OUTCOMES IN COMMUNITY CARE:

COMMUNITY MENTAL HEALTH CARE, QUALITY
OF LIFE AND THE PERSPECTIVE OF SERVICE
USERS

A COMPARATIVE STUDY IN SCOTLAND AND
GERMANY

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Abstract

This thesis examines the effects of community mental health care on the quality of life of mental health service users in Britain - especially Scotland - and Germany.

The analysis is based on current developments in community care policy and practice in the countries of comparison and the perspective of mental health service users in relation to this. The research strategies adopted include qualitative and quantitative methods, in particular a questionnaire survey among mental health service users in Scotland and in Germany.

The examination of outcomes in community care with a specific focus on the concept 'quality of life' shows that quality of life is useful as an outcome measure for the comparative evaluation of community care from a user perspective. The study develops a model of quality of life which highlights significant components of community care identified as health, housing, employment, finances, support and social contacts.

The examination of some of the foundations of health care and social care in Britain and in Germany, and the comparison of specific mental health care policies and legislation emphasise distinct national characteristics and fundamental differences concerning themes and issues in mental health care. Most significantly, the analysis shows a different national emphasis on major policy objectives and concepts such as quality of life or on the role of the service user. Furthermore, the examination of significant components of community care shows how different national policies can affect support options and general availability in community mental health care.

The analysis of the views of mental health service users indicates that their quality of life is directly affected by specific national developments and different national approaches in mental health care. This concerns the availability (or absence) of different support options, but also the role of service users as participants in service provision (Scotland) or rather as

recipients of service provision (Germany). The comparison of different national support options and the analysis of user views in relation to this highlights specifically positive and negative effects on the quality of life of mental health service users. Most appreciated by service users are support options that provide opportunity for choice, independence, personal autonomy and fulfilment. The study shows that community based service provision and especially professional support is extremely important to mental health service users and has a direct and vital impact on their quality of life.

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List of Abbreviations

AWO   Arbeiterwohlfahrt

BADO   Basisdokumentation

BBD   Berufsbegleitender Dienst (Job Assistent Service)

CAPS   Consultation and Advocacy Promotion Service

CMHC   Community Mental Health Centre

CPA   Care Programme Approach (UK)

CPN   Community Psychiatric Nurse (UK)

DEA   Disability Employment Advisor (UK)

DGSP   Deutsche Gesellschaft fuer Soziale Psychiatrie

DHSSI   Department of Health Social Services Inspectorate (UK)

DoH   Department of Health (UK)

DW   Diakonisches Werk (Germany)

EAMH   Edinburgh Association for Mental Health

ECT   Edinburgh Community Trust

EU   European Union

FG   Fieldnotes Germany

FS   Fieldnotes Scotland

GDP   Gross Domestic Product

GDG   Group Discussion Germany

GDS   Group Discussion Scotland

GP   General Practitioner (UK)

GPZ   *Gemeindepsychiatrisches Zentrum* (Community Psychiatric Centre, Germany)

HCP   Home Care Project/Home Care Team (HCT)

HMFJFG   *Hessisches Ministerium fuer Jugend, Familie und Gesundheit* (Hesse Ministry for Youth, Family and Health, Germany)

HMFJFS   *Hessisches Ministerium fuer Jugend, Familie und Soziales* (Hesse Ministry for Youth, Family and Social Issues, Germany)

HMWK   *Hessisches Ministerium fuer Wissenschaft und Kunst* (Hesse Ministry for Science and Arts, Germany)

HMSO   Her Majesty's Stationary Office (UK)

IKP   Insitut fuer Kommunale Psychiatrie, Germany

JRF   Joseph Rowntree Foundation (UK)

LWV   Landeswohlfahrtsverband (Germany)

NHS   National Health Service (UK)

NGO   Non-Governmental Organisation

OF   Offenbach

OTRU   Occupational Therapy and Rehabilitation Unit

PKH   *Psychiatrisches Krankenhaus* (Psychiatric Hospital)

PSD	Psychosozialer Dienst (Germany)
PSKB	Psychosoziale Kontakt- und Beratungsstelle (Germany)
PSSRU	Personal Social Services Research Unit (UK)
PSZ	Psychosoziales Zentrum (Germany)
QLI	Quality of Life Interview
QOL	Quality of Life
REH	Royal Edinburgh Hospital
SAMH	Scottish Association for Mental Health
SHHD	Scottish Home and Health Department
SPDI	*Sozialpsychiatrischer Dienst* (Social Psychiatric Service, Germany)
SSD	Social Services Department (UK)
SSI	Social Services Inspectorate (UK)
SSSC	Social Services Select Committee
SUN	Scottish User Network
SWD	Social Work Department (Scotland)
SWSG	Social Work Services Group (UK)
SWSI	Social Work Services Inspectorate (Scotland)
TAPS	Team for the Assessment of Psychiatric Services
UK	United Kingdom

US   United States

WfB   *Werkstatt fuer Behinderte* (Sheltered Workplace for Handicapped People)

WHO   World Health Organisation

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CHAPTER 1

1.1 INTRODUCTION

In many Western countries the methods of caring for people with mental health problems have come under scrutiny over the last few decades. Specifically, the move from care in large mental hospitals towards a policy of care in the community with a focus upon the provision of a varied set of community based services has become central to contemporary mental health care policy and practice.

This research study emerges from a background of increasing (scientific) interest in the living situation of people with mental health problems in community settings. The study provides an overview on contemporary developments in community based mental health care in Britain, especially Scotland, and in Germany and compares foundations, components and outcomes of community care for people with mental health problems. More specifically, the empirical study evaluates the perception of mental health service users concerning their individual life situation and their quality of life, including an analysis of the support services currently available to them.

This chapter intends to set the theoretical and policy context to the research study into community based mental health care in Scotland and in Germany and outlines the structure of the thesis. The chapter provides relevant background information as well as definitions of important concepts and terminology used for the study and throughout the text, sets out aims and objectives and provides an outline of methods as well as an outline of the structure of the thesis and the contents of chapters.

1.2 DE-INSTITUTIONALISATION AND COMMUNITY CARE

In most industrial countries the period after the Second World War was characterised by a shift from traditional ways of care for psychiatric patients in large psychiatric institutions to community based care in smaller settings. Following a process of de-institutionalisation, countries like Britain and Germany gradually embarked on a policy of community care (*Gemeindepsychiatrie*) and implemented legislative steps to replace long-stay institutions by extramural care and support.

Despite widespread usage, the term 'de-institutionalisation' lacks a standard definition and has been interpreted in many ways. A recent suggestion by Bachrach (1997:23) to define de-institutionalisation as "the replacement of long-stay psychiatric hospitals with smaller, less isolated community-based service alternatives for the care of mentally ill people" appears useful to be applied in the context of this research study, since it extends beyond hospital depopulation to include the provision of alternative services. This definition of de-institutionalisation leads to community care as the most recent policy and legislative framework implemented in many Western countries to encompass both the process of de-institutionalisation and the provision of community based alternatives (i.e. community based support and service provision) as opposed to hospital provision. In the present context de-institutionalisation is understood to describe a historical process in the sense of depopulating mental hospitals, while community care is understood to reflect more contemporary developments – including, for example, the provision of support services - that have evolved out of this process.

The policy of care in the community emerged for various reasons, among which humanitarian motives and financial reasons appear most prominent. It is widely held, for example, that residents of long-stay hospitals frequently lived in physical and social isolation from the outside community and that long-stay hospitals developed a social structure of their own, with residents often becoming 'institutionalised' (Goffman 1961) and oppressed

(Basaglia 1971, Foucault 1967, 1973, Szasz 1961, 1973). This major concern raised by social scientists in many Western countries may have influenced the de-institutionalisation movement and the emergence of community care as a concept and policy framework. In addition, the invention of psychotropic drugs made it possible to treat the symptoms of many mental disorders cheaply outside hospital.

However, especially during the 1950s and 1960s "community care was a professional and political response to the guilt evoked by the restricted life led by people with disabilities in total institutions" (Ramon 1991:x), but it was also suggested that politicians and policy makers eagerly adopted the concept of care in the community as a potentially cheaper option (Scull 1977:153).

It is important to recognise that the transition to community care has not been smooth. Political conservatism as well as psychiatric determinism often oppose more radical approaches and there are still significant ambiguities about the meaning of community care, for it can be argued that it has become something of a slogan to justify the means to quite different politically motivated ends (Bulmer 1987:26ff) such as humanitarian motives versus cost-reduction. The questions: what is 'community' or 'community care' and 'what does it include ?' have been subject to scientific debate and there is widespread recognition that the concept of community itself is complex and difficult to define (Abrams 1977, Bulmer 1987, McGee 1987).

Bulmer (1987:26ff), for example, suggested that *community* could be a (physical) neighbourhood, a defined group of interest with or without geographical boundaries and/or the configuration of a person's connections and ties, while *care* is about attending to individual needs in different ways, physically, socially and emotionally, paid and unpaid, *in* and *by* the community (Bulmer 1987:15-16). Bulmer's interpretations of both *community* and *care* provide a useful basis to approach a definition for this comparative study into community mental health care, because it takes into account the entire life situation of individuals with special needs for

support, for example, people with mental health problems. Bulmer's interpretation of care in particular appears relevant to this study as it refers to tangible and intangible aspects of care, however, focussing on both the health care and the social care dimension. In relation to the mental health field this definition also incorporates the shift from predominantly medical (physical) care to the inclusion of social care. Community based mental health care therefore involves a concern with all aspects of people's lives, including the need for social care. In other words, the emergence of the issue 'social care' has required a shift from the clinical condition (pathology) to living conditions (material, physical, social and emotional well-being).[1]

In this study community care may generally be defined as the formal and informal attendance to the needs of people with mental health problems in their local living environment concerning both the health care and social care dimension. Furthermore, community care in the mental health field and in specific relation to this study can be defined as including a number of important components within which service provision takes place in the countries of comparison: health, housing, employment or day care and other complementary support (see Chapter 5).

1.3   MENTAL HEALTH CARE AND QUALITY OF LIFE

The process of de-institutionalisation and the move towards care in the community took place in many Western countries, albeit at a different pace and with nationally different specifications.

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[1] It must be noted that the tensions between traditional, orthodox medically oriented psychiatric care and treatment and those arguing for the inclusion and consideration of social determinants (or even talk about a 'myth of mental illness' (Szasz 1961)) are still active. What is known as the medical model or the illness model in psychiatry has been repeatedly criticised and indeed has lost much of its credibility (see also Newton J. 1989, Boyle M. 1990, Warner R. 1985, Bentall et al. 1988).

While countries like the United States (US), England or Italy had already embarked on a radical and ambitious policy of hospital closure in the 1950s, other countries like Germany or Scotland started only in the 1970s with policies and programmes to gradually reform their psychiatric care systems. Scottish and German mental health policy have both tended to reflect an ambivalence towards hospital provision, and have never actively pursued a closure programme of the scale and pace adopted in England. While community-based services have been established in both countries, hospital-based services still continue to play a predominant part in mental health care provision. However, notwithstanding the individual national approaches, a new paradigm emerged: the primacy of the community as the environment where care and support should be available for those in need.

Much of the argument concerning the most appropriate forms of care has been ideological in nature, but the process of de-institutionalisation has led to an increasing interest in empirical analysis of the results of this development. Thus, the contemporary debate in community mental health care has more recently focussed on outcomes in community care as well as on outcome evaluation. The closer examination of both the content and the form of community based care has generated an interest in the quality of life of individuals, as reflected in their social and community participation and their access to common commodities such as housing.

In the mental health field the emergence of 'quality of life' as a concept, policy objective and community care outcome has introduced a new set of concerns about the daily life of psychiatric patients, their life experience in the community and their perceptions of that experience. These concerns encourage the debate focussing on issues such as form and content of community care programmes, essential features and support options in community settings or the construction of personal and social lives in the new "homely environments" (DoH 1989 para 1.8, see Chapter 4).

Concurrently, influenced by general tendencies to shift power to users as consumers in a free market, the role of the psychiatric patient is also

undergoing change. While traditionally, the mental health patient had a very passive role and was not subject to much policy or research attention, this situation is currently changing. It is the perspective of individuals involved in the process of community care - often referred to as (service) users - that is receiving growing recognition (Beresford and Croft 1986, Barham and Hayward 1991, Rogers et al. 1993).

Research in the mental health field almost always refers to the resettlement process and has often compared hospital life with community life, however, there is increasing need to investigate community based life as such. This research attempts to look beyond successful physical relocation and extend research objectives to evaluate and compare the general living situation of mental health service users in community based settings including the support available to them. For this purpose the concept quality of life has been adopted to evaluate and compare community mental health care in two countries. Following an interpretation provided by Lehman (1983a:143) and adopted by Barry et al. (1993:43), in this study quality of life is defined as a sense of well-being and satisfaction experienced by people under their current life conditions (see Chapter 2).

The application of 'quality of life' both as a concept and research tool is useful for a number of reasons: first, quality of life is a comprehensive concept focussing upon the entire living situation of individuals including, for example, a need for social and mental health care. Second, significant areas of life or life domains as defined in recognised quality of life research largely match with major support areas in community based mental health care and thus provide a compatible structure to assess the contribution of support services. Significant areas or domains of life have been defined by other quality of life research (Lehman 1988, Barry and Crosby 1995, see Chapter 2 for details) while major support areas evolve from current mental health care policy and practice. The German mental health reforms refer to housing and employment as the two major support areas (Deutscher Bundestag 1975), while the British policy is less explicit about certain areas except housing. However, in the literature support

service provision is often dealt with according to particular areas like housing and employment, both of which usually feature centrally. In this study major support areas are defined as housing or accommodation[2], employment or day care[3], finances and health since they are domains with a comparatively great impact on individual living circumstances in Western societies. Furthermore, to people with mental health problems the areas of housing, employment, finances and health have been found to be of great importance (Kay and Legg 1986, Rogers et al. 1993:83ff). Third, the concept is useful to include the perspective of service users. Most studies in the mental health field are indeed studies developed and carried out by professional experts without major client input. These studies tend to reflect a professional attitude towards mental health care or even a traditional attitude towards the psychiatric system, however, often ignorant of the perspective of those directly affected. This study is based on the assumption that service users are experts in their own right, and furthermore the people mainly affected by community care changes. The study therefore includes the user perspective to evaluate community based life as such, based on quality of life measures.

Quality of life is effective to assess general living circumstances for mental health service users from their own perspective, including the contribution of support services. This can be done by a single country study, but comparing community based mental health care in different countries can contribute to a wider, more comprehensive view of community care policy and its outcome than a single country study. Comparative research can facilitate policy learning and the transfer and/or adaptation of policy ideas. Furthermore, cross national comparisons allow to look at issues from different perspectives including the examination of concepts like quality of life. Comparative research can thus contribute to a broader understanding

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[2] Housing or accommodation are both terms that refer to the general living situation and may also include different support options; on a general basis both terms are used in the text, while further distinctions that require more specific definitions will be provided in later chapters

of policies and concepts. While comparative studies in social policy have generally become more widespread, comparative information about community care systems was rarely available until the early 1990s (Tester 1996:2). Similarly, comparative information on the specific area of community mental health care appeared mainly during the last decade (Freeman and Henderson 1991, Goodwin 1997, Mangen 1985a, Ramon 1996a). All of these studies are predominantly cross-national comparisons of mental health care as part of existing national health and social care systems, concentrating on comparative analysis of national policies and political guidelines. While policy analysis is no doubt an important component in comparative research, research that has included the perspective of service users as a focal point of reference has not been undertaken to date. This comparative study attempts to present the user perspective, but also analyse the policy framework within which this perspective emerges. Furthermore, the concept quality of life has not been applied in a comparative research context before; therefore an attempt is made to examine whether or not the concept can provide a useful theoretical basis for comparative research. The reasons for the selection of the two countries of comparison is outlined in Chapter 3.

