variables and quality of care (as measured by the Quality Indicator for Rehabilitative Care, QuIRC) in models of best fit. Non significant associations are denoted by the script 'ns'. Shaded areas of the table indicate variables which were not included in models of best fit.

<sup>1</sup> The model of best fit was defined as the model with the lowest Akaike's Information Criterion (AIC) value. Models tested included the following independent variables: expenditure/deinstitutionalisation only (Model A); expenditure/deinstitutionalisation and facility characteristics (Model B); expenditure/deinstitutionalisation and country characteristics (Model C); and expenditure/deinstitutionalisation and both facility and country characteristics (Model D).

<sup>2</sup> A negative coefficient indicates hospital-based facilities were associated with higher domain scores

<sup>3</sup> A positive coefficient indicates facilities with full-time equivalent staff to service user ratio  $\geq 0.57$  (the sample mean) were associated with higher domain scores

<sup>4</sup> Number of years elapsed since the introduction of national mental health policies

<sup>5</sup> A positive coefficient indicates that facilities with a maximum length of stay were associated with higher domain scores

deinstitutionalisation. Both hospital-based facilities and facilities of stay were found to be significantly associated with increased social interface domain scores.

National mental health expenditure and deinstitutionalisation were associated with more positive service user ratings of autonomy and experience of care (see Table 7.16). Neither service user ratings of their life satisfaction nor the therapeutic milieu of the facility were statistically associated with national investment in mental health or deinstitutionalisation. Projected service user ratings based on increased mental health expenditure to 10% of the health budget were associated with clinically significant improvements for autonomy, experience of care and life satisfaction. However, increased expenditure was associated with decreased ratings of therapeutic milieu for all countries. Greater deinstitutionalisation (MHDM score greater than 4.5) were also associated with improved service user ratings of autonomy, experience of care and life satisfaction. No clinically significant changes in service user ratings of therapeutic milieu were found with increased deinstitutionalisation.



**Table 7.16 Coefficients of significant associations between independent variables and service user ratings of care in models of best fit**

Independent variable	Service user ratings of care			
	Autonomy	Life satisfaction	Experience of care	Therapeutic milieu
Model of best fit <sup>1</sup>	F	G	E	F
Percentage expenditure	1.97	ns	0.29	Ns
Facility: community-based <sup>2</sup>	2.98			0.75
Facility: staffing intensity <sup>3</sup>	Ns			Ns
Country: mental health policy <sup>4</sup>		0.02		
Country: stigma		ns		
Model of best fit <sup>1</sup>	F	E	H	F
Per capita expenditure	0.07	0.001	0.01	Ns
Facility: community-based <sup>2</sup>	2.95		0.91	0.71
Facility: staffing intensity <sup>3</sup>	Ns		ns	Ns
Country: mental health policy <sup>4</sup>			-0.11	
Country: stigma			ns	
Model of best fit <sup>1</sup>	F	G	H	F
Deinstitutionalisation	4.51	ns	1.10	Ns
Facility: community-based <sup>2</sup>	3.24		0.80	0.76
Facility: staffing intensity <sup>3</sup>	Ns		ns	Ns
Facility: max length of stay <sup>5</sup>	Ns		ns	Ns
Country: mental health policy <sup>4</sup>		0.02	-0.10	
Country: stigma		ns	-1.75	

This table provides coefficients for significant ( $p < 0.05$ ) associations between independent variables and service user ratings of care in models of best fit. Non significant associations are denoted by the script 'ns'. Shaded areas of the table indicate variables which were not included in models of best fit.

<sup>1</sup> The model of best fit was defined as the model with the lowest Akaike's Information Criterion (AIC) value. Models tested included the following independent variables: expenditure/ deinstitutionalisation only (Model E); expenditure/ deinstitutionalisation and facility characteristics (Model F); expenditure/ deinstitutionalisation and country characteristics (Model G); and expenditure/ deinstitutionalisation and both facility and country characteristics (Model H).

<sup>2</sup> A negative coefficient indicates hospital-based facilities were associated with more positive service user ratings of care

<sup>3</sup> A positive coefficient indicates facilities with full-time equivalent staff to service user ratio  $\geq 0.57$  (the sample mean) were associated with more positive service user ratings of care

<sup>4</sup> Number of years elapsed since the introduction of national mental health policies

<sup>5</sup> A positive coefficient indicates that facilities with a maximum length of stay were associated with more positive service user ratings of care

## Chapter 8

### **Discussion**

In countries with a history of deinstitutionalisation, the majority of mental health service users are successfully cared for in community settings. However, the severity of illness exhibited by a very small proportion of mental health service users, the majority of whom have a diagnosis of schizophrenia or schizoaffective disorder, requires the provision of expensive, highly supported care. When deinstitutionalisation was first suggested, there was considerable worry that community-based care could not successfully be extended to this difficult to treat group. The Team for the Assessment of Psychiatric Services (TAPS) project, one of the first to investigate the effects of the closure of mental hospitals in the UK, found it was possible to successfully provide community-based longer term care for service users with the most severe mental health problems (Trieman & Leff 1996). However, there has been continuing debate regarding the most cost-effective care setting for this group, especially as relatively little is spent by governments on mental health care.

Although the World Health Organization (WHO; 2001; 2005) and experts in the field (Prince et al. 2007) have called for countries to increase the deinstitutionalisation of mental health care and its funding, there exists a substantial gap in the literature regarding investigations into the relationships between mental health service provision, expenditure, the quality of care and service user outcomes at the country level. The majority of studies conducted in the area have focused on comparisons of hospital and community-based care. In light of the limited evidence, the aim of my research was to investigate the associations between national mental health expenditure and deinstitutionalisation on (1) the quality of care (as assessed by the Quality Indicator for

Rehabilitative Care, QuIRC) provided in longer term mental health facilities and (2) service user ratings of care (autonomy, life satisfaction, experience of care and therapeutic milieu) in European countries at different stages in the development of community-based mental health care.

Based on the existing evidence, I hypothesised that mental health expenditure would be (hypothesis 1) positively associated with quality of care but (hypothesis 3) negatively associated with service user ratings of care, and deinstitutionalisation would be (hypothesis 2) positively associated with quality of care and (hypothesis 4) positively associated with service user ratings of care.

## ***8.1 Interpretation of findings***

### **8.1.1 Associations with mental health expenditure**

Mental health expenditure, assessed as the percentage of the health budget spent on mental health and the per capita mental health expenditure from the health budget, was positively associated with six of the seven QuIRC domains (human rights, living environment, recovery-based practice, self-management and autonomy, therapeutic environment and treatments and interventions). Increased expenditure was also associated with more positive service user ratings of autonomy and experience of care. These findings are in line with other research and WHO recommendations on national financing of mental health care (2001, 2005).

In the UK, Knapp and colleagues (1999) found longer term psychiatric and social care facilities with low levels of expenditure were more likely to provide a lower quality of care (defined as the level of autonomy given service users, the availability and quality of facility amenities and opportunities for service users to improve their daily living skills) than facilities with higher budgets. Budget restrictions may act as a barrier to a

facility's ability to provide and maintain a clean and comfortable living environment. Limited budgets may also impact on the number and quality of staff facilities are able to employ. More unqualified staff may be employed, reducing the quality of care as staff take on a more custodial role with little provision of evidence-based treatments and interventions. Even if services were able to maintain a balance of qualified and unqualified staff, research suggests a lower staff to service user ratio in hospital settings contributes to dehumanising behaviours (Acker 2010), jeopardising service user empowerment and engagement in care.

National expenditure on mental health was not associated with the social interface QuIRC domain score or service user ratings of life satisfaction and therapeutic milieu. The social interface domain was the only QuIRC domain not significantly associated with national mental health expenditure. The domain includes questions related to service user participation in activities within the facility and the wider community, staff encouragement and support of service users to engage in activities and the strength of social networks. Therefore, social interface domain scores may not be directly associated with increased mental health expenditure as service user involvement in activities and integration within the community may be more strongly related to a number of factors such as service user preferences and functioning, type of facility and national culture.