Principally, if policy objectives such as the improvement of the quality of life and better living conditions (see Chapter 4) for people with mental health problems are taken seriously it is important to find out more about their life in community based settings, their individual perceptions as well as their aspirations for the future. The knowledge deriving from such research is important for identifying potential problems, gaps and failures of care in the community, essential indicators for further policy and practice development.

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[3] Employment or day care generally refer to various kinds of structured daily occupation and include work and other related activities; further distinctions, definitions and characteristics will be provided in later chapters.

1.4 AIMS AND OBJECTIVES

This study principally aims to contribute to knowledge about outcomes of community mental health care in two European countries with particular reference to quality of life as a concept and outcome measure, and to enhance this knowledge by comparing two European countries.

More specific aims which emerge from theoretical issues are: first, to analyse national community care policy in relation to the major theoretical themes of this study and examine the foundations of health care and social care in the countries of comparison, second, to analyse mental health care policy on national and regional level, third, to evaluate and compare the range of community based support options in both countries and explain the differences in service provision, fourth, to evaluate and compare users' satisfaction with community living and support services in both countries and identify issues which may affect the quality of life of people with mental health problems.

The central research question to meet the principal aims is: what have been the effects of community based mental health care policy and practice on the quality of life of service users in Scotland and in Germany?

More specific research questions to meet the specific aims are: first, how do respective national policy foundations affect the delivery of health and social care ? Second, how do both countries approach mental health care ? Third, what kind of support is available to people with mental health problems in the community in both countries ? Fourth, what are major indicators affecting the quality of life of people with mental health problems in the community ?

1.5 OUTLINE OF METHOD

An intersecting set of different research methods is used to examine outcomes in community care and meet the aims outlined above. It includes documentary research in order to analyse respective national mental health care policies and the range of community based support services, and qualitative methods (observation, group discussions, expert interviews) as well as quantitative methods (questionnaire survey) to evaluate and compare the views and perceptions of mental health service users. A case study approach was selected to provide a consistent and coherent picture of community based mental health care in one particular locality in each country - and the user perspective in relation to this - generally reflecting the wider national perspective.

The investigation of the effects of community care on the quality of life of mental health service users is thus based on documentary evidence as well as on qualitative and quantitative data from two selected localities in Scotland and Germany[4]. It includes a comparative evaluation of the major support services available to people with mental health problems in the two case study localities, based on the analysis of official policy documents, key interviews and observation of community based settings.

The results deriving from a questionnaire survey into the quality of life of mental health service users in the case study localities provide data on the user perspective concerning community based living in general and mental health care services in particular. Qualitative methods including key interviews and group discussions were used to gain access to the field of mental health care and identify issues of apparent relevance to mental health service users.

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[4] Throughout the thesis they will be referred to as case study localities as opposed to regions or areas, since these terms appear in a different context. The term region is used to distinguish a regional state from a nation state, while support services are conveniently grouped into areas, for example, the areas of housing or employment etc.

Quantitative methods (questionnaire survey) were used to obtain information from a relatively large sample and provide comprehensive information on the living circumstances of people with mental health problems in both countries and their satisfaction with community living arrangements and support service provision.

1.6 ORGANISATION AND PREVIEW OF THE STUDY

The purpose of Chapter 2 is to provide the theoretical basis to the study. Therefore, theoretical issues in relation to outcome and outcome evaluation in mental health care with a particular focus on the concept of quality of life and its application in the field of mental health care are examined. The first step is to examine outcomes in mental health care and provide a definition for this study. The second step is to examine quality of life as a concept and research instrument and provide a definition for this study. The third and last step includes the examination of the changing role of mental health service users and their increasing involvement in mental health care.

The theoretical framework developed in Chapter 2 is followed by the presentation of methodological aspects outlined in Chapter 3, which includes the justification of the methods selected and an examination of potential and problems in comparative research.

Chapter 4 focuses on relevant policy issues and first examines the two major themes of this study: the concept quality of life and the role of the service user in their policy context before going on to examine the basic policy background to the organisation, administration and delivery of health care and social care in Britain and Germany. The chapter provides information about the policy background on which community mental health care is firmly based in the two countries, including an analysis of

similarities and differences. The chapter attempts to address the first specific aim of this study as outlined above.

In Chapter 5 more specific national and regional mental health care policies and administration in Britain, especially Scotland, and Germany, especially Hesse, are examined and compared. This chapter attempts to address the second specific aim of the study.

Chapter 6 provides empirical evidence about community based mental health care in both case study localities and especially examines the range of support services available to people with mental health problems. The material presented in this chapter draws on the comparative analysis of official information concerning both case study localities and their wider regional entities. In this chapter the third specific aim of this study will be addressed.

Chapter 7 presents the user perspective and draws on aspects concerning the quality of life of people with mental health problems and their satisfaction with community living and support service provision. The material presented in this chapter is based on the results of a questionnaire survey into the quality of life in significant areas of life such as housing, employment or finances. The chapter attempts to address the fourth specific aim of the study.

Chapter 8 provides a summary of the main themes and conclusions on outcomes and effects of community mental health care on the quality of life of mental health service users.

1.6.1 PEOPLE WITH MENTAL HEALTH PROBLEMS

Writing about community mental health care systems in two European countries and particularly about those who use them requires clarity in relation to the terminology used.

The most disabled group of psychiatric patients is often referred to as 'severely mentally ill' yet there is no widely agreed definition. Some commonly used definitions make use of criteria such as diagnosis, degree of disability and/or length and amount of contact with services and in-patient admission rates.

The many types of mental illness are commonly grouped into two categories: psychosis and neurosis. The first includes schizophrenia and manic depressive illness and requires specialist help. The second includes depressive disorders, anxiety states and phobias. Only a small number of people with these conditions require specialist help. Whether they do or do not depends upon the impact of the mental illness on the individual's capacity to manage his or her life. A useful definition of serious mental illness has been suggested by the Mental Health Foundation:

"diagnosis of functional psychosis, neurotic or depressive disorder or alcohol induced psychosis; illness lasting at least six months causing serious difficulties at work, in personal relationships or in living arrangements" (SWSI 1995:9)

This definition incorporates a diagnostic explanation with a measure of the impact of illness on the individual's life. It also includes "that needs change over time and that people with the same psychiatric diagnosis often have different requirements for care and support" (ibid). This definition appears appropriate to be applied to the sample approached for the purpose of this study, because the study did not focus upon people with milder psychological problems but those with severe and chronic mental health problems.

In this thesis I have taken the step of referring to people with severe and chronic mental health problems also as 'service users' or 'clients'. Within these terms I encompass specifically people who use mental health services, not least because this is the group approached by the survey. The application of these generic terms is designed to make the text more

readable, but also to reflect the most widespread contemporary terminology used in Britain/Scotland (users) and in Germany (clients).

Distinct terminology and its use also advances controversy and some people may be in favour of other vocabulary (patients, customers, the mentally ill... to name only a few). However, I would like to stress that my use of terminology is not to confuse or downplay distinct issues put forward by separate groups or individuals. Rather I hope that none of the individuals or groups referred to throughout the text will feel offended or oppressed by being referred to within these phrases.

Finally, I wish to emphasise that community care is a complex issue that stretches beyond the matters considered in this thesis. However, I offer a discussion of aspects that may significantly influence the quality of life of mental health service users, which should inform just how important it is to examine community care critically, from a theoretical, policy and practice point of view. The starting point is the theoretical basis on which this research is firmly placed, i.e. outcome, outcome evaluation and the concept quality of life, outlined in the chapter below.

CHAPTER 2

OUTCOMES IN COMMUNITY MENTAL HEALTH CARE

2.1 INTRODUCTION

Community care has become a prime goal of both policy and practice in many Western countries over the last few decades, and successive governments have gradually implemented essential policy, legislative and practical guidelines (examined in relation to the countries of comparison in later Chapters).

A review of the contribution of medical sociology to the study of severe mental illness by Cook and Wright (1995:95ff) highlights the need for research into the general effects of community care concerning issues such as stigmatisation, community integration and networks, consumer and family movements, social control and client outcomes. The emergence of these issues mirror contemporary developments in mental health care reflecting both a concern with humanitarian but also economic motives, and the last theme in particular, client outcomes, relates to the concerns of this study. On the subject of client outcomes Cook and Wright (ibid) point to shifts in interest and emphasis from clinical to behavioural and quality of life outcomes. Similarly, Prior (1993:174, 175) suggests that with the advent of community mental health care a new range of outcome measures has emerged, including the concept of quality of life, which has become an explicit principle for community mental health care, fleshed out in policy and practice terms.

Taking the lead from this development, this chapter generally aims to set the theoretical context to this research study, and examines outcome, outcome evaluation and the concept quality of life in community mental health care. The chapter includes a literature review on outcomes and outcome studies in mental health care and a review of quality of life both as concept and tool for measurement. More specifically the chapter aims to approach a definition of outcome and of quality of life, and examines potential and limitations of the concept. Finally, the chapter provides the theoretical basis for user involvement in mental health care both in general and in relation to this study.

2.1.1   THE EMERGENCE OF OUTCOME AND OUTCOME EVALUATION

The need to evaluate outcomes in community care is receiving growing recognition in both Britain and Germany. Especially since the implementation of the community care arrangements in Britain (1993), and during the course of various de-hospitalisation programmes (*Enthospitalisierungsprogramme*)[5] of the federal states in Germany, outcome evaluation has been at the top of the agenda for those having a stake in community care[6]. These are, for example, policy makers, purchasers and service providers as well as practitioners and, increasingly, users and carers.

There is also a growing public demand for outcome evaluation, not least caused by the necessity to distribute scarce resources. The emergence of

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[5] *Enthospitalisierungsprogramme* (de-hospitalisation programmes) have been put forward in most German regional states during the 1990s. For the region state of Hesse, the *Bundesland* relevant for the German case study locality, the aims concerning current de-hospitalisation programmes were outlined in region state documents (HMJFG 1993 a,b, HMWK/HMJFG, 1994) and related publications (LWV 1993, 1994).

[6] In following chapters also referred to as 'stakeholders'

health economics as a new discipline, including the use of measurement tools as a means to assess the effectiveness of health care and social care, has also become more important since the policy of community care has been introduced (Knapp 1994:3).[7]

A number of studies to date have focussed upon community care outcome and quality of life, but all these studies have been restricted to national boundaries (Lehman 1983b, Baker and Intagliata 1982, Leff 1993, Barry and Crosby 1995, Gunkel et al. 1996). It is mentioned elsewhere (Chapter 3), that comparative research or cross-national research can provide useful and valuable results for mutual benefit such as learning from other countries' experiences and policy transfer. Thus, it seems surprising that in the field of community mental health care cross-national studies are not more widespread especially in the light of the fundamental changes in most Western countries. These changes include a focus on community care as opposed to hospital care together with an interest in the quality of life of people as reflected by their individual living arrangements and personal preferences.

The remaining chapter highlights a development which has primarily informed the conceptual focus of this study and the design of research instruments.

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[7] Health economics, i.e. the effectiveness and cost effectiveness (of a service or a policy) have become part of the community care jargon and reflect important benchmarks of the increasingly cost and market oriented approach of the modern welfare state. The area of health economics including relevant studies is not considered in more detail here, although health economics and in relation to it effective mental health care can be clearly seen as an outcome, however, especially from the perspective of service providers. For more detailed information on effective mental health care see Knapp 1994 and Huxley et al. 1990, or studies into cost effectiveness: Knapp et al. 1992, Knapp 1994, Hallam 1994, Cambridge et al. 1994).

2.2 OUTCOME AND OUTCOME EVALUATION IN COMMUNITY CARE

It has been pointed out elsewhere (Abrams 1977, Bulmer 1987) that community care is a broad and complex concept that has different meanings for different people, for example, policy makers, professional staff, managers, users and carers. In addition, community care embodies aspects of both health and social care. But while it may be relatively easy to conceptualise health outcomes in terms of acute health care (for example, hospital provision, admission rates and recidivism) it is much more difficult to conceptualise social care and assess less tangible aspects or outcomes like, for example, quality of life. Nocon and Qureshi (1996:25) suggest that social care be expected to embrace a wider range of outcomes than health care, including areas such as material welfare and employment. This is also evident in relation to the concept quality of life examined further below, which especially includes a wider range of outcomes focussing on different life domains such as health, housing, work or finances.

However, also important in relation to outcome and outcome evaluation is the consideration of different perspectives. Outcome or outcome evaluation may be seen from a variety of perspectives, which may have an impact on definitions and measurement, especially, for example, in relation to who determines what is effective mental health care? Is it, for example, policy makers or funding authorities, is it mental health services and professional managers or is it service users and carers, or, ideally, all of them jointly together? The approach of a definition as well as the formulation of clear aims and objectives concerning outcome or outcome measurement may differ among different stakeholders depending on dispositions, preferences and expectations. Users may have different preferences or expectations than, for example, policy makers whose priorities may also include expenditure cuts regardless of users' preferences. Clearly, different views on what may be needed to provide

effective service provision can complicate the establishment of commonly accepted benchmarks for effective service provision.

Another problem related to this may be that perspectives are not always clear. For example, it may be a kind of hidden strategy by policy makers to avoid the formulation of clear aims and objectives for outcomes in mental health care, such as place numbers or services to be created. In relation to service provision Nocon and Qureshi (1996:24) point out that in order to see whether intended outcomes are being achieved, it is necessary to consider what the objectives of services are, and how these objectives might be translated into specific measurements. This may be possible as long as objectives have been clearly formulated and can be assessed against practice development. But if aims and objectives are vague and unspecific (as, for example, in some British policy documents, which will be shown in the policy chapter), performance measurement can be problematic.

In this study outcome is conceptualised as the impact or effect of a policy (Community Care in Britain or *Gemeindepsychiatrie* in Germany) and how it is transferred into practice; especially, the effect on service users. In the present context outcomes in community care focus on community living arrangements including the care dimension in relation to both health care and social care. This conceptualisation focuses on the perspective of service users and generates the selection of a concept and measures appropriate to evaluate their perspective such as quality of life.

The evaluation of the impact or effect of a policy of community mental health care is closely related to the services established to provide care and support according to national policy recommendations. Thus, the contribution of services to outcome in community care is also an important issue both in general and in relation to this study.

McCollam and White (1999:191) evaluated social work services for people with mental health problems and refer to a definition by Goldberg and Connelly (1982) applied earlier in a study into elderly care who defined the

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evaluation of services as being about 'constructing explanations of what takes place and making judgements about the merit of an activity by measuring it against specific criteria'. On a wider basis this conceptualisation can be applied in relation to this study; specific criteria for measurement in this study is the concept quality of life examined further below.

First, relevant outcome studies in the mental health field are examined below.