Hospital-based facilities had the highest social interface scores in both the expenditure and deinstitutionalisation models. This finding seems counter intuitive given one of the arguments for deinstitutionalisation was increased social integration. However, there are several possible reasons for this association. Questions associated with the social interface domain may be more accurately answered by managers of hospital-based

facilities. Social interface includes participation in activities both within and outside the facility. While staff may know what service users do and who visits them while in the facility, the heightened restrictions often placed on service users in hospital may make it easier for staff to monitor their activities outside the facility. As a result, hospital-based staff may more accurately answer social interface related questions and score higher than community-based facilities.

The involvement of family members in a service user's care is an integral component of the social interface domain. One study found very poor provision of family interventions in community mental health teams in London (Krupnik et al. 2005). Limited availability of family interventions may have a negative impact on social interface domain scores. There was also evidence that service users may have reduced interaction between family members and staff (80% of service users reported contact with their family members while community mental health team staff reported 20% of their service users had contact with their families; Krupnik et al. 2005). Extrapolating from this, it is possible that service users receiving care in community-based facilities may be better able to keep their relationships private due to the greater freedoms afforded to them and less enquiry from staff about where they go when out of the facility.

Country-level and service-user-level characteristics may also impact on the encouragement, opportunities and success of social interface. A country's cultural emphasis on familial bonds may have an effect on social interface domain scores. Increased involvement of families may result in higher availability of family interventions and stronger social networks. In this research, Spanish facilities reported the highest levels of social interface followed by the UK, Portugal and Italy. With the

exception of the UK, these countries have historically strong familial ties (Alesina & Giuliano 2010). Stronger family ties may lead to staff expectation that family members participate in the service user's care by taking part in interventions themselves, attending care planning meetings and supporting activities within the community. Although the UK is culturally less family orientated than Spain, Portugal and Italy, recent policy and guidance strongly supports family and carer involvement in service users' care (Department of Health 2011). In addition, in the UK there is an ongoing programme, Time to Change, which aims to reduce community-level stigma and improve community integration (Royal College of Psychiatrists 1998). Therefore cultural conceptions of the role of families in mental health care and programmes aimed at reducing stigma, variables not included in my analyses, may have influenced this domain score.

Researchers have found high levels of self-stigma among individuals in receipt of mental health care, which may impair their desire or confidence in developing relationships. Data from people with schizophrenia in 27 countries around the world found 72% concealed their diagnosis (Thornicroft et al. 2009). Two-thirds of respondents anticipated, but did not experience, discrimination while looking for employment or developing a personal relationship. The authors concluded that increased support of service users to participate in the community and develop close personal relationships may not be effective if levels of self-stigma are not addressed.

Service user ratings of life satisfaction were very similar across all countries with only a 0.5 point difference between the scores of the highest and lowest scoring countries. National expenditure was not associated with service user ratings of life satisfaction. These findings corroborate those of the European Psychiatric Services – Inputs Linked

to Outcome Domains and Needs (EPSILON) study which found no association between the cost of psychiatric care and service user life satisfaction in five European countries (Knapp et al. 2002).

Expenditure was not associated with service user ratings of therapeutic milieu. However, community-based, rather than hospital-based, facilities were significantly associated with higher ratings. Service users in community-based facilities had significantly higher therapeutic milieu scores than service users in hospital. Therefore, the amount of money available for care may be less important than the place where the service user is located. There exists substantial evidence that service users prefer to live in the community (Trieman & Leff 1996). Community facilities are often less regimented and more facilitative of service user autonomy than hospital-based facilities (Kruzich & Kurzich 1985; Cullen et al. 1997; Trauer et al. 2001; Fakhoury et al. 2002; Rickard et al. 2002; Fakhoury et al. 2005). As a result, service users may feel they have more control over their lives and are better able to lead a normal life, leading to more positive ratings of their care.

As increased expenditure was found to be largely associated with the quality of longer term mental health facilities, hypothesis 1 was partially supported. The findings do not support hypothesis 3 since the relationships between expenditure and service user ratings of autonomy and experience of care were positive.

**8.1.2 Associations with deinstitutionalisation of mental health services**  
National progress towards deinstitutionalisation, as measured by the deinstitutionalisation tool presented in Chapter 5, was positively associated with six of the seven QuIRC domains (human rights, living environment, recovery-based practice, self-management and autonomy, therapeutic environment and treatments and

interventions). In countries with greater deinstitutionalisation of mental health care, the increased variety of care settings (e.g. hospital, supported housing, group homes and independent tenancies) may make it easier to place service users in a setting most appropriate for their level of need, which is likely to lead to improved living environment and greater service user autonomy (Chapter 2). Recovery-based practice has been adopted in more economically developed and deinstitutionalised countries such as the UK, USA and Australia. It follows that less economically developed European countries may have less of a focus on the more community-orientated aspects of recovery. Increased deinstitutionalisation may also improve the availability of treatments and interventions in longer term mental health facilities as care is focused on preparing service users for more independent living.

Deinstitutionalisation was not associated with the QuIRC social interface domain. Like mental health expenditure, hospital-based facilities were significantly associated with higher social interface domain scores. Presence of a maximum length of stay was also found to be significantly associated with higher social interface domain scores. The presence of a maximum length of stay may be indicative of a facility which anticipates service users' transition to independent living. If it is expected that service users move on after a set period of time, staff may have increased incentive to encourage and support service users to become more involved in the community. Strong relationships with family and friends may help to facilitate this. Supporting mental health service users to interact confidently with their community is associated with the recovery model (Anthony 1993) which aims to help service users live a life they deem complete, despite the possible continued presence of symptoms associated with their disorder.



The degree to which mental health services were deinstitutionalised was positively associated with service user ratings of autonomy and experience of care. As previously discussed, provision of deinstitutionalised care allows for service users to receive care in the most appropriate setting possible. This form of service provision supports the greatest degree of autonomy for service users based on their support needs. In countries where deinstitutionalisation is more advanced, such as the UK, psychiatric reform has expanded to include greater service user engagement in treatment decisions and a focus on improving community integration (Royal College of Psychiatrists 1998; Department of Health 2009). As a result, staff in all settings, including longer term facilities, may be more likely to promote service user autonomy (as seen in the significant association between increased deinstitutionalisation and increased autonomy and self-management QuIRC domain score). Greater deinstitutionalisation of care and well developed community mental health services tend to be found in countries that, due to their economic strength, have been able to progress from a concept of deinstitutionalisation to service user led and recovery-based practice. Less deinstitutionalised countries probably still harbour more of the dependence on 'looking after' or 'guarding' cultures of asylums.

Deinstitutionalisation was not associated with service user ratings of life satisfaction or therapeutic milieu. As life satisfaction ratings varied little across countries, a significant association was not found. Although number of years since the introduction of mental health policies was positively associated with ratings of life satisfaction, the small coefficient (0.02) indicated this was of little clinical impact. Service users in countries with longer histories of mental health policy had significantly higher life satisfaction. However, this relationship was also not clinically important.

The results of my analysis provide partial support for hypothesis 2 as deinstitutionalisation was associated with six of the seven QuIRC domains. Hypothesis 4 was also only partially supported as service user ratings of life satisfaction and therapeutic milieu were not significantly associated with deinstitutionalisation scores.

## ***8.2 Strengths and limitations***

This work is the first to investigate the relationships between national characteristics of mental health care, expenditure and deinstitutionalisation, and the quality and service user ratings of longer term psychiatric and social care facilities. The data used in this thesis are likely to represent the most comprehensive information on quality of longer term mental health care facilities currently available internationally. The results provide evidence of the positive associations between increased expenditure and deinstitutionalisation and (1) quality of care and (2) service user ratings of care. In addition, national (stigma and length of time elapsed since the introduction of mental health policies) and facility (location of facility, staffing intensity, presence of a maximum length of stay) characteristics were found to have significant associations with quality of care and service user outcomes, corroborating previous evidence. The nine countries included in the analyses were chosen, in part, for their ability to reflect differences in the provision of hospital and community mental health care across Europe. Therefore, the findings of this research are generalisable across Europe.