2.2.1 OUTCOME STUDIES IN MENTAL HEALTH CARE

The evaluation of outcomes in community mental health care has focussed on a number of issues and themes. Over the years an increasing number of empirical studies have investigated the transition from hospital based life to community based living, and the move of mental health patients out of long-stay wards into community settings. As studies began to appear in the UK and later also in Germany they often took as their theme hospital closure programmes and resettlement (Gibbons and Butler 1987, Häfner 1985, Kruckenberg et al. 1995, Leff 1993, Leff et al. 1994, McCreadie et al. 1983, 1985, Simic et al. 1992,) and along with hospital closure, improvement in the patient's quality of life through the process of resettlement and integration into the community became goals central to the theme of de-institutionalisation (see also Bachrach 1975, Linn et al. 1980, Lamb 1981, Stein and Test 1978).

This section reviews some of the earlier outcome studies, most of which have concentrated on the resettlement process of mental health patients from hospital based settings into the community. The material presented is necessarily selective and concentrates on studies focusing on de-

institutionalisation and resettlement programmes in Britain, especially Scotland, and in Germany.

The table below summarises the key characteristics of relevant studies, before they are examined in more detail.

	key features	key findings
England		
Leff 1993 Leff, O'Driscoll 1993	TAPS - Multiple measures study including cost examination, Resettlement: mental hospital/community (follow-up over ten year period (n=770)	Improvement in living circumstances of discharged patients, increased levels of satisfaction with community living compared to hospital life
Scotland		
McCreadie 1983,1985	Study of resettlement of long-stay patients	A third of patients is appropriately placed outside hospital, but two thirds need hospital provision
Gibbons and Butler 1987	Resettlement: mental hospital - community (Follow-up after one year)	Majority of patients showed significant improvements in the community
Germany		
Häfner 1985,Häfner, Klug 1982	Mannheim Case Register Study, resettlement of long stay patients	Reduced bed-need, but no details concerning living circumstances 25 per cent of long stay patients needed hospital provision
Kruckenberg 1995	Relocation of patients into community Resettlement: mental hospital-community, follow-up (n=80)	Relocation was considered positive by majority of patients
Albrecht 1994, Vieten 1996	Resettlement: mental hospital – community, follow-up (n=64)	Small population requires hospital provision, majority prefers life outside hospital setting

Table 2-1: Outcome studies in mental health care: England, Scotland, Germany

In the mental health field the TAPS Project - a large scale evaluative study - is the most extensive study of its kind in Britain (Leff 1993). The Team for the Assessment of Psychiatric Services (TAPS) was established in 1985 and developed a batch of schedules for the assessment of 770 long-stay, non-demented patients in two large mental hospitals in the UK (Friern and Claybury - in North-East London) over a ten-year period. The primary task of TAPS was the evaluation of the effects of service changes on individual patients rather than on service provision as a whole. Therefore clients' demographic details were recorded and their psychiatric and physical well being and quality of life in hospital and at intervals after moved into the community was monitored (O'Driscoll and Leff 1993). Early findings from

the long-term outcomes research suggest that there are improvements in clients' symptoms after five years. During their first year after leaving hospital, clients reported an increasing number of friends and, although these social networks did not expand further over the next four years, an increase in the number of confidants was recorded, so relationships appeared to be deepening (Leff et al. 1994). Overall the project reported increased levels of satisfaction with living situation and increased freedom and independence in the community (Leff et al. 1994).

There are no large scale comprehensive studies in Germany which, for example, are comparable to the longitudinal design of the British TAPS study, but smaller studies exist like the case register study by Häfner (1985).

Häfner and Klug (1982) and Häfner (1985) used a particular research technique to evaluate the outcome of community based psychiatric care and made use of a case register to monitor changes within a defined population of psychiatric service users. The information stored and updated provides a comprehensive database for assessing outcome and change over time. This research technique may be useful for obtaining gross data in relation to particular regions, yet the available data is not very detailed lacking, for example, more precise information on individual living circumstances and personal perceptions. Although registers can be useful in determining indices of service need, they give no information about more subtle parameters such as quality of life. Nevertheless, they do provide an overview of patterns of care for the psychiatric population in a defined area.

Häfner and Klug (1982) and Häfner (1985) used the Mannheim case register to show that in their region a sharp decline in the 'old' long-stay[8] population was followed by a much smaller increase in 'new' long-stay

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[8] In this study 'old' long-stay population refers to patients that have lived in mental hospitals most of their lives, while 'new' long-stay population refers to patients that have been resettled into the community but require longer periods of in-patient treatment

patients, and thus reduced bed need. And yet, the study in Mannheim concluded that 25 per cent of schizophrenic patients needed to be in a mental hospital. However, while the study provided general information on the resettlement of patients, it did not provide a more detailed account on living circumstances and quality of life like the TAPS study in England. The TAPS study also aimed for the comprehensiveness of the case register format but with much greater detail, especially about the well-being of individual patients (O'Driscoll and Leff 1993).

The experience of the closure of *Kloster Klinik Blankenburg*, a large psychiatric hospital near the City of Bremen received considerable attention within professional quarters in German discussion in the early 1990s. Kruckenberg et al. (1995) evaluated the development of community based psychiatric care in Bremen following the closure *of Kloster Klinik Blankenburg*, and the overall experiences for the former patients. It was broadly concluded that the relocation had been a very positive experience for the majority of the patients (Raab 1995:13-16) and only very few wanted to return to hospital. But it was also pointed out that a minority of patients had feelings of loss and lack of security adversely affecting community based living and quality of life.

The University of Bielefeld followed a de-institutionalisation project in North Rhine Westphalia (Albrecht et al. 1994) where three psychiatric wards for long-term patients were closed down. The aim was to relocate the long-term patients together with the staff into community based alternatives[9] to hospital provision, mainly into group homes or hostels. Sixty-four patients were initially involved in the project, but nine had rejected leaving hospital, because they felt not (yet) sufficiently prepared to cope with life outside hospital. As an option they were offered a transfer to a different part of the building and a living arrangement based on group home style was arranged. The remaining patients left hospital and moved into community based alternatives. The study showed that for long-term

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[9] Community based alternatives in this context are housing options, which generally include hostels and small group homes as well as supported accommodation in individual flats and houses.

patients, especially elderly ones, a change in living circumstances is not an easy option but that most of the former patients had coped remarkably well. The frequency of psychiatric crisis and in-patient hospital admissions decreased during the course of the three year study, despite the teething problems the new living arrangements had brought about. In relation to well-being and satisfaction with life the researchers discovered a tendency towards a 'critical dissatisfaction' replacing the 'resigned adaptation' prevalent with hospitalised patients who were never exposed to challenges and external stimuli (Vieten et al. 1996:6).

These German studies correspond with other British studies in that results suggest that a small population of mental health clients require a more secure living environment.

Early Scottish studies by McCreadie et al. (1983,1985) and Livingston and Bryson (1989) clearly stressed the importance of community based support services, but interestingly, these studies found this worthwhile only for a rather small percentage of those suffering from severe and chronic mental illness. For example, McCreadie et al. suggested that only one third of the (mental) hospital population under 65 could, given appropriate support, live outside hospital whereas the rest were appropriately placed in hospital. Such estimates, based on staff judgements about patients living in the community, have been criticised as being very conservative reflecting a traditional attitude to discharge (Petch 1990:6).

The Scottish Affairs Committee (House of Commons 1995:v) noted similar arguments and refers to the greater professional conservatism in Scotland that may have sustained the comparatively heavy reliance on institutional patterns of care, in contrast to England and Wales. The studies by McCreadie et al. as well as Livingston and Bryson seem to confirm such argument.

Other more recent Scottish studies (Gibbons and Butler 1987, Simic et al. 1992, Petch 1990) have produced more encouraging findings. Gibbons and Butler (1987) for example, studied long-stay patients moving from a

district general hospital ward and a mental hospital and followed them up a year later. They discovered that significant improvements were shown in time spent in the community, social interaction, activity and abnormal behaviour and none of the patients wanted to return to hospital wards. Those patients in the study remaining on the wards showed no comparable changes and did not want to be where they were.

Most of the earlier outcome studies compared community based living with life in hospital settings and evaluated patient attitude in relation to this, clearly indicating that patients mostly favoured community living arrangements compared to hospital life. Except for the rather conservative Scottish studies by McCreadie et al. (1983, 1985) this can be said for the majority of studies in Britain and in Germany.

However, in both countries many of these studies concentrated on health measurement with a focus on a clinical rather than a social dimension, which may not be directly relevant to outcome measurement in social care services, a point which has also been made by Nocon and Qureshi (1996:102). There is, nevertheless, increasing need to include the social dimension of community life - including the care dimension (i.e. support service provision) - to receive a fuller and more comprehensive view of community care and community living. The so called long-stay population of the traditional mental hospital will gradually disappear, being replaced by a community-based population of mental health clients requiring both comprehensive health *and* social care. Consequently, evaluation and measurement of living circumstances in community based settings must include both the health care and the social care dimension. The concept quality of life seems to provide a useful framework for the inclusion of both the health and social care dimension which will become evident in the next section, when the emergence of the concept and relevant profiles for measurement are examined.

2.3 QUALITY OF LIFE AS COMMUNITY CARE OUTCOME

Quality of life as a concept emerged in the early 1980s, when many authors proposed that the notions of cure and progress had a relative pertinence for chronic mental patients, and that an important step would be accomplished towards the humanisation of services if they could only maintain and enhance the quality of life of this clientele. Quality of life then became a major issue in the assessment of patients' needs and of the impact of services on their lives. Improved quality of life is now widely recognised as an explicit priority of the community alternatives to hospital based care. The importance of quality of life as a desired outcome of community care for chronic psychiatric populations has been highlighted by a number of practitioners and researchers in this area, first in Anglo-American countries and later also in Germany (Baker and Intagliata 1982, Lehman et al. 1982, Barry and Crosby 1995, Priebe und Hoffmann 1993, Gunkel et al. 1996).

Baker and Intagliata (1982:69ff) cite five reasons for the rapid adoption of the notion of quality of life in the field of community mental health care. First, given the current state of medical knowledge, increasing the comfort of patients with severe and persistent mental health problems is a more realistic target than curing them. Second, the community support programs set up to take over from the psychiatric hospitals work with a complex set of interventions. A multidimensional variable such as quality of life offers the possibility of evaluating interaction of elements, that viewed individually, would have effects too small to perceive. Third, the concept of quality of life takes into account a new priority in program planning: client satisfaction. Fourth, quality of life offers a new viewpoint that takes into account the client's life as a whole rather than concentrating mainly on a person's pathology, which is in line with the holistic health perspective promoted by the WHO (1991:5). Lastly, talking about quality of life echoes a dominant theme in current political discourse. Altogether, Baker and Intagliata highlight that quality of life accents a holistic approach

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to mental health care, embracing the whole life situation rather than focussing on pathology.

The five reasons cited above provide both background information on the emergence of the concept and a useful framework for further utilisation of the concept. Baker and Intagliata propose that it is care instead of cure, that has helped to making quality of life a focal point for mental health evaluation. In this context it is not just individual living circumstances on their own, which can be subject to evaluation; furthermore, the contribution of mental health services to the individual quality of life can also be part of an evaluative framework, which is a relevant aspect in relation to this study. Clearly, there are other, different perceptions dwelling on a more traditional conceptualisation of mental disorders where people are simply treated negatively, while mainly positive perceptions focus on potential gains to the client, the helping professions and the general community. Baker and Intagliata focus upon a principally positive understanding and indeed provide good reasons for employing quality of life measurements. Particularly relevant in the context of my study is the holistic approach and unequivocal point of view, including the focus on both dimensions, that of health and social care in general, and in relation to service provision.

Baker and Intagliata do not explicitly draw on the possibility of active user involvement in relation to either the concept itself or quality of life measurements. They confirm a gradual turning away from narrow views of the patient's life predicaments in favour of seeing them in their 'person-situation-configuration' (Oliver et al. 1996:16), which means that a more holistic perspective is being applied including, for example, the health context but also to the social context of a person's life. However, although a central role is being ascribed to individuals in their living context, the individual as active participant has been left out.

A number of additional reasons suggesting that the concept has an almost universal appeal have been pointed out by Oliver et al. (1996:17): it is a popular notion with users and carers alike; it is easily understood by professionals of various disciplines involved in the diagnosis, treatment

and after-care of people with health problems and therefore provides a common basis for multi-disciplinary work. [10]

While the concept is primarily relevant to community care, a good deal of research and development has taken place in relation to mental health care. In accepting the necessity for considering a range of issues wider than treatment response or symptom levels, the concept quality of life has profoundly altered the perception of the type of care that should be offered, as well as the objectives of that care. It caused a shift from the objective assessment of services and care needs to the user's subjective perceptions of his or her needs. Mercier (1994:166) has pointed out that "the concept of quality of life has introduced a new set of concerns about the daily life of psychiatric patients, their life experience in the community, and their perceptions of that experience". This indicates yet another reason to employ quality of life measurements in research concerning mental health service users: the concept provides a good basis to focus upon the experiences and views of service users.

In common with other complex concepts such as community care, it has been pointed out that quality of life is a complex matter which incorporates many aspects of an individual's existence (Torrance 1987). The generality of the concept 'quality of life', together with conceptual and methodological difficulties concerning its definition and measurement requires a closer examination and a clear definition. This will be provided further below when the theoretical basis of this study is outlined. Before, the most important quality of life studies are reviewed below.

2.3.1 QUALITY OF LIFE STUDIES

Studies into the quality of life of psychiatric patients have started to emerge in the late Seventies and during the Eighties, at first in the US,

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[10] Other authors who have also suggested similar reasons for considering quality of life measures include Zautra and Goodhart 1979, Cochrane 1983, Bigelow et al. 1982, Lehman et al. 1982

then in the UK and later also in other European countries like Germany. The main focus of most of the studies was hospital closure and the process of de-institutionalisation, i.e. the resettlement of patients into the community. Not surprisingly, definitions for a concept such as quality of life are many and varied and guidance to the possible contents of quality of life measurement is thus diverse. The most relevant quality of life studies that are significant to this study for conceptual reasons and/or because they refer to the countries of comparison are summarised in the table below. These studies mainly refer to quality of life either as a sense of well-being, closely linked to a situational context, or as some other combination of objective and subjective well-being.

	key features	key findings
US		
Baker and Intagliata 1982	Assessment of living circumstances and influence on well being and satisfaction	Finances, unemployment, personal safety and health are sources of dissatisfaction for clients in the community
Lehman et al. 1982, Lehman 1983	Influence of objective and subjective living conditions on well-being, interviews with residents in group homes (n=278)	Social problems affect qol, clients preferred life outside hospital
UK		
Simpson et al. 1987	Comparison of patients qol in acute ward, hostel ward and group homes	Qol was lower on hospital wards than in community settings
Barry and Crosby 1995, 1996	Assessment of qol together with levels of psychiatric, social behavioural functioning before and after discharge (n=65)	Individual qol is improved in community settings provided that adequate support is available
Scotland		
Simic et al. 1992	Qol before and after discharge (n=24), cost examination	Majority of patients can live outside hospital and prefer this, provided that support is available in the community
Petch 1990	Study of potential and effectiveness of supported accommodation projects in Scotland (n=145)	Supported Accommodation is central, but accompanying support is also significant
Germany		
Gunkel et al. 1996	Qol of mental health clients in community settings (n=110)	Social problems (finances, loneliness, isolation) have been reported to be major problems for mental health clients in the community

Table 2-2: Quality of life studies in mental health care: US,UK, Scotland and Germany

One of the first and most significant quality of life studies was carried out by Lehman et al. (1982) in the US. The descriptive study focussed upon

the quality of life of psychiatric patients in various life domains (see first model diagram further below) and to carry out this study with 278 residents of group homes the author developed the "Quality of Life Interview" to extract demographic and clinical data and objective and subjective quality of life indicators from eight areas of life (Lehman 1988:52ff). The authors intention was to assess the relative contribution of socio-demographic characteristics and objective and subjective living conditions to global well-being (Lehman 1983a). The results of this study reveal how important subjective perceptions are to the appreciation of life in general. An overall feeling of well-being was most closely associated with four subjective variables: satisfaction with personal health, leisure activities, social relations and financial situation. Among the objective indicators, the most closely connected to an overall feeling of well being were: not having been the victim of robbery or assault, making less use of health services, and having a great number of satisfying social contacts in the residence, a job, and more privacy. Individual characteristics related to global well being were: being married, having a higher level of education, and not using drugs.

The study showed that the quality of life of chronic psychiatric patients was principally affected by social, not medical, problems. Moreover, patients' psychopathology had no bearing on the subjective perception of either their overall lives or the individual areas of study, except that of physical health (Lehman 1983b).

American studies (Lehman et al. 1982, Lehman 1983, Baker and Intagliata 1982) of the quality of life of chronic clients living in the community were the first which pointed to the many social problems affecting their quality of life. Both studies report that life areas such as finance, unemployment, personal safety and health are consistent sources of dissatisfaction for chronic clients. Although clients generally reported a lower quality of life compared to that of the general population, the majority reported satisfaction with being out of hospital and did not express a desire to return to hospital. This was also confirmed by another study (Lehman et

al. 1986) that compared the quality of life of chronic clients in a state hospital with that experienced by clients in supervised community residences. They found that hospital patients report a lower quality of life than clients living in the community and that in-patients and community residents differed most in their satisfaction with living situation.

The work of Lehman et al. has informed other studies into the quality of life of psychiatric patients and has provided the basis to develop a theoretical framework for this study as will be seen further below. The most significant aspect, however, that has emerged out of Lehman's work and which has influenced the debate surrounding quality of life as a new concept in the 1980's and into the Nineties, can be seen in the increasing importance ascribed to the social dimension of (community based) life and the potential problems and concerns of individuals. This development may have influenced the gradual process to increasingly focus the academic and political (i.e. in research and policy) attention concerning mental health care not only on health care but also on the dimension of social care.

A smaller British study by Simpson, Hyde and Farragher (1987) concentrated on different care settings and compared the quality of life of chronic clients in an acute ward in a district general hospital, a hostel ward and group homes stressing a number of deficiencies in relation to hospital-based care. Simpson et al. report that quality of life was lower on the hospital ward than in the other two settings and that lack of safety and comfort in the hospital seriously detracted from residents' quality of life.

Another more recent study in Britain (Barry and Crosby 1995, 1996) has used quality of life as an evaluative measure in assessing the impact of community care on people with long-term psychiatric disorders. Barry and Crosby's quality of life study formed part of a larger research project concerned with the resettlement of 65 long-stay clients from a psychiatric hospital in Wales. Quality of life was employed as one of a range of outcome criteria being used to evaluate the impact of the resettlement process on the lives of individual clients as they are discharged from

hospital. Employing a repeated measures longitudinal design, the study assessed clients' quality of life together with levels of psychiatric, social and behavioural functioning on the hospital wards prior to discharge. Follow-up assessments were then carried out after discharge. The researchers modified and adapted Lehman's Quality of Life Interview retaining the same basic structures. The schedule covered objective and subjective indices in nine life areas together with indices of general well-being. The implementation of the quality of life instrument used in the study propounds that it does provide valuable information on the life situation and subjective perceptions of clients whose views may be rarely represented in the planning process. This last aspect seems to point to a process that has increasingly influenced the debate surrounding community mental health care within the last decade especially in Britain: the representation of user views in the planning process. It is indeed likely that studies like those carried out by Lehman et al., albeit to begin with less explicit, or Barry and Crosby have supported the process that user involvement and participation has become increasingly recognised in community care policy and practice development. Altogether, however, this is more the case in Britain than in Germany, an aspects discussed later in the chapter.

Barry and Crosby (1996:210) identified a need for prospective longitudinal studies which trace the same people as they move from one care setting to another, which would allow a more direct comparison of quality of life under different care regimes. Their findings are based on a long-stay psychiatric population and therefore may not apply to a younger non-institutionalised sample (Barry and Crosby 1996:216). This is important to note as, if community care is to succeed, the former long-stay population of large psychiatric hospitals will gradually disappear and the composition of the psychiatric population will have a different structure.

Overall, Barry and Crosby's findings suggest that it is possible to maintain people with long-term psychiatric disorders in the community and improve their quality of life through the provision of adequately supported

community residential schemes. They (1996:216) also argue that quality of life is a useful evaluative framework against which to assess the outcomes of care provisions.

A Scottish study carried out in Edinburgh by Simic et al. (1992) showed a similar pattern to other British studies as it followed the resettlement process of long-stay patients. The study specifically looked into the quality of life of adults moving out of a long stay ward in the Royal Edinburgh Hospital, and involved 24 patients who were discharged and followed up in the course of the study. Simic et al. combined, firstly, formal measures with descriptive information, and, secondly, patient judgements and with a range of professional opinions, to form an overall picture of quality of life over a period of time. The researchers concluded that there was an improvement in the quality of life but underlined the importance of new forms of provision, especially supported accommodation. The study of Simic et al. confirms the findings of other similar studies that community based living is generally preferred to hospital life.

Another Scottish study by Petch (1990) particularly focussed upon the domain of housing and compared eleven supported accommodation projects across Scotland. Many of the residents in these projects had severe mental health problems but experienced an improvement in their quality of life living in the community. The effectiveness of supported housing is, Petch argues, cogently demonstrated. The study also stresses, however, that housing and accommodation alone will not make community care. Highlighting the importance of qualitative support, Petch rejects the narrow view of housing as just 'bricks and mortar' in relation to community care policy (Griffiths Report 1988).

Overall, the Anglo-American studies reviewed above have shown that in relation to quality of life two themes in particular have become increasingly important: the recognition that social issues affect the quality of life of people with mental health problems and, consequently, that social care and social support is at least as important as health care.

In contrast to Anglo-American countries, but presumably influenced by the development, German studies into the quality of life of mental health clients started to appear only rather recently within the last few years.

A research project by the *Berliner Forschungsverbund Public Health*[11] (Zaumseil 1995) to begin with, did not explicitly draw on the concept quality of life, but looked into the changes of living circumstances for psychiatric clients in two areas of Berlin (East and West) over a period of three years from three perspectives: users, carers and professionals. Qualitative methods were used to assess the situation of chronic psychiatric patients with the aim to develop (model) hypotheses, which would help to explain the social reality of chronic patients in relation to local conditions. The interpretation of subjective perspectives took place within the context of the social and cultural background. A hypotheses that emerged out of recurring typology is that the network of individual arrangements in relation to support and care in everyday life produced a phenomenon which was earlier labelled 'dissociation' (Zaumseil und Leferink 1992, Schürmann 1994). It refers to living circumstances or 'support arrangements' which are characterised by a confusing variety of organisations with different - and even contradicting - aims, concepts and convictions. In this context the researchers also identified a general lack of co-operation and coordination among service providers causing confusion for users, carers and professionals alike (Zaumseil 1995).

A more recent qualitative study from Berlin (Gunkel et al. 1996) has focussed particularly upon the quality of life of psychiatric clients in community settings. Interviews were carried out with 110 individuals from various community care settings. Among the problems most frequently mentioned as having a strong impact upon the quality of life were lack of

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[11] The 'Berliner Forschungsverbund Public Health' was founded in 1995 with the aim to support and stipulate research activity into community based alternatives to institutional care. It is funded by the Bundesministerium für Forschung und Technologie (Ministry for Research and Technology). In 1995 the German research programme 'Public Health' provided a framework for further research in the field of community care, including a focus on quality of life issues.

finances, loneliness and isolation. Similar to the Anglo-American studies, the importance of the social dimension of life became particularly evident in this study.

It is important to note that the major German studies reviewed in this chapter have all taken place within the framework of a more or less clinical background. That means, the research teams have usually been attached to a university clinic (*Universitätsklinik*) or the relevant psychiatric department of a clinic and grant-holders are usually psychiatrists rather than, for example, social scientists. Although it is assumed that a number of smaller research projects increasingly take place outside these 'official' research boundaries (Gruyters et al. 1996), well-funded research into non-medical psychiatric care and treatment is only slowly going into other university departments like the social sciences. Principally, the current situation is characterised by a rather strong medical orientation of the German research community in the field of mental health care, which has also been confirmed by the German Society for Social Psychiatry (*Deutsche Gesellschaft fuer Soziale Psychiatrie*-DGSP).

In 1994 the DGSP founded a 'research initiative' *(Initiativkreis Forschung)*. The initiative carried out a survey into ongoing and planned research projects and found nearly 200 projects. The main findings summarise the activity in different research areas. In relation to the established areas of psychiatric research 20% of the projects covered mainly etiologic or phenomenological questions, 11% covered epidemiological questions and more than half (55%) mainly dealt with the evaluation of treatment. Findings also informed that 35.7% of the projects have taken place in an entirely clinical setting (psychiatric ward) or partly-clinical, for example day clinic (22.4%), while only 21.9% of the projects have been carried out in community based alternatives, such as supported accommodation (6.1%) or other services (15.8%) (Gruyters et al. 1996). The findings confirm the dominance of a medically oriented research practice lacking, for example, more comprehensive approaches including other sciences and different perspectives.

Principally, the emergence of the concept quality of life has placed a new emphasis on the living situation of psychiatric patients in the countries concerned here, with an increasing focus on the social dimension of life and life in non-hospital settings. The review of major quality of life studies in the field of mental health care has similarly shown that it is social rather than medical problems that adversely affect the quality of life of psychiatric clients. This indicates that the social dimension of community living and indeed community care must be taken into account as an important issue in the lives of people with mental health problems.

In general comparison the review of Anglo-American and German studies into the quality of life of people with mental health problems has indicated the emergence of two themes: the incorporation of the social dimension of care and the growing influence of the user perspective. These themes are not only relevant to contemporary community care policy and practice development but also to this study. It will be seen later in the chapter how the particular framework developed for this study evolves.

However, apart from the aspects or themes that have been identified to be of general relevance and also to this study, there are other approaches which have influenced the quality of life debate, but appear to be more and more outdated since mental health care increasingly takes place in different care settings. The examination of relevant studies in the field of mental health care in both countries has shown that the majority of studies focussed on people going through the resettlement process, i.e. from hospital based care into community care, and thus compared, for example, hospital life with community based life. This will not be enough in the future as there is need for a next step: while it has been shown by the majority of studies that people with mental health problems prefer community life compared to hospital life, the next step includes shifting the focus on studies concentrating on community living with all its different patterns and support networks. There is an increasing requirement to include clients who are not part of the so called 'long-stay population' and who have not lived in mental hospitals for most of their lives. A different

clientele, also with severe and chronic mental health problems - but perhaps younger and less institutionalised - will require more differentiated sets of measures. Thus, the need to focus research on the group of service users circulating in community based mental health settings, thereby often using a variety of facilities, is evident. It is not just accommodation but also employment and day care as well as community links and social contacts which play an important role in the everyday life of the mental health population with serious and chronic conditions. The evaluation of community based mental health care will increasingly have to concentrate on sectors or catchment areas and examine, for example, a particular community care network in its local context and, in relation to it, the quality of life of those using this network. In this setting the individual service user should have a central role to play with a clear focus on individual perceptions and personal experiences as an important contribution to progressive development, which will become more evident at the end of the chapter.

The life or rather the quality of life for mental health service users to adhere to the context of this study is influenced by many factors, not least by the availability of community based support services. This will be seen below on a more general basis and in later chapters in particular relation to this study.

2.3.2 THE CONTRIBUTION OF SERVICES TO 'QUALITY OF LIFE'

A number of studies have pointed out that the quality of life of psychiatric patients is greatly affected by the availability of adequate support services. Consequently, the living situation of mental health clients in the community can not be examined without a look at the support services available in

community settings. The contribution of services to the individual's quality of life is therefore an important issue.

The majority of studies into the quality of life have automatically included the quality of services to some extent. Most common have been studies that compare the objective and subjective quality of life according to various types of living arrangements. Some of these studies have compared inpatient and outpatient facilities, for example: a state psychiatric hospital and supervised community residences (Lehman et al. 1986, Lehman et al. 1991); acute wards in a district general hospital, a ten-bed hospital ward and group homes (Simpson et al. 1987) and patients in intensive in-house treatment, intensive outpatient treatment , and regular outpatient treatment. These studies all similarly concluded that hospitalised patients' perception of their quality of life was more negative than that of patients living in the community (Lehman et al. 1986, 1991, Simpson et al. 1987).

Among non-hospitalised patients, those living in more structured environments, such as hostel wards (Simpson et al. 1987) were less satisfied than those living in less restricted environments. This may be related to more rigid care regimes in restricted settings, causing negative feelings of control and suppression, a lack of personal autonomy and freedom to exercise choice concerning aspects of everyday life. Therefore it is important to recognise the nature of living arrangements, for example, living in a rather institutionalised but community based setting may not be an improvement at all. Clearly, the nature of a service is as important as its location and institutional practices may not be exclusive to hospitals.

While some of the studies described above indicate a relationship between enhanced quality of life and service provision, others suggest that it is not at all certain that a direct relationship exists between participation in a service and an improved subjective quality of life in the corresponding life domain. Studies in the US (Bigelow and Young 1991, Huxley and Warner 1992) have not found a direct link between receiving services in a given life area and the perception of quality of life in that same area. The

improvement of objective living conditions, for example, provided by available services like supported accommodation does not necessarily result in greater satisfaction of clients. Here the concepts of personal aspirations and subjective importance may be helpful in understanding why there is not a more direct relation between intervention and change in how a client perceives his or her quality of life (Kilian 1995) or between objective living conditions and subjective quality of life, aspects which will be examined in more detail further below.

However, mental health service provision is an area where the contribution of services to the quality of life is crucial. Although there have been a number of studies that have compared objective and subjective indicators in direct relation to service provision, it is not just the objective availability in terms of place numbers or how many day care centres are around in one area that are significant. There are other aspects, that also contribute to an enhanced quality of life. According to an American study (Baker et al. 1985) people with mental health problems identified as the most important people in their lives, those whom they talked to when they had problems, those whom they called on in emergency situations, and those whom they asked for help with certain tasks. Apart from the role of the family and friends in the support network, professionals figure prominently when it comes to finding someone with whom to discuss personal problems. In emergency situations, professionals and semi-professionals represent an important source of help, in addition to family and friends. Given the important role that professionals play in their clients' lives, support services and in particular workers in mental health services are directly implicated in their quality of life. Mercier (1994:180) has pointed out that "services are therefore more than a means to a better quality of life"; often "they are direct participants in that quality of life" (ibid).

In general, most of the studies indicate that the use of services plays a significant role in the client's general living context. Services can respond to many different needs, depending on the living conditions of their recipients. For a person living in a group home, for example, participation

in leisure and other activities can fulfil his or her need for stimulation, while for those living in parental homes, a day care centre can provide a change of scene. Individuals living alone may favour day care centres appreciating aspects such as community meals, leisure activities and communication - all of which could help compensate for more or less precarious living conditions. The contribution of support services is thus significant and support must be seen as an important aspect in the life of people with mental health problems.