The variables investigated were measured in a transparent and uniform fashion which, as far as possible, allowed for the most appropriate cross-country comparisons. Calculations of the direct costs of mental health care often include the costs associated with social care, employment and the justice system in addition to health care costs. However, these costs are not always publicly available and differences in their

calculation are difficult to control for. By using the amount of the health budget spent on mental health care to represent national mental health expenditure, I was better able to compare like-with-like costs.

The development and use of a novel, objective tool for the measurement of national progress towards deinstitutionalisation allowed for transparent, international comparisons. The tool was based on a synthesis of mental health legislation and policies from ten European countries and WHO recommendations on the implementation of deinstitutionalisation. Designed for compatibility with publicly available data, the tool was able to circumvent limitations in obtaining national data. All items were agreed upon by an international panel of experts in the field and tested for reliability and internal consistency.

The quality of longer term mental health care was assessed using the QuIRC, a validated and internationally agreed measure of quality of care developed specifically for longer term facilities for service users with severe mental health problems. Service user ratings of care were measured using validated measures of autonomy, life satisfaction, experience of care and therapeutic milieu.

Despite the strengths of this work, there are several limitations which must be considered when interpreting the findings. The nine countries and 192 facilities that participated were recruited as part of the DEMoBinc project. Data from Germany and Spain only included facilities from a single region of the country, Saxony and Andalucía, respectively. This limits the generalisability of my results as they may not be representative of all facilities in these countries. Nevertheless, my results are more likely to be relevant to other European countries since the nine countries were recruited

to be representative of European variations in national wealth and systems of mental health care provision.

The data included in my research was cross-sectional. As a result, models of best fit were able to evaluate associations between variables but could not provide evidence of causal relationships.

Although the QuIRC is a validated tool, its testing could not assess inter-rater reliability between managers from different countries, as they need to be well informed about a facility before they can complete the instrument. Inevitably, therefore, managers' responses will reflect their view of the facility and the care it is able to provide. This may lead to inflated or deflated QuIRC domain scores. This potential limitation is adjusted for when a country's QuIRC domain scores are compared to the mean domain scores of other facilities in the same country. Nevertheless, care must be taken when making international comparisons as differences in national mean domain scores may not represent the true differences.

The relationship between cost, service provision and quality is complex and likely to be affected by a host of variables. This research was constrained to facility and service user variables collected as part of the DEMoBinc project (Chapter 3) and country variables reported in the literature. Although this limited the variables I was able to consider, those included in my models reflect characteristics which have been found to be relevant to quality of care (e.g. location of facility, staffing levels, stigma) and are probably the most comprehensive data available.

A further limitation was the lack of available mental health expenditure data in Greece and the lack of data on the national level of stigma in the Czech Republic. As a result,

data from the Czech Republic were excluded from all analyses and Greek data were excluded from analyses that included mental health expenditure.

Mental health expenditure did not contain all aspects of the costs associated with mental health care. Research into the costs of mental health problems often include the costs of social care, the education system, the criminal justice system, the welfare system and informal care in addition to health care costs (Knapp 1997). Only the amount of the health budget allocated to mental health care was used as a measure of national mental health expenditure and this has been found to be the lowest contributor to the costs of mental health problems (The Sainsbury Centre for Mental Health 2003; McCrone et al. 2008; Centre for Mental Health 2010). As a result, the figure is not a true reflection of national mental health expenditure. Actual expenditure on mental health will likely be much higher than the figures used but the use of mental health expenditure data reported by the majority of countries and calculated in much the same way allows for the most appropriate comparison across the countries of interest.

### ***8.3 Implications of the findings***

The findings of my research add support to calls for governments to increase their mental health budgets and deinstitutionalise care as both were associated with improved quality of care and more positive service user ratings of autonomy and experience of care. However, these actions are not enough to ensure the provision of higher quality longer term psychiatric and social care facilities. Increased mental health funding must be targeted and evidence-based, while greater deinstitutionalisation requires long-term planning based upon service users' needs.

Evidence of the relationship between general health expenditure and service user outcomes supports the supposition that increased mental health spending does not

always result in improved care. For example, the United States spends more on health care than most industrialised countries, while its people have relatively poor health outcomes (Organisation for Economic Co-operation and Development 2012). Spithoven (2009) attributes this finding to the increased costs associated with administration fees and medication, a result of a decentralised health care system, rather than high medical costs. Closer to home, health expenditure was found to be positively correlated with improvement in infant mortality but not life expectancy in 15 European countries (Nixon & Ulmann 2006).

The current international economic slowdown may result in some governments, particularly those where the economy is in recession, scaling back on mental health expenditure and the availability of community mental health services. This could lead to poorer care for service users with the most severe mental health problems as the cost of their care is highest. Disinvestment in longer term mental health services has been shown to be a false economy, resulting in increased need for out of area placements and longer term mental health care provided by the private sector in socially dislocated facilities, which cost more and do not always provide care appropriate to the needs of service users and their families (Killaspy & Meier 2010).

The findings of this research suggest that there is a critical level of investment (10% of the health budget) in mental health care required to provide high quality longer term mental health care. An increase in mental health spending to 10% of the health budget may appear to be a daunting challenge for these countries. However, the amount needed to reach this target is equivalent to less than 1% of gross domestic product (GDP; see Table 8.1). To understand this figure better, one can compare it to the amount of money richer countries were able to top slice from their budgets to introduce more money into

**Table 8.1 Percentage of gross domestic product required to increase mental health expenditure to 10% of the national health budget**

Country	Percentage of health budget spent on mental health in 2005	Total additional expenditure as a % of GDP required to reflect 10% of health budget
Bulgaria	2.5	0.58
Italy	5	0.45
The Netherlands	7	0.27
Poland	3.5	0.40
Portugal	2.3	0.79
Spain	5.9	0.34

their economies and stimulate market growth following the 2008 international economic downturn. The International Monetary Fund (IMF), the organisation which aims to support global economic cooperation, reported that the average amount of money reclaimed from existing budgets to introduce into the economy across G-20<sup>12</sup> countries from 2008 to 2010 was 1.33% of GDP per annum (International Monetary Fund 2009). However, even the average top slice for Indonesia, India and Turkey, which are lower income countries outside the G-20, was 0.53% of GDP. These budgets are greater than the amount needed to improve mental health care in the countries of interest. This suggests that a relatively small investment in mental health care, focused on community mental health services, can be associated with greatly improved quality of care and service user ratings of care. One parallel could be the economic argument made in the UK for investment in the Improving Access to Psychological Therapies (IAPT) project, made on the basis of its projected reduction in welfare costs consequent on reducing unemployment amongst people with common mental disorders (Clark et al. 2009).

<sup>12</sup> The G-20 is a group of finance ministers and central bank governors from the world's 20 largest economies.

History shows that it is not easy to provide appropriate community-based mental health care as this process requires complex planning with a long-term view of service user needs and cost-effectiveness (Knapp et al. 2011). Inadequate provision of appropriate community-based services has been linked to poor accessibility and delivery of treatment (Lamb & Bachrach 2001). The negative impact of inadequate provision of services may be compounded for service users considered difficult to place as this small but vulnerable group is already less likely to receive treatments and interventions to improve their functioning (Hodgins 2009). As a result, they may be more likely to fall victim to the 'revolving door' (recurrent admissions) and less likely to progress in their recovery.