2.3.3 DEFINITION OF 'QUALITY OF LIFE' AND THEORETICAL BASIS

For the purpose of this study I shall use a definition of quality of life referred to by Lehman (1983:143) and also by Barry et al. (1993:43) who focus on a 'sense of well being and satisfaction experienced by people under their current life conditions'. The definition is useful to embrace the entire life situation including, for example, living circumstances like housing, employment and finances, but also in relation to support service provision. The extent to which community based support facilities can have a positive impact on the lifestyles of long-term clients and maximise their quality of life is an important test of the success of community care service arrangements in translating policy objectives into practice. To some extent outcome measures such as quality of life can be useful to monitor how effectively users' needs are being met and whether a policy or a service meets a defined objective.

Despite a number of potential limitations of a quality of life profile for operational use, which will be examined later in the section, the concept can provide a virtuous and conscientious basis to include the perspective of people with severe and chronic mental disorders on their general life situation. The perspective of mental health service users, and in a wider sense the role of the service user in policy and practice, is most significant

in the context of this study, and will be examined more closely in the final section of this chapter.

Overall, the concept quality of life is considered useful for the evaluation of the effects of community care from a user perspective, providing a holistic conceptual framework. I have employed quality of life as the conceptual basis on which a framework for this study will be developed for a number of reasons: first the concept provides a useful and comprehensive basis to include the health dimension but also the social dimension concerning significant areas of life, e.g. housing, employment or finances. Second, the concept appears useful to be applied in a comparative context in two different countries, provided that comparative measures can be developed that match with the respective national characteristics and, third, the concept is useful to include the perspective of service users. The development of these measures is set out below.

Among the most prominent theoretical models and quality of life profiles is the work of Lehman et al. (1982) and Baker and Intagliata (1982). Lehman et al. (1982) examined nine aspects of the lives of people with chronic mental health problems as illustrated in the diagram (2-1) below:
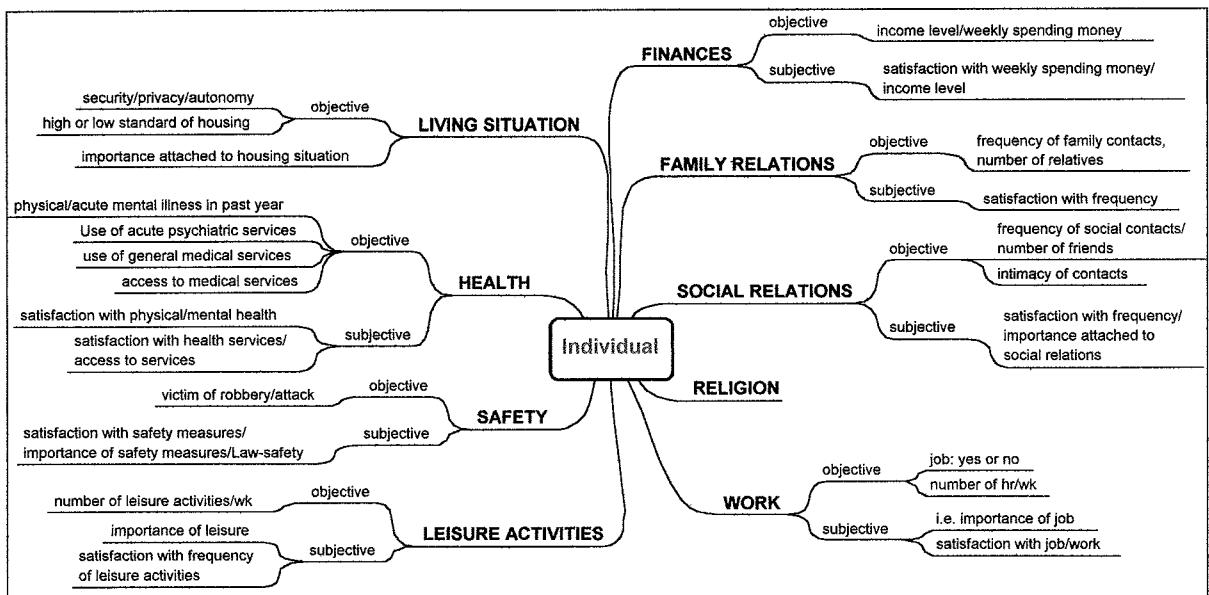
Diagram 2-1: Quality of life profile according to Lehman (1988)

The Lehman model concentrates on a combination of objective and subjective indices such as living situation (objective) and satisfaction (subjective). The focus is on objective and subjective living conditions in what is called 'life domains' such as living situation, finances, health etc.

For the purpose of this study I have revised the Lehman model as illustrated in the diagram (2-2) below:
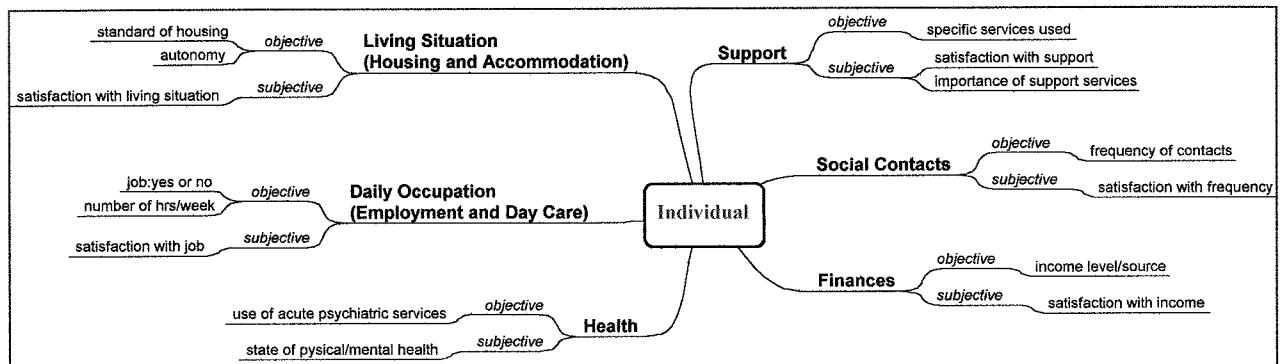
Diagram 2-2: Quality of life profile developed for this study

Based on the perspective of service users of what they felt were important areas to their lives, the eight life domains as illustrated in the model devised according to Lehman's original profile were re-arranged into six significant life domains:

Health, Living Situation (Housing and Accommodation), Daily Occupation (Employment and Day Care), Finances, Support, Social Contacts.

For the purpose of this study only six domains appeared relevant to service users, as became evident in group discussions preparing a profile (questionnaire) for mental health service users in Scotland and Germany (see also Chapter 3). Lehman's original domain 'work' was changed into 'daily occupation' to allow potential respondents to include other common day time activities such as visiting a day care centre or sheltered employment or even staying at home. Lehman's domain 'leisure activities'

employment or even staying at home. Lehman's domain 'leisure activities' and 'family contacts' were both included in a new domain: 'social contacts'. Most interestingly, Lehman's domain 'safety' did not seem to concern mental health clients in Europe. Service users in group discussions were most explicit that 'safety' in the sense of protection from robbery or criminal attack was not a matter of concern to them. It is difficult to explain this apparent difference, but it may be related to the area of investigation in the US (San Francisco) and the rate of criminal offences there, or a more general attitudinal difference between the American and European way of life or perhaps a general tendency among American citizens towards safety measures. However, according to the apparent lack of interest in Scotland and in Germany 'safety' was not included as a domain in the model diagram developed for this study.

The remaining domains of Lehman's original profile finances, health and living situation were included in the new diagram. Finally, support was included as a new domain. The model diagrams above both put emphasis on the individual, i.e. the mental health client or service user, being placed at the centre. The services required to support the individual surround the client and to some extent appear in relation to the different life domains in both model diagrams. The most significant modification between both models, however, is related to the emergence of the support dimension as illustrated in the second model. While generally support is to some extent inherent in all the domains identified by other researchers and also in relation to this study, the support dimension has been added to generally widen the perspective, but also for a number of specific reasons: first, research (Mercier 1994) has highlighted the principal relevance of support for people with mental health problems in various ways, second, the evaluation and comparison of support services and the contribution of support services to users satisfaction and their quality of life is one of the research objectives (Chapter 1) and third, service users in group discussion (see Chapter 3) have attached general significance to support service provision.

The diagram designed for this study was developed with the aim of applicability to the countries compared, i.e. Scotland, as part of Britain, and Germany. Therefore an attempt was made to ensure that the domains selected were both known and of potential relevance to service users. The issue was raised in the group discussions where even more domains were chosen (for example, sexuality or religion/spirituality were named as being potentially significant). However, they were not included since central to the model for this study - being based on Lehman's original profile – was not the general question of how many possible life domains there may be in addition to those appointed by Lehman, but rather whether Lehman's domains were altogether relevant to service users in Germany and Scotland. However, also central for the selection of domains (and to some extent, therefore, of Lehman's profile as a useful basis) has been the aspect that the life domains were to some extent identical to areas of support in both countries in order to include the support dimension and also the contribution of services in relation to single life domains. The contribution of services refers to the general support provided in areas such as housing or employment (i.e. place numbers and general availability), but does not include more specific aspects such as the quality of an individual service.

The life domains identified as relevant to this study appear again in two major ways: first, they match to a large extent with major components of community care within which policy development and service provision is taking place (Chapter 5) and they are used as a structuring basis for questionnaire development (Chapter 3).

Overall, the concept quality of life seemed particularly useful to this study concerning the design of research instruments, allowing for the possibility to draw on previous work and recognised tools developed for other studies (Lehman 1988, Barry and Crosby 1993). Both, the concept quality of life and the profile developed for this study also appear appropriate for use in the present comparative context: the concept can be applied in a similar context as significant life domains and components of community care - as identified in later chapters - are largely matching in the countries of comparison. This similarity is perhaps based on a similar cultural and economic background and similar living standards (i.e. Western, industrialised countries) where perceptions and aspirations concerning

achievements and performances may altogether not be too different; however, to apply the concept in a less similar international context can be difficult and may require an altogether different approach concerning definitions and measures for adaptation.

2.3.4 POTENTIAL AND LIMITATIONS OF QUALITY OF LIFE PROFILES

It has been shown that the increasing interest in the evaluation of quality of life especially in the mental health field has led to the development of a variety of standardised tools (see Lehman and Burns 1990) especially in Anglo-American countries, some of which are now available in German translations (Lauer 1993, Priebe and Hoffmann 1993).

The majority of quality of life studies of people with chronic psychiatric disorders are cross-sectional in nature or involve comparisons between groups in different care settings. Many of the descriptive, comparative and evaluative studies focus on objective and subjective living conditions in what is called 'life domains' with respect to support services aimed at social inclusion. Often they concentrate on a combination of objective and subjective indices, for example living circumstances (objective) and satisfaction (subjective).

Although the work of Lehman was based on earlier studies of psychiatric patients and general quality of life work (Campbell, Converse and Rogers 1976, Andrews and Withey 1976), it has been criticised on the grounds that more distinct criteria for quality of life remained elusive (Kilian 1995:97-101). Most notably, the validity of the subjective measures has been questioned. A particular aspect of critique was that Lehman et al. based their model on the assumption that quality of life is the result of the subjective assessment of objective circumstances in various life domains,

and did not sufficiently consider the influence of different individual perspectives and attitudes.

Both, Baker and Intagliata (1982) and Lehman (1983a,b) comment on the need to clarify the stability of the subjective quality of life indicators over time and to determine their sensitivity to objective life changes. But although both Lehman et al. and Baker and Intagliata accept that the subjective judgement of objective circumstances is influenced by individual personal characteristics and life changes, their model concepts remain partial in that they do not adequately assess the subjective value or importance individuals attach to life situations and circumstances (Kilian 1995:99). For example, individuals may express great subjective satisfaction with objective circumstances for a variety of reasons. It may be that objective circumstances indeed correspond with personal preferences and aspirations, but another interpretation may be that objective circumstances in relation to, say, employment, are so unimportant for a person's subjective satisfaction that objective circumstances have little or no effect on subjective satisfaction. It is also possible that a person has reduced his or her aspirations according to objective pre-conditions, for example, a generally narrow labour market and high unemployment; in this case subjective satisfaction may be the result of resignation and adaptation. Especially in the mental health field, where many people have experienced the decline of their social status through the loss of job/house/friends or perhaps have never been able to achieve these goals, aspirations may range on a very low level.

Becker et al. (1993:239) raise similar criticism and have tried to eliminate some of the limitations associated with the Lehman model. They argue that the lack of consensus about domain content means that equal weighting for all domains, or even unequal but pre-set weighting, may not reflect the importance ascribed to them by individuals. Their own Quality of Life Index for Mental Health (QLI-MH) is based on existing scales but covers a range of objective and subjective, generic and specific domains. Consequently the questions used by Becker et al. not only cover

subjective satisfaction but also the importance ascribed to particular life domains.

The work of Lehman et al. in particular has provided a basis for many subsequent quality of life studies (Simpson et al. 1987, Oliver 1991, Barry and Crosby 1995,1996). Lehman's scale is probably the most widely used scale in the area of outcome evaluation in relation to quality of life and the schedules have been most extensively examined and adapted for similar research purposes. Furthermore, their work can also be seen as a foundation for increasing user involvement and participation. Especially, because their conceptual approach and their quality of life profile provides a useful basis to involve service users directly by asking them about issues relevant to their lives and subjective well-being.

While the majority of quality of life studies of people with chronic psychiatric disorders were cross sectional in nature or involved comparisons of groups in different care settings (Baker and Intagliata 1982, Lehman et al. 1986, Simpson et al. 1987), Barry and Crosby (1996) carried out a longitudinal study tracing the same people as they move from one care setting to another thus allowing a more direct comparison of quality of life under different care regimes. Barry and Crosby (1996:215) also acknowledge that it is problematic to assess subjective well-being, because expressed levels of life satisfaction are not absolute indicators of life quality, they are relative measures and their reporting is subject to the influence of a whole host of cognitive and social factors.

Consequently, it seems important to accept that quality of life is not only a complex concept but also a relative property, which has both strengths and weaknesses. It has been shown before that the concept has the potential of being rather comprehensive including, for example, the dimensions of health care and social care. This can be seen as a particular strength, while problems such as the measurability of subjective well-being may be seen as a potential weakness. The latter, however, is not new and efforts are being made by researchers to tackle the questions surrounding quality of life indicators and even the WHO has recommended intensive research

into the area (WHO 1991). However, to tackle some of the problems related to subjectivity, specific methodological components may be helpful. For example, more detailed questions into subjective perceptions may be a useful addition to gross data collection; also, the involvement of those concerned (in this study mental health service users) in developing a quality of life profile may not altogether solve the problem, but can be helpful to identify potential areas of interest and concern. Oliver et al. (1996:83) admit that the construction of the 'perfect instrument' may be illusory and further point out that it is better to produce something, perhaps less than perfect, but feasible, useful and with an ethical basis, capable of being employed now. In an attempt to justify the usefulness of employing a quality of life profile for this comparative case study I would like to follow their notion and an earlier remark made on the same subject that 'a crude or somewhat unreliable measure of an important variable is preferable to a highly precise but irrelevant measure' (Malm et al. 1981:484).

The examination of the concept quality of life including a review of previous studies into the area has led to the development of the theoretical basis for this study. This was followed by a discussion of the problems surrounding the concept and especially its measurement. It has been shown that despite the problems examined above the concept has nevertheless a great potential. It was thus selected as a prime concept for this study and the specific reasons are summarised as: first, it is a comprehensive and holistic concept embracing the entire life situation of individuals, second, recognised research instruments could be adapted for use in a comparative context, and third, the perception of mental health service users could be included as a central element.

It is recognised though, that care is needed when measuring quality of life. Based on the perception of service users the tool developed for this study should allow general comparisons of community based care and the effects on the quality of life of mental health clients in two different countries including the contribution of support services. For more detailed accounts on these issues a number of open questions concerning

personal preferences and experiences were included in the questionnaire to validate the problematic area of subjective satisfaction – at least to some extent. In addition, an attempt was made to broadly exclude potential uncertainties by a number of methodological accomplishments such as group discussions or expert interviews in order to clarify relevant themes and issues thus preparing the design of the quality of life profile applied in this study. Altogether, the profile was designed to be relatively short and straightforward in order to be appropriate for self-completion (see also Chapter 3).

For the purpose of this study quality of life measures used in previous work appeared most appropriate to be adapted for a comparative context for the following reasons: the selection of significant life domains could be applied similarly in Scotland and in Germany. For example, life domains such as housing, employment and finances feature centrally in most peoples lives in modern industrial societies and in this sense both countries share a similar framework of values and aspirations. Furthermore, the contribution of services could also be included in the evaluation. Support services in the mental health field are often directly related to significant life domains such as housing or employment and thus significant life domains often also match with major areas of support. Consequently, the tool developed for the purpose of this study was based on measures introduced above by Lehman and Barry and Crosby, but was modified to meet particular requirements for this study, for example, to adapt the tool for comparative research, to develop a tool for self-completion and, finally, to include the perspective of service users.

As a survey tool based on the concept quality of life it is expected that the profile developed for this study (based on the model diagram above) will give a baseline measure against which to judge the broad direction of community mental health care in the countries of comparison and users' satisfaction in relation to this. It is recognised though, that quality of life interviews are probably best constructed to include a wider range of both objective and subjective measures (see also Oliver et al. 1996) than those

that can be applied in the context of developing a survey tool for self-completion, and especially subjective measures may need more in-depth questioning for validation. However, when data material is presented in later chapters, the critical aspects raised in this section will be taken into account.

Principally, the present comparative study attempts to provide basic knowledge on community care development in two countries from a user perspective, especially concerning the quality of life of mental health service users in community settings. It has been outlined before that central to the concept quality of life as well as to this study are therefore mental health service users and their perceptions. This warrants a more detailed discussion about the general role of service users in the field of mental health care and their increasing significance in policy, practice and evaluation provided in the following section.

2.4   USER INVOLVEMENT AND PARTICIPATION

It has already been highlighted in the previous chapter that the perspective of service users, their involvement and participation is central to this study. This is based on the assumption that service users are the people mainly affected by a policy such as community care and furthermore, are – simply as users of services - experts in their own right. This notion is influenced by a development that has generally affected mental health care especially in Anglo-American countries during the last few years. This section examines the changing role of the mental health patient to become what is now often called a 'service user'.

Over the last decade there has been increasing recognition of the need for 'user participation' and 'user involvement' in community care and the related policy and academic debate has started to focus on those issues

(Beresford and Croft 1986, Rogers et al. 1993, Barham and Hayward 1991, Wilson 1995). In the mental health field user involvement and participation is currently more advanced in Britain, including Scotland, than in Germany, which is evident in policy, practice and research. For example, German policy documents rarely refer to service users as active participants in developing plans and programmes for further development in mental health care and user groups acting as political campaigners are relatively rare.

However, despite the current national differences concerning a user-focussed policy of mental health care (see Chapter 4), certain factors have been of general importance in giving rise to the issue. For example, the movement within Western industrialised countries since the Second World War towards increasing civil rights for disadvantaged groups has influenced the political and policy debate. This was stirred by movements in a number of countries, where action concerning disability rights had started earlier than in Britain, like for example, North America, Scandinavia or the Netherlands. The UK and Germany have both witnessed the growth of self-help as a concept and the consequent establishment of a wide variety of self-help organisations during the Eighties, but the current situation is nevertheless different in both countries. Especially during the last fifteen years Britain has seen a rapid growth in political activity and 'user involvement' has gained official approval. In contrast, German self-help groups in the mental health field often have a therapeutic rather than a political focus, and usually have minimal organisational structure in a regional or national sense. They operate entirely on local level and therefore appear rather isolated and scattered.

It is not entirely clear what may have influenced the rapid adoption of a more user-friendly policy and practice in Britain, where over the last ten years more than 350 local, regional and national user groups have emerged (Campbell 1996:219).

Campbell (1996:220ff) has suggested a number of reasons for the rapid growth of the user movement in the UK, two of which seem particularly

striking concerning the national differences. First, health services and social services have been opened up to consumerist approaches over the last twenty years in Britain. This has begun to influence the way in which mental health services are planned and provided - and the way in which service users as consumers are viewed. Although the consumerist ideology has serious limitations concerning active participation, the growth of the idea has perhaps contributed to a more open attitude of service providers and purchasers to consider the views of people with a mental illness diagnosis.

Second, the anti-psychiatry movement defended by people like R. D. Laing, David Cooper and Thomas Szasz[12] in the 1980s was particularly strong in Britain compared to Germany, which may have had an effect on the growing strength and increasing political awareness of users in Britain.

The increasing relevance of user movements in mental health care is obvious in Britain, and whether influencing factors emerge from an economic background and a changing welfare mix (see Chapter 4) or from a politically motivated background, possibly both, cannot be answered sufficiently within the scope of this study. However, despite comparatively little recognition in German mental health care except for more recent yet cautious developments in research as shown above in relation to quality of life, the significance of service users to this comparative study is on the one hand based on other quality of life research that provides a useful conceptual basis for more user involvement as shown in the previous section. The centrality of user views to this study is on the other hand based on the assumption that service users – as people mainly affected by community care changes – need to be central to any evaluation concerning outcomes in community care. Consequently, the perspective applied in this comparative study into the effects of community care on the quality of life of service users is that of service users themselves.

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[12] For more information on what has been termed 'anti-psychiatry' and a review on therapeutic alternatives to orthodox mental health care see Braun and Hergrueter 1980. *Antipsychiatrie und Gemeindepsychiatrie* Frankfurt, New York:Campus

The UK user movement continues to grow and diversify at a much faster pace than in Germany and a number of immediate problems have already been highlighted, which are important to look at. Campbell (1996:223) has pointed out that many user groups are now at the stage when organisational growth becomes problematic. He propounds that user organisations are increasingly required to consider the issue of representativeness to maintain credibility and effectiveness. For example, strategic overall approaches may be needed to address concerns whether involvement in planning and consultative mechanisms really work, which requires general positions or demands around this type of user involvement (ibid:224) put forward by regional or national user organisations.

In a similar context Ross (1995:798) maintains that the involvement of users at the level of service planning is, in any case, nearly always a matter of users fitting into existent structures of dominance where the minority presence and perspective of one or at best two users - i.e. representing users as a group - will be unable to compete with the professional power base and interests. Research has also indicated that there seems to be an assumption that users cannot realistically be involved in service planning and decision making processes because they are incapable of understanding budgets and budgetary allocation and constraints (Ross 1995:799). More generally, it was pointed out that staff attitudes towards user involvement initiatives and their commitment to the principle of user participation are possibly the most crucial factors in determining the extent and level of user involvement (ibid). The research exploring the reality behind the rhetoric of user involvement in day care services (Ross 1995) has nevertheless identified encouraging examples of good practice amongst day centre staff and other care professionals, often in less than conductive environments. At the same time the research has uncovered a considerable amount of discontent amongst service users, aimed both at 'the system' and at individual workers with whom they came into contact. It is important to note that pledges of user involvement are one thing, and acting upon them another.

Empowerment[13] is one of the latest key concepts to be introduced in relation to user involvement and user participation. It is defined as "a process, a mechanism by which people gain mastery over their lives" (Rappaport 1987:122) and can happen in various ways. In relation to service delivery empowerment requires an egalitarian, collaborative partnership approach to mental illness which focuses on minimising differences in status between patients and staff (Rappaport 1985, Tobias 1990). In relation to policy planning empowerment requires that service users have influence over plans and decisions, and that their ideas are taken seriously. It is argued that programme components and policy objectives that really increase power of people with mental health problems in terms of economic resources (for example, vocational rehabilitation, financial support) or status are associated with greater perceptions of mastery and thus greater life satisfaction (Rosenfield 1992:301).

Empowerment can also be seen as being directly relevant to the concept quality of life and thus to this study. Increasing empowerment as defined above can support a process that is relevant to the individual quality of life as defined earlier in this chapter: to developing a sense of well-being and satisfaction experienced by people under their current life conditions. As has been stressed at the beginning of the section, empowerment is a process rather than an condition, and as a process (ideally supported by mechanisms such as policy guidelines to enable and guarantee user participation) potentially helpful to increase individual autonomy and independence leading to better well-being and personal satisfaction. For example, it is likely that gaining more power over one's life and developing a sense of self mastery (in other words, developing autonomy and

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[13] The concept of empowerment is often also used in relation to consumerism, which has emerged as an attempt to redress the balance of power between producers and purchasers of services, and which has now spread to the public sector. The debate around consumerism also employs 'empowerment' to describe a situation that enables consumers or their representatives to exercise informed choice through information about services, policies and objectives (see Lewis 1991)

independence) increases individual well-being and satisfaction concerning relevant aspects of everyday life.

Furthermore, the profiles developed for recognised quality of life studies as introduced in the previous section can be seen as instruments to give mental health service users a say in matters of their concern. This opportunity, for a long time denied to mental health patients, can make people more aware of their immediate concerns, aspirations and perspectives, and potentially enable them to take more action concerning their interests. While the knowledge of such issues does not necessarily lead to more influence in the quarters of hitherto powerful stakeholders such as politicians or policy makers, it may be seen as a first step to gain more power in the future. It is, after all, a process that needs to happen on at least two sides as has been pointed out by Ramon (1999:17). She suggests that empowerment needs to take place on at least two sides as the phrase emphasises the need to give power to people with disabilities, and for them to take it and use it. Clearly, power includes the right and the capacity to influence decisions which are deemed unsatisfying, yet often this sort of power is usually not in the hands of people with dependency needs. All too often people with mental health problems do not participate in the decision-making process and are in a way victims of both a lack of power because of their exclusion from the decision-making process and perhaps even by a lack of competence and experience to exercise power.

Means and Smith (1994:72) have emphasised that the victims of non-decision making may not always be aware that they are victims because they do not always appreciate their real interests. They further note that creating opportunities for greater participation, dialogue and control over services may not be enough, since many service users will not be fully aware of their real interests (ibid) and that empowerment requires a general raising of awareness about society's discrimination and oppression of people with disabilities.

It has been pointed out that empowerment is related to a sense of self-mastery, which appears to be central to attaining a high level of functioning

and good outcome from illness (Warner 1991:125), and to a rise in confidence in acting on one's own behalf. To encourage people with disabilities to master their own life and learn to make informed decisions is unquestionably an important step to empowerment. User groups can play a significant role as they provide a valuable basis to develop self-confidence and a sense of power and capability, on a collective as well as on an individual basis. In theory, a policy of community care can provide a basis for this process, for example, through the official propound of user participation in community care planning and development (see also Chapter 4).

Campbell (1996:224) demands that the user movement, i.e. user groups and organisations and their representatives on local, regional and national level, must address the problems more clearly. He claims that "the overall questions of how much is really open for change within a medically dominated mental health system, and whether improving services without changing social and cultural attitudes towards those who use them is a satisfactory goal, persist on the horizon and are insufficiently addressed by user activists". This quotation refers to the British context but may be applied to other countries, like for example Germany, although the German user movement has not yet arrived at a comparable degree of organisational structure with active user groups campaigning for their interests on national, regional and local level.

Nevertheless, the principal problem addressed is not only related to Britain. The issues raised by Campbell have something to tell about underlying aspects influencing the limited opportunity of users' to participate more fully in society, an aspect which leads us back to what has been pointed out before: that empowerment requires a general raising of awareness about society's discrimination of people with abilities (Means and Smith 1994:72). However, although it may be agreeable that social and cultural attitudes need to change to approach more genuine social participation for people with disabilities, it is also clear that social and cultural attitudes are opaque to immediate outside scrutiny and change.

While policies may be changed, established social and cultural attitudes may resist change for a long time. But it is possible that studies like those into the quality of life of mental health service users - including the present one - can contribute to the process of empowerment by dissemination and publication. In relation to this study it is also the methodological approach that may support empowerment to some extent: to involve service users on various stages of the research and discuss issues of concern (see also Chapter 3).

The problems addressed above are related to power, the sharing of power and the ability and willingness to give power to those formerly powerless, for example, people diagnosed with a mental illness. While certainly all stakeholders involved may need to develop new skills for a partnership approach, service users may achieve competence and confidence by a number of means. For example, a recent evaluation of the National User Involvement Project in England by the Joseph Rowntree Foundation (1999) has found that service users needed a range of training and support in order to be fully involved in decision making. The researchers concluded that employing experienced user consultants can be an effective method of assisting local groups to involve a wider range of service users if the work is well planned in advance, is undertaken in full partnership with local organisations of disabled people and if systems are in place to continue the work afterwards (JRF 1999). It is a continuing process that includes empowering people to accept rights and entitlements such as participation in policy and practice development once uncommon, to take them and make best use of them.

However, attention must be drawn to the use of 'self-help' and 'empowerment' as a strategic weapon to reduce public expenditure. The sudden popularity of volunteers and private initiatives was seized upon by conservative political circles eager to exploit the self help movement, for their own ideological purposes, as a popular endorsement of their policies of rolling back the state and reducing public social services.

In this study the experiences of service users as well as their views and perceptions feature centrally for reasons explained before. Users have been involved at various stages of the research process (see Chapter 3) in order to ensure that the identification of major issues of interest is based on users own perceptions rather than, for example, on professional opinion. The concept of empowerment is therefore seen as a central element to the design of this study, but also to community care policy and practice development which will be addressed again in later chapters. The relevance of empowerment to the concept quality of life - and vice versa - emerges from recognised quality of life research and relevant instruments. It has been shown that the views and perceptions of service users are often central to quality of life studies and it is not unlikely that (increasing) opportunity to voice own views and concerns may support the process of empowerment, defined before as a process or mechanism for users to 'gain mastery over their lives' (Rappaport 1987:122).

2.4.1 USER INVOLVEMENT AND OUTCOME EVALUATION

The involvement and participation of mental health service users may take place at all levels of policy planning and practice development including outcome evaluation. In practice this happens relatively rarely.

In the area of outcome evaluation Nocon and Qureshi (1996) have found that outcome measurement is often not informed by users' views about community care. They pointed out that performance measurement often focussed on activity indicators, on inputs and processes, rather than on outcome for service users. For example, knowing how many places of supported accommodation are provided to users does not indicate how effectively users' needs are being met.