In order to impact, to a clinically significant degree, on quality of care and service user ratings of autonomy and experience of care, projections suggest that deinstitutionalisation would need to be well advanced, equivalent to a score of more than 4.5 (maximum score: 5) on the deinstitutionalisation tool. Greater deinstitutionalisation is reflected in the closing down of mental hospitals, improved availability of mental health care in primary care settings, provision of community residential care, a clearly defined national mental health budget and a sufficient number of mental health professionals to provide local community-based care. Movement toward this goal requires a strong commitment to mental health care from government, mental health professionals and the public.

Countries with established community mental health services can take steps towards greater deinstitutionalisation without increased spending. For example, it is vital that service users receive tailored care based on their needs as many may not require highly supported care. Improvement in initial assessments of need and regular assessment



thereafter will assist in this process. The savings achieved can then be used to improve the availability of treatments and interventions, increase staffing levels and train primary care staff to treat less severe mental health problems.

Parallels in the relationships between mental health expenditure, deinstitutionalisation, quality of care and service user ratings of care are not surprising as expenditure and deinstitutionalisation were highly correlated ( $\alpha = 0.61$ ,  $p \leq 0.001$ ) in this sample. Nevertheless, appropriate expenditure is necessary but not sufficient to ensure the provision of high quality mental health care. Improvement in outcomes will depend on the allocation of national funds to individual facilities and services and their provision of new, evidence-based services and interventions. As mental health expenditure increases, so does the ability to provide appropriate care in the community as suggested by the balanced care model recommended by the WHO (Thornicroft & Tansella 2003). In countries where deinstitutionalisation has been implemented for several years, as the level of deinstitutionalisation increases, care in the community should be extended to include service users with more severe mental health problems. The change in characteristics of service users in receipt of community-based care is associated with increased costs of community care as evidenced in the TAPS study (Knapp et al. 1990). However, this should not put politicians or service providers off as the cost of community care for the most difficult to place service users has still been found to be less than the cost of equivalent care in hospital (Lamb & Bachrach 2001). The Royal College of Psychiatrists in the UK has published guidance on the service components required to support people with complex mental health problems through their recovery over a number of years (Wolfson et al. 2009). These include inpatient and community-based facilities as well as a range of supported accommodation (from psychiatric units in hospital to independent tenancies) with community teams providing tailored input.

Although increased expenditure and deinstitutionalisation were associated with greater quality of care and more positive service user ratings of care, countries which spent less on mental health care and had less deinstitutionalised care still scored highly on some domains. Therefore, countries deemed ‘more advanced’ may have lessons to learn from countries with fewer financial resources and less deinstitutionalised services as we work toward international provision of high quality mental health care and improved service user outcomes. Portugal, the country with the lowest level of mental health expenditure but above average deinstitutionalisation, had the highest social interface domain score while the Netherlands and Germany, two countries with high levels of mental health expenditure and deinstitutionalisation, had two of the lowest scores for this domain. Spain, which spent around the European Union average on mental health, had low levels of deinstitutionalisation but relatively high scores in five QuIRC domains (human rights, recovery-based practice, social interface, therapeutic environment, treatments and interventions). However, service user ratings of care in the country were less positive. Greece scored highly on the QuIRC domains recovery-based practice and self-management and autonomy, as well as service user ratings of life satisfaction, autonomy and therapeutic milieu, despite its relatively low level of deinstitutionalisation. These anomalies may be a reflection of cultural differences among the countries included in this research. As previously discussed, countries with stronger familial ties, including Portugal and Spain, had higher social interface domain scores. This may be associated with increased expectations of family involvement in care by families and staff. Higher QuIRC domain ratings and service user ratings of care may also be a result of improved care standards implemented following national attention to abuses in the Greek mental health care system in the late 1980s (Karastergiou et al. 2005). More positive service user ratings of care in Greece may also reflect higher life satisfaction and autonomy

scores in the general population (at least prior to the recent economic crisis). These anomalies suggest the potential importance of a host of additional factors in the success of mental health care.

In models of best fit, stigma, facility type, staffing intensity and presence of a maximum length of stay were also significantly associated with QuIRC domain scores and service user ratings of care. The stigma associated with mental health problems has a significant impact on the funding, availability and success of mental health care. Research in this area has found that although improved knowledge about schizophrenia and its treatment is associated with general tolerance of individuals with schizophrenia, it did not extend to openness to forming close relationships with them (Thompson et al. 2002). Reluctance to form relationships with individuals with schizophrenia may be a result of the symptoms associated with the disorder (e.g. delusions, hallucinations, apathy and impaired cognition) which make it difficult to interact with individuals with the disorder and decrease the chances of forming close relationships. Many countries also find it difficult to challenge stigmatising attitudes due to biased media portrayals of individuals with schizophrenia as dangerous and unpredictable (Ferriman 2000). Sartorius (2007) suggests that the stigma results in individuals with mental health problems being perceived as unimportant by society which acts as a barrier to the adequate funding of mental health care. The results of my analyses partially corroborate these findings. Although I cannot be certain of the direction of the relationship, increased national levels of stigma were associated with decreased treatments and interventions and therapeutic environment QuIRC domain scores, possibly reflecting societal disregard for service users' care. However, greater levels of stigma were also associated with higher living environment and self-management and autonomy QuIRC domain scores. These conflicting findings are difficult to interpret but may suggest

investment in building to contain individuals rather than treatments and therapies to help them recover.

Facility location was strongly associated with QuIRC domain scores and service user ratings of care. Community-based facilities were associated with increased living environment and self-management and autonomy QuIRC domain scores as well as service user ratings of autonomy, experience of care and therapeutic milieu, corroborating previous findings that care in the community is better able to provide less institutionalised care with greater flexibility and increased opportunities for service user involvement in the recovery process (Chapter 2). In addition to a significant association with social interface, hospital facilities were associated with greater therapeutic environment QuIRC domain scores. As service users in hospital are more likely to have poorer levels of functioning than those in community-based facilities, staff may spend more time helping them gain mastery of activities of daily living, interacting with family members and provide family interventions, providing more activities within the facility, creating care plans and holding care planning meetings, all of which are assessed in the QuIRC as part of the therapeutic environment domain. Although therapeutic environment scores were higher in hospital facilities, service users in the community recorded higher scores on therapeutic milieu. Therapeutic milieu was assessed using five questions which tapped into the service user's general satisfaction with the facility, staff and other service users, and to what degree their activities increase their self-confidence and provide them with the chance to see "how good [their] abilities really are" (Røssberg & Friis 2003, p. 120). This fits with reports that service users in the community have greater satisfaction than service users in hospital (Cullen et al. 1997; Fakhoury et al. 2002; Fakhoury et al. 2005).

A greater staff to service user ratio was significantly associated with higher therapeutic environment and treatments and interventions domain scores. Trieman and Leff (1996) found service users with the severest mental health problems had positive outcomes when they moved to community settings with high staff intensity (1:1 or higher). A higher staff to service user ratio allows staff members to spend more time delivering treatments and interventions, and supporting service users in improving their activities of daily living (Falloon et al. 1998). A greater staff to service user ratio may also protect against staff burnout (Acker 2010), increasing the potential for staff to forge strong, positive relationships with service users. However, a higher ratio was also associated with decreased living environment domain scores. This may be a reflection of more money invested in treatments and staffing levels as opposed to buildings.

Presence of a maximum length of stay was associated with increased recovery-based practice, treatments and interventions and social interface QuIRC domain scores. Presence of a maximum length of stay is in line with the recovery model (Anthony 1993) as the expectation that service users will move on to less supported care keeps staff motivated to prepare service users for independent living. As a result, service users may be encouraged to increase their involvement within the community and strengthen their personal relationships. Additionally, provision of treatments and interventions and client-centred care focusing on move-on may also increase. Although presence of a maximum length of stay helps to ensure service users are cared for in the most appropriate setting, we must also ensure staff are not under pressure to move service users on prematurely as this may precipitate relapse.

Despite the findings that expenditure and deinstitutionalisation are positively associated with higher quality mental health care, there still exists a need for continual assessment

of quality. Recent scandals of inhumane treatment in mental health facilities, such as the European Court of Human Rights ruling against Bulgaria in its treatment of individuals with intellectual disabilities (European Court of Human Rights 2012) and abuses of mental health service users at Winterbourne View Hospital in the UK (Department of Health 2012), prove that, in both middle and high income countries, appropriate standards and inspections must be put in place to ensure that the quality of care provided is high and that the dignity and human rights of service users are upheld.

Many developed countries have accreditation and service monitoring systems to ensure psychiatric and social care facilities continue to provide a high quality of care. Until recently, no measure of quality specifically for longer term mental health care facilities existed. The QuIRC has been shown to provide an accurate and reliable measure of quality of care in longer term mental health care facilities and has been adopted as part of the UK's accreditation process. Future plans for its incorporation into Portuguese quality assessment processes and local and national audits in the Czech Republic and the Netherlands are being discussed. Longer term facilities in 15 countries in Europe, the Americas and Australia have used the tool to compare their QuIRC domain scores to other, similar facilities within the country on a regular basis.

#### ***8.4 Recommendations for future work***

A number of aspects of my research lend themselves to further development. As highlighted in the previous section, this study only investigated associations between variables. By collecting longitudinal data on service user outcomes from a random selection of longer term mental health facilities in different European countries, a deeper understanding of the potential causal relationships between mental health investment, deinstitutionalisation, quality of care and clinical impact may be reached. A

wider variety of variables, for example, the strength of familial ties, general population ratings of autonomy and life satisfaction, national expenditure on longer term mental health care facilities, costs of social care, education and criminal justice system associated with severe and enduring mental health problems, and levels of staff burnout, should also be collected in order to build more robust models in which the direct effects of expenditure and deinstitutionalisation can be better understood.

My research suggests that there is a relationship between expenditure and quality of longer term mental health care. Similarly, my findings suggest a relationship between the degree to which mental health care is provided in the community and quality of care. Potential mechanisms through which national expenditure impacts on quality in individual facilities and service user ratings have been posited based on my findings and those of previous research. However, additional work is needed to evaluate these hypotheses.

My research has focused on upper middle and high income countries (World Bank 2009). Recent scandals in the provision of mental health services in these countries has highlighted the importance of continued research and inspections of mental health care in countries with more advanced mental health investment and deinstitutionalisation. Additionally, as many developing countries are beginning to increase the availability of mental health care, research is needed to evaluate the impact of financial investment and the provision of mental health care on the quality of care provided and service user outcomes in these countries. Research may include an evaluation of the appropriateness of the QuIRC for mental health facilities in developing countries and investigation into governmental and non-governmental organisation expenditure on mental health care.

The findings of this work could be used to develop interventions to improve the quality of specific domains of care based on the practices and experience of countries with the highest scores in that domain. For example, Spain could draw upon the example of care provided in Germany to improve the living environment of its longer term mental health facilities. Conversely, Germany could develop an intervention to improve its social interface domain score based on the Spanish experience.

Large international studies are likely to be expensive. In order to accelerate the rate of progress in this area it may be beneficial to develop research networks where collaborations could be more easily formed and data shared. Furthermore, the use of a standardised set of variables, including expenditure data (incorporating social care, education and criminal justice costs associated with mental health problems), QuIRC domain scores and service user outcomes, in research into the longer term care of individuals with severe mental health problems may allow for meta-analyses of international data, adding considerable strength to findings. The WHO could also collect relevant country-level data on deinstitutionalisation and mental health expenditure for subsequent editions of the Mental Health Atlas.



## Chapter 9

### **Conclusions**

Despite the deinstitutionalisation of mental health care in many European countries, a small proportion of individuals with severe mental health problems still require longer term care in psychiatric and social care facilities. Care for this group is costly, due to the high degree of support they require, and represents a substantial amount of the national mental health budgets across countries. Recently the World Health Organization (WHO) has begun to lobby actively for countries to increase their mental health budgets and continue to deinstitutionalise care in light of research focused on individual facilities and studies evaluating the closure of mental hospitals which suggest an association between increased investment in community services and positive outcomes. However, there is a substantial gap in our knowledge of this area as no research has measured the impact of national financial investment and deinstitutionalisation on the quality of mental health care.

The lack of an internationally applicable measure of quality of care has meant that international projects assessing the impact of country, facility and service user variables are largely non-existent. The recent development of the Quality Indicator for Rehabilitative Care (QuIRC), an internationally agreed and validated measure of the quality of longer term psychiatric and social care facilities, has made cross-country comparisons of quality of care possible. This thesis also describes the development and testing of a novel, objective tool to assess national deinstitutionalisation of mental health care. These assessment tools have made it possible to examine national levels of mental health expenditure and deinstitutionalisation in relation to the quality of longer

term mental health care and service user ratings of care in a pan-European context for the first time.

My results showed that increased national mental health expenditure was associated with higher quality on 1) the QuIRC domains of human rights, living environment, recovery-based practice, self-management and autonomy, therapeutic environment and treatments and interventions and 2) service user ratings of autonomy and experience of care. Increased deinstitutionalisation of mental health care was also associated with higher quality on 1) the QuIRC domains of human rights, living environment, recovery-based practice, self-management and autonomy, therapeutic environment and treatments and interventions and 2) service user ratings of autonomy and experience of care.

An increase in mental health expenditure to 10% of the health budget would potentially lead to clinically significant improvement in every quality of care domain, except social interface and service user ratings of autonomy, experience of care and life satisfaction. Although increasing mental health expenditure to 10% of the mental health budget accounts for less than 1% of gross domestic product, it is unlikely that this knowledge would be enough to initiate change. Clinically significant improvements in quality of care and service user ratings of autonomy and experience of care require a high level of deinstitutionalisation (deinstitutionalisation score of 4.67 out of 5). However, increasing mental health expenditure and deinstitutionalisation levels is not easily achieved. Accomplishing these goals requires the public to believe that this is an urgent problem, politicians to reallocate funds and health care providers to use the increased budget to better meet service users' needs.

Several countries with low levels of expenditure and deinstitutionalisation were found to have the highest scores for some domains and service user outcomes. Portugal had the highest mean social interface domain score despite having the lowest level of mental health expenditure and average deinstitutionalisation. Greece, a country with a low level of deinstitutionalisation, scored highly in the recovery-based practice and self-management and autonomy domain scores as well as service user ratings of life satisfaction, autonomy and therapeutic milieu. These findings may be related to cultural expectations of family involvement in care in Portugal and higher general population ratings of autonomy and life satisfaction in Greece. However, these findings highlight that countries with high levels of expenditure and deinstitutionalisation can learn from the experiences of less deinstitutionalised countries to improve their own provision of care.

This is the first investigation of the relationships between mental health expenditure and deinstitutionalisation and (1) the quality of care and (2) service user ratings of care in longer term mental health psychiatric and social care facilities. The data used possibly represent the most comprehensive on longer term mental health facilities available. However, the strength of my findings is tempered by methodological limitations. The cross-sectional nature of the data collected means no inferences to causal relationships can be made. The small sample included in the analyses limit the generalisability of the findings, although the countries included were chosen to represent the variety in national wealth and mental health service provision seen across Europe. Future research should aim to address these limitations. Improved reporting of national mental health characteristics will also assist researchers in making international comparisons. Research focused on understanding the mechanism through which increased national

expenditure relates to improved quality of longer term care is also needed to ensure effective use of funds.

Although more work is needed to further understand the impact of mental health expenditure and deinstitutionalisation on quality of care and service user outcomes, my findings suggest significant positive associations between these variables. This thesis provides evidence in support of the WHO's recommendation for increased national mental health expenditure and adds weight to existing evidence which suggests that service users with severe and enduring mental health problems can be successfully cared for in the community.