It has been mentioned before, that a more holistic approach including the views of users (and other involved groups like carers and professionals) is

beneficial and indeed vital, not least for outcome evaluation. Users are, after all, the people mainly affected by community care changes and should therefore be seen and treated as experts, not least concerning the evaluation of community care. This is also highlighted in the work of Beresford and Croft (1986) who emphasise the need for genuine participation by users in research about services. The experiences, perceptions and views of service users are important to receive an authentic picture of subjective needs, service performance and quality. This comparative research also follows the recognition that to know what the users of a service think and feel about a service is an important part of evaluation, and that the evaluation of outcome in community care should be informed by users' views about the services they require. While the recent British policy and community care legislation propounds user involvement on various levels (local, regional, nation) of policy planning and practice development (see also Chapter 4), it has nevertheless been pointed out, that the last group whose views are sought in evaluation are frequently the users: the direct consumers, the patients or clients who are users of the service, and the indirect consumers, the families of users who fill the role of informal carers (WHO 1991, Atkinson and Elliott 1994:156). Rogers et al. (1993:5), citing a review on patient satisfaction literature by Hall and Dorrian (1988), argue that obtaining the views and levels of satisfaction from psychiatric patients has seriously lagged behind other client groups.

However, the evaluation of the perspective of service users may not immediately produce straightforward results and new insights, which was indicated by the results of a German study. In contrast to more conventional practice, where professional researchers study users of psychiatric services, a study in Berlin (Terporten et al. 1995) had quite a different design. The perspective of users of psychiatric services was investigated by a group of users themselves. In this study a group of users investigated subjective quality of life, assessment of psychiatric treatment and needs of other users. A special questionnaire was constructed and used. According to the findings, psychiatric institutions were on average

good and satisfaction with different life domains was also fairly good. The problems and results of the study have been described as similar to what is being generally experienced by professional researchers (Gruyters and Priebe 1994). The vague assumption, that patients may have better access and provide new approaches to investigating the perceptions of other patients has not been confirmed in the study. It has been speculated, however, that the researching patients have themselves been subject to a long-standing influence by professionals, for example in relation to approaches, concepts and terminology, which may have had an impact (Terporten et al. 1995). It is also possible, that users' perceptions are influenced by relatively low aspirations concerning life satisfaction or future perspectives; after all, for a long time mental health clients have not been asked about their opinion concerning, for example, the support services they prefer. Therefore the critical reflection of individual circumstances by service users themselves must be seen as a relatively new activity in the field of mental health care. Obviously, service users need to gain more experience as active participants – provided that they are treated as equal partners - to develop a sense of independence, self-confidence and autonomy.

A positive outcome that has been highlighted by the study (Terporten et al. 1995) were the discussions among users in relation to the project in particular and research in general. The project itself and the presentation of results has encouraged discussion and stimulated the debate among users, which, in turn, has facilitated the ability to develop a critical argument, justify own standpoints and gain a sense of self-mastery in relation to this. It is very likely that this effect is useful to facilitate user involvement and participation and eventually increase empowerment.

Empowerment, as has been shown before, is not only a currently relevant key concept in Britain, but can be seen as being directly relevant to the quality of life of people with mental health problems for reasons explained above. This study is based on the assumption that empowerment can positively affect the quality of life, i.e. increase individual well-being and

satisfaction, and, furthermore that outcome evaluation from the perspective of service users by using quality of life instruments can contribute to the process of empowerment. Consequently, the involvement of service users is one of the central aspects in this study. Based on the recognition that service users are the people mainly affected by mental health care policies and respective legislative changes they are seen as experts in their own right. Furthermore, it is recognised that for mental health services and their users the struggle for involvement must be concerned with a wider aspiration of people with mental health problems to participate more fully in society.

2.5 SUMMARY AND CONCLUSION

This chapter examined outcomes in community care, in particular the concept quality of life and its application in community mental health care. Furthermore, an attempt was made to approach a definition of the concept and develop the theoretical basis for this study. It has therefore been central to this chapter to examine some of the theoretical implications concerning outcome – conceptualised as the impact or effect of a policy - and outcome evaluation, and especially the concept quality of life. Finally, the involvement and participation of service users in mental health care and the impact on the quality of life was examined.

A review of relevant outcome studies has indicated that formerly studies concentrated mainly on the resettlement process, while there is now increasing need to focus entirely on clients in community settings and their living and support arrangements.

It has been argued that the concept quality of life can provide a useful framework to assess the living circumstances of mental health clients in the community. Using the inherent problem between broad use of quality

of life as a concept and the difficulty of defining complex concepts as a starting point, it has been shown that the concept is useful to be applied in the context of this comparative research: quality of life is a holistic concept covering both the health and the social care dimension, the concept is useful to include the user perspective and it is useful for comparative evaluation focussing on both community living as well as community based support in the selected countries, Germany and Scotland.

A model diagram was developed to illustrate the theoretical dimension of the concept in relation to this study on the one hand and to provide a research framework for the evaluation of the quality of life of mental health service users in two countries on the other. Based on the theoretical model of Lehman's quality of life profile the model developed for this study focuses on the inclusion of significant life domains but also on the inclusion of the support dimension. The development of the model diagram for this study is based on the hypotheses that formal and informal community support is important to the quality of life of people with mental health problems.

In this chapter an attempt was made to highlight the importance of a user perspective in community mental health care. It has been argued that service evaluation from a user standpoint is necessary to receive a full and comprehensive view. The use of the concept quality of life to evaluate community care from a user perspective provides both: a focus on the user perspective and a comprehensive approach to significant areas of life (including a focus on the support dimension). Quality of life as a multi-focussed measure may therefore be used to assess the contribution of services to the individual quality of life; and it is a most useful concept for investigating the required scope or the perceived quality of community based service provision from the client's perspective.

There is, however, a need to be aware of the limitations of the concept and current methods of assessing quality of life. It has been shown that particularly the reliance on subjective satisfaction measures remains a problematic area for evaluation. While the problems concerning subjective

measurement, for example, in relation to individual satisfaction may not be entirely solved, it is important to take the limitations into account and refer to them whenever the interpretation of results requires caution. Barry and Crosby (1996:215) provide a useful suggestion when propounding that satisfaction measures are best interpreted in the context of objective quality of life indicators and ideally as one of a range of outcome measures monitoring change over a period of time.

Overall, this chapter has examined outcome evaluation and emphasised the significance and scope of applicability of the concept quality of life, but has furthermore highlighted the importance of research from a user perspective. In this context the chapter has stressed the relevance of a British key concept known as empowerment, which is seen as relevant to further development concerning more user participation in general, to the concept quality of life in particular and not least to this study. Principally, an attempt has been made to show that individual outcomes are a most important measure, both in relation to this study but also concerning the general success or failure of community care policy and practice. Consequently, eliciting the perspective of individual clients on their current life situation is an essential aspect of any exercise attempting to assess the outcome of community care and of concepts such as the quality of life. Based on this notion the present study has been undertaken.

The following Chapter provides the methodological background into the study concerning the effects of community based mental health care policy and practice on the quality of life of service users in Scotland and in Germany before subsequent chapters address the specific aims of the study as outlined in Chapter 1.

CHAPTER 3

METHODOLOGY AND METHODS

3.1 INTRODUCTION

This chapter presents the research strategies adopted in this study and includes a discussion of the methodology and methods selected. The introduction into the main themes of the research and the general methodological approach is followed by a discussion of the major research methods including the selection criteria applied. In addition, the composition of the sample is accounted for, and the focus on the micro level of community based mental health service provision is explained.

Issues of relevance such as the process of negotiating access to potential respondents are pointed out, before data collection issues are explored. The selection of a main data gathering method, the self-completion questionnaire, is explained and attention is given to the many issues surrounding questionnaires, in particular those employed to evaluate the quality of life for people with mental health problems.

In relation to data collection particular attention is given to data collection problems, especially concerning cross-national research. Implications regarding language and national terminology, in conjunction with the difficulty to find comparable sets of data are examined. In this context validity and reliability of the data are discussed, especially, for example, the impact of different national characteristics or specific national terminology.

The chapter finishes by describing the methods employed to analyse the collected data.

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I chose my research area as care in the community for people with mental health problems in Scotland and Germany. The selection of the topic as well as the two countries of comparison has been influenced by previous professional experience in the field of mental health care in Germany and an academic interest in community care policy and practice development, but also by previous personal contacts concerning the countries of comparison. Based on contemporary developments in community care as set out in Chapter 2, I identified the outcome of community care policy and practice concerning the effect on service users as my major research topic. In particular, I wanted to explore the views, perceptions and experiences of mental health service users in both countries in relation to community based living and community based support, with specific emphasis on issues concerning the quality of life of people with mental health problems.

This study's focus is thus to examine the outcome or effects of community mental health care policy in Scotland and Germany, with special relation to the quality of life of people with mental health problems. Therefore, an intersecting set of different research methods is used in this study ranging from documentary analysis in order to examine respective national mental health care policies to qualitative and quantitative methods to evaluate and compare community based living and community based support from a user perspective. The main aims and objectives of the study have been outlined in Chapter 1.

3.2 STUDY DESIGN

3.2.1 CASE STUDY

The research design adopted was that of a comparative case study. In order to compare care in the community for people with mental health problems in two countries I have chosen to adopt the case study format for various reasons.

The case study format appeared useful to examine and compare the outcome or effect of a policy such as community care in some detail. The selection of two smaller geographical settings in Germany and Scotland provides the basis for more detailed examination, which would not be possible on national level. Dockrell (1995:51) similarly suggested that case studies are useful to approach variables and research questions concerning individual naturally occurring entities (i.e. geographic/cultural regions, cities), which allow an examination of current events and concerns and provide the basis for theoretical generalisations (ibid). In other words, the examination of how community care works can be obtained in one particular locality and the case study format is useful to provide a detailed and consistent picture of this locality. At the community level, more detailed, more comprehensive, and case related data on use of services can be obtained, which provide a better basis for the understanding of functional associations and individual consequences. The investigation of the effectiveness of a small scale, less complex system can contribute not only to the mosaic of knowledge, but also to an understanding of the functioning and effectiveness of the complex (national) systems which they reflect in a simplified form. Descriptive analysis of small-scale systems of care, e.g. the community level, representing national health systems en miniature, can provide valuable information for the interpretation of national health care systems (Wing and Bransby, 1970).

Runyan (1982) has pointed out that case study methods are inherently more suitable for such tasks as describing individual experiences, developing idiographic interpretations of experiences and developing context specific predictions, plans and decisions. As the evaluation and comparison of the views and experiences of service users is central to this study, a case study approach seemed appropriate. Using the case study format it is more likely that the views of service users concerning community living and community based support are consistent with the individual characteristics found in each case study locality. In this case, a link can be drawn between local circumstances (i.e. community care service provision) and the perception (i.e. satisfaction) of service users in relation to this. The case study format can therefore provide a basis for a better understanding of links and connections between general policy development, practical outcome and the perception of service users.

This has been similarly pointed out by Treece and Treece 1982, who suggested that case studies provide a rich source of hypotheses, and display individual events within a total network of relationships, demonstrating links. Therefore case study evidence may be used to alert planners and practitioners to factors which may affect further planning. It enables an informed judgement to be made prior to a course of action. For example, it allows practitioners to see behind what is taken for granted, removing the flattening effect of habit (Ruddock, 1985:123-127).

Based on the case study format this research study includes a descriptive analysis of two small scale systems of care to examine the different patterns of service provision and – in relation to this – an evaluation of users' satisfaction concerning issues affecting their quality of life that are directly related to community care policy and practice. The analysis of two small scale systems of care is partly based on an approach applied by Schunk (1996), who in a study into elderly care charted the 'welfare mix pattern' (i.e. the available range of services) in one particular locality (see Chapter 6). Especially in the present context of comparative research this approach is a useful framework for analysis, because it can provide a comprehensive and coherent picture of community based mental health

care on a small scale. Furthermore, the presentation of the user perspective is directly related to the welfare mix pattern available in the case study localities under comparison.

3.2.2 COMPARATIVE CROSS NATIONAL RESEARCH

The purposes for undertaking cross-national research are various and conditions which favour the development of comparative research have emerged influenced by the scientific trends. With increasing globalisation and indeed europeanisation the scope of (and demand for) comparative research will probably expand even more in the future.

Thus, a significant reason for conducting comparative research stems from the increasing interdependence which characterises the world today. Problems, policies and issues cross borders and the policies of one country may affect other countries. The efforts to harmonise national policies on certain issues are on top of Europe's political agenda today (convergence), and the attempts by international and transnational organisations such as the European Union to establish common standards in different policy areas has motivated research on the various experiences countries have had in addressing common problems. A comparative look at policies or programmes like, for example, health and social care or indeed community care has thus become more salient to the academic research community and is the basis for general policy transfer.

As part of the growing interest to learn from other countries' experiences and approaches to social and health care, comparative research projects are now commissioned on a variety of topics. The present research study evolves from this background and before potential and limitations of cross-national research are examined, a definition of the domain and the delineation of the principal types of cross-national research is provided below.

Heidenheimer et al. (1990:2-3) have defined the field of comparative public policy as "the study of how, why and to what effect different governments pursue a particular course of action or inaction". This definition covers a wide range of different concerns and analytical approaches and captures the central elements of comparative research. Clearly, a concise definition is more valuable than the ambiguous notion that cross-national research is any research that transcends national boundaries.

Particularly significant in relation to this comparative study is the contribution to the development of a relevant knowledge base for both domestic and foreign policy. Furthermore, the examination and application of relevant concepts (e.g. quality of life) can contribute to further theory development, especially concerning the application of concepts in a comparative context. Comparative research can fill important gaps in knowledge about how other countries deal with similar issues and about the background and effect of alternative strategies for solving common problems. Comparative research can thus aid in the specification of the conditions under which one country can learn from another, and comparison can put judgements about policy processes and outcomes into a broader and more refined perspective. For the purpose of this study comparative cross national research is defined as research that mutually informs community mental health care policy and practice through the identification of relevant concepts and respective national models of 'good practice'[14].

Comparative research also includes a number of potential difficulties that must be addressed. First, it is difficult to produce reliable data sets for international comparisons as administrative, conceptual, cultural and sometimes language differences mean there are bound to be problems. Especially in projects researching peoples lives, experiences and attitudes, this additional problem may turn out to become an additional

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[14] As part of what can be called a community care jargon 'good practice' has become a popular phrase in Britain; the phrase refers to positive developments in community care policy and practice and appears in discussions as well as in policy documents

burden for the researcher. Possible difficulties in comparative research have been summarised by Jones (1985:172) who identified personal social care as one of the least researched and least documented areas for comparative study. Some of Jones' critical remarks are related to the difficulty to generate 'quantities of good hard data', which is a general problem in researching peoples attitudes and experiences, where particular methodological weaknesses have been associated with qualitative investigations (Bryman 1988), and hard data is difficult to receive. Similarly, this is evident in relation to the concept quality of life, where particular methodological problems have been identified in relation to satisfaction measures (see Chapter 2). Such problems, however, do not only count for comparative research, but in comparative research they may become an additional problem, especially when national data-sets are incompatible and difficult to compare.

The difficulty to compare national data sets are often related to two major problem areas: technical and terminological problems. The technical side refers to the situation that one country may be able to provide data sets on one particular subject area, for example supported accommodation, while another country can not provide such data. The terminological problem can pose additional difficulties, because even if similar data sets are available in the countries of comparison, the national terminology may incorporate different meanings. This also refers to the equivalence of definitions if concepts, policies and practical outcome are compared.

Data gathering may be further complicated by a medical determination prevalent in the field of psychiatric care. Ramon (1996a:9), in her review on mental health in Europe, notes, that most of the available figures have been collected according to definitions provided by mainstream psychiatry; hence the strengths and weaknesses of the data relate to the dominance of the clinical-somatic model of mental distress. A good example for this is reflected in the terminology, when according to most statistics 'beds' are counted to indicate the availability of acute psychiatric care (i.e. hospital care).