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## Appendix A

### Characteristics and Quality of Included Studies

<b>Characteristics and quality of studies included in living conditions domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Baker & Douglas 1990 (USA)	Mostly schizophrenia	729	Cohort study (supported and unsupported community housing)	10/14
Brunt & Hansson 2002 (Sweden)	Severe mental illness	33 patients 50 staff	Cross-sectional study (small group homes)	8/14
Corrigan 1990 (USA)	Severe mental illness	Not applicable	Descriptive review (hospital unit and outpatient facilities)	6/14
Cournos 1987 (USA)	Chronic mental illness	Not specified	Descriptive review (community residential facilities)	6/14
Cullen et al. 1997 (UK)	Not specified	42	Cross-sectional study (hospital and community residential facilities)	7/14
Dijkstra et al. 2006 (The Netherlands)	Not confined to mental health patients	5412	Systematic review (30 studies) (hospital-based facilities)	12/14
Fakhoury et al. 2002 (UK)	Severe and enduring mental illness	3,577 patients 166 staff	Systematic review (28 studies) (supported housing)	7/14
Fakhoury et al. 2005 (UK)	Schizophrenia or related psychotic disorder	41 patients 39 staff	Cross-sectional study (supported housing)	5/5; 9/14
Hawthorne et al. 1994 (USA)	Severe mental illness	104	Before and after study (community-based residential facilities)	9/14
Johansson & Eklund 2004 (Sweden)	Minority schizophrenia	61	Cross-sectional study (psychiatric inpatient ward)	8/14
Kruzich & Kruzich	Majority	87	Cross-sectional study (residential)	10/14

<b>Characteristics and quality of studies included in living conditions domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
1985 (USA)	schizophrenia		care facilities)	
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Mares et al. 2002 (USA)	Severe mental illness	164	Cross-sectional study (board and care homes)	9/14
Rickard et al. 2002 (Spain and UK)	Functional psychotic illness	136	Cross-sectional study (community residences)	10/14
Santone et al. 2005 (Italy)	Severely impaired patients	265 facilities	Cross-sectional study (residential facility)	9/14
Shrivastava et al. 1999 (UK)	Not specified	Not specified	Descriptive review (psychiatric facility)	6/14
Trauer et al. 2001 (Australia)	Not specified	125	Cohort study (community care facility)	10/14
van Wel et al. 2003 (The Netherlands)	Not specified	129	Cross-sectional study (psychiatric hospital)	8/14
<b>Characteristics and quality of studies included in interventions domain: Cognitive behavioural therapy</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Barrowclough et al. 2006 (UK)	Schizophrenia or schizoaffective disorder	113	RCT (inpatient and outpatient facilities)	12/14
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
National Institute for Clinical Excellence 2002 (UK)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Pfammatter et al. 2006 (Switzerland)	Schizophrenia or psychosis	Not specified	Systematic review & meta-analysis (4 meta-analyses, 17 studies) (facility not specified)	14/14

<b>Characteristics and quality of studies included in living conditions domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Pilling et al. 2002b (UK)	Schizophrenia or related disorder	528	Systematic review & meta-analysis (8 studies) (facility not specified)	14/14
Turkington et al. 2006 (UK)	Schizophrenia	336	RCT (inpatient and outpatient facilities)	12/14
<b>Characteristics and quality of studies included in interventions domain: Family interventions and psychoeducation</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Carrà et al. 2007 (Italy)	Schizophrenia	101 relatives	RCT (facility not specified)	12/14
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
McFarlane et al. 2003 (USA)	Schizophrenia	Not specified	Descriptive review (facility not specified)	6/14
Mueser & Bond 2000 (USA)	Schizophrenia	Not specified	Descriptive review (inpatient and outpatient facilities)	6/14
National Institute for Clinical Excellence 2002 (UK)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Pekkala & Merinder 2002 (Finland)	Schizophrenia or related serious mental illness	1125	Systematic review & meta-analysis (10 studies) (inpatient and outpatient facilities)	14/14
Pfammatter et al. 2006 (Switzerland)	Schizophrenia or psychosis	Not specified	Systematic review & meta-analysis (31 studies) (facility not specified)	14/14
Pharoah et al. 2006 (UK)	Schizophrenia or schizophrenia-like conditions	4444	Systematic review & meta-analysis (43 studies) (community facilities)	14/14
Pilling et al. 2002b (UK)	Schizophrenia or related disorder	1128	Systematic review & meta-analysis (18 studies) (facility	14/14

<b>Characteristics and quality of studies included in living conditions domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
			not specified)	
Pitschel-Walz et al. 2006 (Germany)	Schizophrenia or schizoaffective disorder	236 patients 125 relatives	RCT (hospital wards)	12/14
Rabovsky & Stoppe 2006 (Germany)	Schizophrenia	Not applicable	Discussion paper (inpatient facility)	7/14
Rummel-Kluge et al. 2006 (Germany, Austria, Switzerland)	Any, but focuses on patients with schizophrenia	337 facilities	Cross-sectional study (psychiatric institutions)	10/14
<b>Characteristics and quality of studies included in interventions domain: Vocational therapy</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Bond et al. 1997 (USA)	Severe mental illness	2191	Systematic review (17 studies) (facility not specified)	12/14
Bond et al. 2001 (USA)	Severe mental illness	Not applicable	Descriptive review (facility not specified)	6/14
Crowther et al. 2001 (USA)	Schizophrenia and schizophrenia-like disorders, bipolar disorder, depression with psychotic features	2539	Systematic review & meta-analysis (18 studies) (inpatient and outpatient facilities)	14/14
Drake et al. 2003 (USA)	Not specified	499	Cohort study (facility not specified)	9/14
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Mueser & Bond 2000 (USA)	Schizophrenia	Not specified	Descriptive review (inpatient and outpatient facilities)	6/14
National Institute for Clinical Excellence	Schizophrenia	Not applicable	Clinical guidance (inpatient and	Not applicable

<b>Characteristics and quality of studies included in living conditions domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
2002 (UK)			outpatient facilities)	
Twamley et al. 2003 (USA)	Schizophrenia and other disorders	1617	Systematic review & meta-analysis (11 studies) (facility not specified)	13/14
<b>Characteristics and quality of studies included in interventions domain: Social skills training</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Bustillo et al. 2001 (USA)	Schizophrenia, severe mental illness	962	Systematic review (5 studies) (facility not specified)	12/14
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
National Institute for Clinical Excellence 2002 (UK)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Pfammatter et al. 2006 (Switzerland)	Schizophrenia or psychosis	Not specified	Systematic review & meta-analysis (19 studies) (facility not specified)	14/14
Pilling et al. 2002a (UK)	Schizophrenia or related disorder	417	Systematic review & meta-analysis (9 studies) (facility not specified)	14/14
Roder et al. 2001 (Switzerland, Austria, and Germany)	Schizophrenia	73	Case-control study (psychiatric institution)	8/14
Roder et al. 2002 (Switzerland, Austria, and Germany)	Schizophrenia	105	Case-control study (psychiatric institution)	10/14



<b>Characteristics and quality of studies included in interventions domain: Cognitive remediation</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Pfammatter et al. 2006 (Switzerland)	Schizophrenia or psychosis	Not specified	Systematic review & meta-analysis (6 meta-analyses, 19 studies) (facility not specified)	14/14
Pilling et al. 2002a (UK)	Schizophrenia or related disorder	203	Systematic review & meta-analysis (5 studies) (facility not specified)	14/14
Wykes et al. 2007 (UK)	Schizophrenia	85	RCT (facility not specified)	11/14
<b>Characteristics and quality of studies included in interventions domain: Arts therapies</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Gold et al. 2005 (Norway)	Schizophrenia or related psychoses	266	Systematic review & meta-analysis (4 studies) (inpatient facilities)	14/14
Ruddy & Milnes 2005 (UK)	Schizophrenia	137	Systematic review & meta-analysis (2 studies) (facility not specified)	14/14
Ruddy & Dent-Brown 2007 (UK)	Schizophrenia	210	Systematic review & meta-analysis (5 studies) (inpatient facilities)	14/14
<b>Characteristics and quality of studies included in interventions domain: Integrated therapy</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Lenroot et al. 2003 (USA)	Schizophrenia	Not applicable	Descriptive review (facility not specified)	5/14
Mueser et al. 2006 (USA)	Schizophrenia or major mood disorder	32	Cohort study (non-residential community facilities)	10/14
Roder et al. 2006 (Switzerland)	Schizophrenia	1393	Systematic review (30 studies) (psychiatric institutions)	14/14

<b>Characteristics and quality of studies included in interventions domain: Treatment of co-morbid substance misuse</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Drake et al. 2004 (USA)	Severe mental illness and co-occurring substance use disorder	4,313 residents 1,982 outpatients	Descriptive review (outpatient and inpatient facilities)	7/14
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Ziedonis et al. 2005 (USA)	Schizophrenia and substance abuse disorder	Not applicable	Clinical guidance (facility not specified)	Not applicable
<b>Characteristics and quality of studies included in interventions domain: Medication management</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
National Institute for Clinical Excellence 2002 (UK)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
<b>Characteristics and quality of studies included in interventions domain: Compliance therapy</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Eckman et al. 1990 (USA)	Schizophrenia	160 patients unknown number of staff	Case-control study (inpatient, outpatient and community residential facilities)	10/14
Eckman et al. 1992 (USA)	Schizophrenia	41	RCT (inpatient and outpatient facilities)	11/14
Kemp et al. 1998 (UK)	Majority schizophrenia	74	RCT (inpatient facility)	10/14
Kuipers et al. 1994 (USA)	Chronically mental illness	60	RCT (hospital facility)	10/14
McIntosh et al. 2006 (UK)	Schizophrenia or related severe mental disorders	56	Systematic review & meta-analysis (1 study) (facility not specified)	12/14

Seltzer et al. 1980 (Canada)	Majority schizophrenia	67	RCT (psychiatric institute)	9/14
Streicker et al. 1986 (USA)	Majority schizophrenia	75	Case-control study (psychosocial rehabilitation agency)	9/14
<b>Characteristics and quality of studies included in interventions domain: Occupational therapy</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Buchain et al. 2003 (Brazil)	Schizophrenia (treatment resistant)	26	RCT (facility not specified)	9/14
Oka et al. 2004 (Japan)	Schizophrenia	52	Before and after study (inpatient and outpatient facilities)	9/14
<b>Characteristics and quality of studies included in interventions domain: Supportive therapy</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Buckley et al. 2007 (UK)	Schizophrenia	1762	Systematic review & meta-analysis (21 studies) (inpatient and outpatient facilities)	13/14
<b>Characteristics and quality of studies included in interventions domain: Coping skills training</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Leclerc et al. 2000 (Canada)	Schizophrenia	99	RCT (inpatient wards and outpatient clinics)	12/14
Lecomte et al. 1999 (Canada)	Schizophrenia	95	RCT (long-stay wards, short-stay wards, outpatient clinic)	11/14

<b>Characteristics and quality of studies included in physical health domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Anath et al. 1992 (USA)	Mostly schizophrenia	75	Cross-sectional study (inpatient facility)	7/14
Bazemore et al. 2005 (USA)	Not specified	102 hospitals	Cross-sectional study (hospital facility)	10/14
Kilian et al. 2006 (Germany)	Schizophrenia, bipolar disorder, major depressive disorder, neurotic disorder, somatoform disorder	363	Cross-sectional study (inpatient facility)	9/14
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Mitchell & Malone 2006 (UK)	Schizophrenia	Not specified	Descriptive Review (facility not specified)	6/14
National Institute for Clinical Excellence 2002 (UK)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Osborn et al. 2003 (UK)	Schizophrenia, schizoaffective disorder or other non-affective chronic psychotic illness	495	Cross-sectional study (general practices)	9/14
Osborn et al 2006 (UK)	Schizophrenia, schizoaffective disorder or other non-affective chronic psychotic illness	222	Cross-sectional study (general practices)	10/14
Tang et al. 2004 (China)	Majority schizophrenia	98	Cross-sectional study (psychiatric rehabilitation facility)	8/14

<b>Characteristics and quality of studies included in restraint and seclusion domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Addington et al. 2005 (Canada)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Bower et al. 2000 (USA)	Not specified	Not specified	Systematic review (223 studies) (inpatient psychiatric facilities)	7/14
Donat 2002 (USA)	Severe mental illness	53	Case-control study (psychiatric hospital)	6/14
Donat 2003 (USA)	Severe mental illness	53	Case-control study (psychiatric hospital)	7/14
Fisher 1994 (USA)	Not specified	Not applicable	Descriptive review (inpatient facilities)	6/14
Gaskin et al. 2007 (Australia)	Not specified	Not specified	Systematic review (16 studies) (psychiatric facilities)	11/14
Janssen et al. 2007 (The Netherlands)	Not specified	Not specified	Cross-sectional study (admission and long-stay psychiatric wards)	10/14
Khadivi et al. 2004 (USA)	Not specified	Not specified	Cross-sectional study (psychiatric inpatient facility)	6/14
Kostecka & Zardecka 1999 (Poland)	Not specified	866	Cross-sectional study (psychiatric hospital wards)	10/14
Lehman et al. 2004 (USA)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
McCue et al. 2004 (USA)	Not specified	10,753	Cohort study (inpatient facility)	12/14
McGorry et al. 2005 (New Zealand and Australia)	Schizophrenia and related disorders	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Muralidharan & Fenton 2006 (USA)	Not specified	0	Systematic review (0 studies) (inpatient facility)	12/14

<b>Characteristics and quality of studies included in restraint and seclusion domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
National Institute for Clinical Excellence 2002 (UK)	Schizophrenia	Not applicable	Clinical guidance (inpatient and outpatient facilities)	Not applicable
Nelstrop et al. 2006 (UK)	Not specified	Not applicable	Systematic review (36 studies) (inpatient facilities)	12/14
Palazzolo et al. 2001 (France)	Not specified	Not specified	Descriptive review (psychiatric hospitals)	6/14
Wynn 2002 (Norway)	Not specified	235	Cross-sectional study (psychiatric hospital)	9/14
Wynn 2004 (Norway)	Majority schizophrenia	12	Qualitative study (hospital wards)	3/5
<b>Characteristics and quality of studies included in therapeutic relationship domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Allen et al 1985 (USA)	Chronic and severe psychiatric disturbances	37	Cross-sectional study (long-term hospital unit)	9/14
erger 2006 (Canada)	Not specified	46 patients 17 staff	Cross-sectional study (inpatient and outpatient facilities)	5/14
Catty 2004 (UK)	Not specified	Not specified	Descriptive review (facility not specified)	6/14
Clarkin et al. 1987 (USA)	Schizophrenia, personality disorder, affective disorder, acute illness	96	Cross-sectional study (inpatient facility)	7/14
Fakhoury et al. 2005 (UK)	Schizophrenia or related psychotic disorder	41 patients 39 staff	Cross-sectional study (supported housing)	5/5; 9/14
Gehrs & Goering 1994 (Canada)	Schizophrenia or	22 client-therapist dyads	Case-control study (continuing)	9/14

<b>Characteristics and quality of studies included in restraint and seclusion domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
	schizoaffective disorder		care)	
Gigantesco et al. 2002 (Italy)	Not specified	855 patients 265 relatives	Cross-sectional study (inpatient and outpatient facilities)	9/14
Hellzén 2004 (Sweden)	Long-term mental illness	32	Focus group (psychiatric group dwellings)	4/5
Howgego et al. 2003 (USA)	Not specified	533 patients 131 case managers/therapists	Systematic review & meta-analysis (2 meta-analyses & 7 studies) (inpatient and outpatient facilities)	12/14
Johansson & Eklund 2004 (Sweden)	Minority schizophrenia	61	Cross-sectional study (psychiatric inpatient ward)	8/14
McCabe et al. 1999 (UK)	Schizophrenia	258	Cohort study (psychiatric hospital)	9/14
McCabe & Priebe 2004 (UK)	Severe mental illness	2055	Descriptive review (facility not specified)	7/14
Mueser et al. 2002 (USA)	Serious mental illness	3,079	Descriptive review (inpatient and outpatient facilities)	6/14
Snyder et al. 1995 (USA)	Schizophrenia or schizoaffective disorder	15 care home operators 30 patients	Case-control study (residential care homes)	8/14

<b>Characteristics and quality of studies included in autonomy and service user involvement domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Ahuja & Williams 2005 (UK)	Not specified	Not specified	Descriptive review (facility not specified)	4/14
Lewis 1995 (USA)	Severe mental illness	Not applicable	Descriptive review (nursing home)	5/14
Linhorst & Eckert 2002 (USA)	Mostly schizophrenia	Not specified	Descriptive review (psychiatric hospital)	4/14
Linhorst et al. 2005 (USA)	Severe mental illness	Not applicable	Qualitative study (psychiatric hospital)	2/5
Simpson & House 2002 (UK)	Not specified	3796	Systematic review (13 studies) (facility not specified)	13/14
Timko et al. 1993 (USA)	Schizophrenia or organic brain syndrome	403	RCT (psychiatric hospital and nursing home)	12/14
<b>Characteristics and quality of studies included in staff training and support domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Alexander et al. 2005 (USA)	Severe mental illness	1638	Cross-sectional study (inpatient facilities)	9/14
Bradshaw et al. 2007 (UK)	Not specified	23 mental health nurses	Before and after study (facility not specified)	8/14
Corrigan et al. 2001 (USA)	Severe mental illness	Not specified	Descriptive review (facility not specified)	6/14
Linhorst 1995 (USA)	Severe and persistent mental illness	7 focus group members	Focus group study (long-term inpatient facilities)	8/14; 3/5
Sowers 2005 (USA)	Not specified	Not applicable	Clinical guidance (facility not specified)	Not applicable



<b>Characteristics and quality of studies included in clinical governance domain</b>				
<b>Study (Country)</b>	<b>Type(s) of Mental Illness</b>	<b>Number of Participants</b>	<b>Type of Study (Type of Facility)</b>	<b>Quality Assessment</b>
Cape & Barkham 2002 (UK)	Not specified	Not specified	Systematic review (120 studies) (facility not specified)	5/14
Janssen et al. 2005 (Germany)	Schizophrenia	Not specified	Cohort study (psychiatric hospitals)	12/14

## Appendix B

### B.1. Draft measure of a quantitative tool to assess levels of deinstitutionalisation at a country level

1. The closure of mental hospitals in the country:

- has not happened (no beds in general hospitals)
- is in early transition (more beds in mental hospitals than general hospitals)
- is in late transition (more beds in general hospitals than mental hospitals)
- has been completed (no mental hospitals)

2. Staff in general hospitals are trained in mental health.

- no
- yes

3. Access to mental health treatment in primary care is:

- unavailable
- limited
- widely available in both urban and rural areas

4. Primary care staff are trained in mental health.

- no
- yes

5. Psychotropic medication is available in general hospitals.

- no
- yes

6. Psychotropic medication is available in general practices.

no

yes

7. Please describe the availability of the following types of community mental health services:

	unavailable	limited	widely available in both urban and rural areas
day centres/clubhouses/drop-in centres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
community mental health centres/ outpatient clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
home care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
psychosocial services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
residential care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
rehabilitation (vocational, occupational)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
crisis teams	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
specialised services (e.g. child/adolescent, elderly, refugee)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Continuity of care is maintained across primary, secondary and tertiary care settings.

no

yes

9. Mental health services are overseen by a local or national governing body or organisation.

no

yes

10. Service users, carers and advocates are included in discussions/decisions regarding care.

- never
- sometimes
- always

11. An accreditation process for mental health facilities has been established.

- no
- yes

12. Service monitoring/auditing systems have been established.

- no
- yes

13. Services are provided using clearly defined catchment areas.

- no
- yes

14. Mental health services are provided close to a service user's place of last residence.

- never
- sometimes
- always

15. Financial resources for mental health care are clearly defined within the national budget.

- no
- yes

16. Financial resources are adequate for appropriate and comprehensive care.

- no
- yes

17. Staffing levels are adequate.

no

yes

18. Mental health legislation is in place.

no

yes

19. Mental health policy is in place.

no

yes

20. Mental health is included in general health legislation/policies.

no

yes

21. Mental health legislation/policy is integrated into other related policies/legislation (e.g. social services, education and employment, justice).

no

yes

22. Collaboration with other relevant government organisations (e.g. social services, education and employment, justice) exists.

no

yes

## B.2. Draft deinstitutionalisation tool sent to expert panel for comments

1. Describe the closure of mental hospitals within the country.

- It has not happened (no beds in general hospitals).
- It is in early transition (more beds in mental hospitals than general hospitals and community facilities).
- It is in late transition (more beds in general hospitals and community facilities than mental hospitals).
- It has been completed (no mental hospitals).

2. Number of psychiatric beds per 10,000 inhabitants

based in mental hospitals:

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based in general hospitals and  
community units:

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3. Describe access to mental health treatment in primary care within the country.

- Access is not mentioned.
- There is no access to mental health treatment.
- There is a general statement of availability.
- There is evidence of a clear programme for neurotic disorders.
- There is evidence of a clear programme for neurotic and psychotic disorders.

4. Are primary care staff are trained in mental health?

Not mentioned

No

Yes

5. Are staff in general hospitals trained in mental health?

Not mentioned

No

Yes

6. Is psychotropic medication is available in general practices?

Not mentioned

No

Yes

7. Are mental health services are provided using clearly defined catchment areas?

Not mentioned

No

Yes

8. Please describe the availability of the following types of community mental health services.

	Not mentioned	Unavailable	Limited availability (general statement of availability)	Evidence of availability for neurotic disorders	Evidence of availability for neurotic and psychotic disorders
Day centres/Clubhouses/Drop-in centres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community mental health centres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ambulatory care/Outpatient clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Residential care/Supported housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rehabilitation (vocational, occupational)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crisis teams	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialised services (e.g. child/adolescent, elderly, refugee)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



9. Are financial resources for mental health care clearly defined within the national budget?

- Not mentioned
- No
- Yes

10. Please provide the number of mental health professionals per 100,000 inhabitants.

Psychiatrists: \_\_\_\_\_

Psychiatric nurses: \_\_\_\_\_

Psychologists: \_\_\_\_\_

Social Workers: \_\_\_\_\_

11. Is mental health legislation in place?

- Not mentioned
- No
- Yes, specific mental health legislation exists
- Yes, mental health legislation is included in general health legislation

12. Is a mental health policy in place?

- Not mentioned
- No
- Yes, specific mental health policy exists
- Yes, mental health policy is included in general health policy

13. If yes, does the mental health policy include a commitment to continuity of care across primary, secondary and tertiary care settings?

- Not mentioned
- No
- Yes
- Not applicable

14. If yes, do mental health policy documents include a commitment to the provision of care close to a service user's place of current/last residence?

- Not mentioned
- No
- Yes, outpatient care only
- Yes, inpatient care only
- Yes, outpatient and inpatient care
- Not applicable

15. Have accreditation and service monitoring/auditing systems of mental health facilities been established?

- Not mentioned
- No
- Yes

16. Is mental health legislation/policy integrated into other related policies/legislation (e.g. social services, education and employment, justice)?

- Not mentioned
- No
- Yes

17. Does collaboration with other relevant government organisations (e.g. social services, education and employment, justice) exist?

Not mentioned

No

Yes