Doty (1988) identified three major problems in her comparisons of the treatment of chronically ill patients in different countries, which appear relevant in the context of this study. Firstly, there may be an extremely wide range of services that should be included in the comparison, but the number cannot really be reduced without some measure of randomness. For example, the services included in my comparative study were the major services operating in the case study localities and they were grouped into significant areas of support such as accommodation or employment; smaller projects that did not fit into these categories may have been left out because they were unable to be traced or remained unknown to the researcher. Secondly, there remains considerable inconsistency in the concept apparatus. For example, a day care centre in Scotland is different from a day care centre in Germany. And, thirdly, the statistics provide only poor coverage particularly for community care. This last aspect, statistical coverage, may have changed in more recent years as statistics are increasingly available (e.g. Community Care Bulletin in Scotland or the Landeskoordination in Hesse/Germany). The problem remains, that statistics are often not compatible, which is particularly relevant in cross-national research. For example, statistics may only cover national, regional or local entities and/or concentrate on respective national particulars and concepts which may not be similarly available in the countries under comparison.

In this study I have addressed such problems whenever necessary, and have explained differences to the extent that the interpretation of data material was possible and the context correct.

3.3 METHODOLOGIES AND INSTRUMENTS

This study used an intersecting set of different research methods including documentary analysis as well as qualitative and quantitative methods.

The main research method is quantitative based on a questionnaire survey in two selected case study localities.

Documentary analysis mainly included the analysis of relevant policy material, especially official policy guidelines and respective legislation, but also reports and more general information such as brochures and promotional material concerning community mental health care. Documentary analysis was employed to analyse mental health care policy on national, regional and local level and obtain comparative data on concepts, specific national characteristics and developments in mental health care. The data that derive from documentary analysis are furthermore seen as important for the interpretation of user views.

Qualitative methods, especially interviews, are often time consuming but considered more appropriate to obtain a more detailed account of people's attitudes and perceptions, while quantitative methods, for example questionnaires, may be less time consuming but also less detailed especially if a fixed set of questions does not allow more detailed expressions. Knapp et al. (1992) have suggested that quantitative measures rarely precisely mirror the social or personal reality they seek to describe, but are valuable in providing a broad consumer view and in offering points of comparison. However, while interviews often cover smaller samples, the potential of quantitative methods like questionnaires is that larger samples can be covered.

In the particular case of this study I wanted to approach a large proportion of mental health service users in each case study locality and provide findings which might not be representative for the national mental health population but for the case study localities. It was anticipated though, that the findings could be applied to the wider national situation. For example, the views of service users concerning preferred living arrangements and support options may be applied to the wider national level as reflecting at least a tendency of general user preference.

Quantitative methods were selected as the major research instrument, while qualitative methods were selected as a useful addition.

The collection of data took place over a period of 16 months (from October 1995 until February 1997) in both countries. Qualitative data included key interviews and group discussions with mental health service users and staff, but also the observation of community settings and facilities at the beginning of the research period, while quantitative data included the questionnaire survey as the major component of the data collection process.

3.3.1 QUALITATIVE METHODS

3.3.1.1 EXPERT INTERVIEWS

In many European projects, national experts are required to provide descriptive accounts of selected trends and developments derived from national data sources. The researchers then synthesise information on key themes and issues (see for example Ditch et al. 1996). I have referred to this technique to some extent although on a much smaller scale.

In the planning stages of my research I consulted a number of experts in both countries including mental health service users, professionals of various support services and academic staff in order to identify key themes and developments in relation to community based mental health care. All these specialists provided valuable advice to help selecting the relevant from the irrelevant in order to identify the key issues in community care policy and practice and, most importantly, to design a questionnaire that would most effectively produce reliable data sets and incorporate practical as well as scientific considerations.

A total of 23 loosely structured interviews (13 in Scotland, 10 in Germany) based on an interview guide (see Appendix) took place beforehand at major support services and organisations in the case study localities.

Usually, my request for an interview was positively accepted and took place with a senior member of staff (care manager, social worker, team leader etc.); except for the user–led service CAPS (Consultation and Advocacy Promotion Service) in Edinburgh, where the interview partners were both non-professionals[15] and qualified professionals such as social workers. Notes were made to record the answers to the key questions. The intention was, first, to obtain relevant information about the situation of community based mental health care in Edinburgh and Offenbach respectively and further about experiences, preferences and potential gaps in relation to service provision. This was considered relevant to gain access to the field and prepare the planned survey (design of the questionnaire, information concerning relevant questions). Second, the interviews were intended to raise interest and motivation among professionals to function as transmitters and provide access to service users.

3.3.1.2 GROUP DISCUSSIONS

Assessing users' satisfaction with the services they receive is assuming greater importance and a wealth of information has developed in this area, including methodological challenges. Hansson et al. (1993) suggest that most studies have used interviews or questionnaires developed by professionals with little or no user input, but to evaluate services truly from a user perspective it is necessary to see the world from the user's point of view. Barham and Hayward (1991) suggest that, in order to capture users' experience, a shift in research style is required from the quantitative to the qualitative, and towards a more collaborative way of working with the subjects of research. Similarly Rogers et al. (1993) suggest that there needs to be more of an attempt to involve users themselves in research.

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[15] At CAPS in Edinburgh a number of previous psychiatric patients were employed as support workers

For this study I decided to include users' in the very early stages of research and involve a number of users in the questionnaire design. This can be seen as an element of what has been introduced as Participatory Action Research by Whyte (1990), a research strategy which involves the research objects from beginning to end. It had been anticipated that user input into questionnaire design was a vital contribution to develop a questionnaire truly reflecting the user perspective. Therefore, a number of discussions with user groups were arranged and potential questions and areas of interest were subjected to debate. The user questionnaire was thus developed and the final draft was circulated for comment among members of a user group in Edinburgh and among users in Germany. It must be acknowledged though, that the final decision in relation to what kind of questions eventually became part of the questionnaire remained the responsibility of the researcher.

However, as Donabedian (1987) suggested, users are indispensable sources of information in judging the quality of care, and there is no reason why a user perspective could not be built into all mental health research, particularly when evaluating service provision. In relation to this study service users have been a valuable source of information and their input into planning and questionnaire design has contributed to the successful inclusion of most significant issues from users' own perspective into the questionnaire.

It has to be acknowledged though, that users generally wished more detailed questioning in relation to most of the issues raised during the discussions, but were at the same time aware that a self-completion questionnaire was a fairly restricted instrument.

3.3.1.3 OBSERVATION OF THE SETTING

Observation of the setting took place in and around service agencies from the major support areas. In most cases this was connected with expert

interviews introduced above, and often a guided tour was provided to show what the support service could provide and what the facilities were. Most of the service agencies involved in the survey (see Appendix) were visited and observation of the setting included, for example, location of the service and building structure, availability of facilities, opportunity for privacy or independence. In this study the observation of the setting was used as an additional tool to underline specific aspects in relation to support areas where the actual setting showed particular strengths or weaknesses like, for example, regarding the comparison of hospital provision. Notes were made to record major details of each setting. These notes were later analysed according to their community care relevance[16], and results are included in the comparison of services (Chapter 6) when the welfare mix in the case study localities is presented.

3.3.2 QUANTITATIVE METHODS: QUESTIONNAIRE SURVEY

3.3.2.1 QUESTIONNAIRE DEVELOPMENT

Questionnaires have much in common with interviews. Careful planning and considered wording are just as necessary to achieving successful outcome. The main aim of both is to get the respondent's point of view. Interviews are usually fairly time consuming and therefore cover smaller samples, while questionnaires are useful for gathering facts (and a broad attitudinal view) from larger samples. As I wanted to cover a larger sample, I selected questionnaires as the main research instrument.

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[16] Community care objectives (i.e central location of services, privacy and independence) that can be applied for observation of a setting have been elicited from policy guidelines (Psychiatrie Enquete 1975, Expertenkommission 1988, Community Care Plans)

I wanted to develop a questionnaire that was comprehensive, relevant and content valid (Brewer and Hunter 1989). In other words the questions were to cover important areas of everyday life as well as the community support network and, in addition, the experiences clients have had in relation to this. In order to try and ensure content validity I reviewed the literature, talked to colleagues and interviewed experts from the field.

Also important, content validity was confirmed by qualitative data that derived from clients' reports (group discussions) of issues of importance in their lives. Further validation involved a combination of peer review and continued feed back from service users during the initial stages of the research including the design of the questionnaire.

One of my particular concerns in relation to questionnaire design was the formulation of survey questions appropriate to yield answers which would permit cross-national comparisons; also required was the selection of comparative outcome measures. While the latter could be solved after a literature review, the major concern remained: the formulation of questions which could be translated into another language - and thus also transferred into the context of a different care system and setting. This particular aspect is considered in more detail in the section on data collection problems.

In order to design the questionnaire 3 group meetings had been arranged at different support services in Edinburgh and Offenbach respectively. The first meeting took place at the *Stafford Centre* in Edinburgh, a drop-in centre located in the middle of Edinburgh, where issues of concern were discussed with service users and staff. Other discussions took place at the *Craigmillar Day Centre* and at *CAPS, the Consultancy and Advocacy Promotion Service*, both also in Edinburgh. Similar meetings with service users took place in Stadt und Kreis Offenbach, for example, at *the Gemeindepsychiatrische Zentrum* and *Tagestaette* in Langen and the *Werkstatt fuer psychisch Kranke* in Offenbach.

The questionnaire was thus designed with the input from users in both countries, and the first draft was again reviewed by discussion with various

experts ranging from academic staff at Stirling University to users and professionals in Edinburgh and Offenbach.

Most interesting points emerged from the discussion with service users after the draft questionnaire had been circulated among service users in Edinburgh. For example, the language that is most appropriate. Users were clearly concerned that the language should be neither discriminating nor patronising. For instance, it was criticised that the term 'mental illness' appeared in my questionnaire rather than 'mental health problem'. In general relation to the widespread use of specific terminology I was given another example which I found most significant. The users I spoke to argued that the term 'the mentally ill' should be abandoned from widespread use as the emphasis is upon the illness rather than the person. Instead, it was suggested to use the term 'people with mental health problems' as a more positive phrase with the emphasis upon the person rather than the illness.

Another, quite different, problem became evident while discussing potentially important issues with service users. The range of interesting and important questions is apparently huge yet there is no way to consider everything. Similarly, Nocon and Quereshi (1996) have pointed out that one of the major difficulties in relation to outcome measurement is that the large range of potentially relevant issues means that outcomes measures are often long and complex, or that a large number of different measures is needed.

Clearly, some kind of structuring and focussing was inevitable with regard to theme focus and questionnaire development; it was determined by other distinguished measures, most notably, the recognised quality of life research instruments developed by Lehman et al. (1982) and Barry and Crosby (1993) and the feed-back received from group discussions and expert interviews. The theoretical implications of quality of life as concept and tool for measurement have been discussed before and the theoretical framework developed for this study (see Chapter 2) provides the basis for the design of the questionnaires, especially concerning the selection of domains (i.e. significant areas of life). Therefore, the framework within

which the questions should range was to some extent pre-determined by the researcher at the beginning of the group discussions. This was helpful to avoid confusion while considering many interesting questions concerning community based mental health care.

Nevertheless, it is worthwhile mentioning that many users I spoke to, particularly in Edinburgh, were concerned with other important community care themes, where they felt a satisfaction survey would yield useful results, but which were not included in the questionnaire. For example, the satisfaction with hospital discharge plans was mentioned, as was the satisfaction with the practical implications and outcome of user participation, such as co-operation with professionals and authorities.

The user questionnaire was thus drafted taking into account the issues of importance that derived from expert interviews and group discussions, the literature, consultation with colleagues and, most notably, other quality of life research measures as discussed in Chapter 2. The quality of life interview (QoLI) developed by Lehman et al. (1982) had been modified and adapted for use with a long-stay psychiatric population by Barry and Crosby (1993) in Britain; I have used their schedule, the Bangor Quality of Life Schedule to develop my own questionnaire, and made a number of alterations.

These alterations were to some extent simplifications with the aim to develop a questionnaire which was useful in two major ways: first, the profile needed to be appropriate for the application in two different countries and second, the profile needed to be appropriate for self completion. While the Bangor Quality of Life Schedule is a structured self-report interview schedule, covering - like Lehman's original profile-objective and subjective indices of quality of life in nine life domains, I wanted to design a questionnaire for self-completion. According to my study design I wanted to obtain the views of as many users as possible in the respective case study localities, and therefore a tool for self-completion seemed more appropriate than interviews, which would have been far to time consuming.

Consequently, a questionnaire was essential which was fairly easy to complete. Therefore, the designed questionnaire was considerably shorter than the schedule developed by Barry and Crosby (1993). Objective life experiences, together with their subjective evaluation by satisfaction scales were covered across only six life domains: <u>Health, Living Situation, Daily Occupation, Finances, Support and Social Contacts.</u> The selection of six life domains out of originally nine in both, the Lehman and Barry and Crosby schedules was influenced by the results from group discussions about participants' general perception of important issues and themes. Participants generally confirmed the importance of these six domains to their lives, which has in turn influenced the development of the theoretical basis to this study (see Chapter 2).

Overall, questionnaire design was based on three major elements: previous quality of life research tools (Lehman 1982, 1988 Barry and Crosby 1993), theoretical considerations as discussed in chapter 2 and the views of mental health service users as drawn out of group discussions. Consequently, the structure of the user questionnaire reflects a pattern similar to previous research tools, but was adapted to meet particular requirements of this study, especially to develop a tool for comparative evaluation and self-completion.

The final questionnaire had up to 40 questions including 6 open questions. The questionnaire also contained a number of questions to assess sociographic details.

Attitude was measured using Likert-type scales, for example, the perceptions of users in relation to satisfaction with - or the importance of - community-based support like day care or housing support. Each question into satisfaction - or importance - was accompanied by a 7-item scale.

Although the majority of the questions were pre-coded in form of multiple choice questions, there was a small number of open questions to allow individuals to respond in any way they wished. Most of the questions required only the preferred options to be ticked, while in six places respondents had the opportunity to give more detailed answers and

express their opinion. Therefore, although every effort was made to create a relatively short questionnaire, with simplified question and response formats, it was a fairly demanding questionnaire; inevitably this may have reduced the response rate.

The questions were similar to those used in previous surveys, but while interviews are more commonly applied for surveys in the mental health field, the different methodological approach has produced results with a different focus. While the approach lacks the detail of other measures such as in-depth interviews, it has the advantage of brevity and provides global ratings.

3.3.2.2 THE PILOTING

A pilot study was conducted after all the necessary research instruments had been identified. This small scale version of the main study was especially important to test the validity of the main research instrument, the questionnaire. It was also helpful to test the mechanisms by which data were to be collected , e.g. how questionnaires were distributed, and completed questionnaires collected, and the effectiveness of methods that could be used to promote response rate.

The questionnaires were piloted in Stirling at *the Stirling Association for Mental Health* after users and staff had been consulted and had agreed to participate. The piloting revealed a number of weaknesses, most notably, the ranking in relation to a certain type of question appeared to be confusing. Apparently, the formulation of individual questions had not been clear enough to understand the way to rank the possible answers. However, this was changed as was the length of the questionnaire. Initially the questionnaire contained 48 questions which was reduced to a number of 40 questions.

Therefore, through the process of piloting, gaps could be identified and important themes could be found which were not captured by the initial

framework, and they became then included as questionnaire themes. At a later stage attempts were made to incorporate those findings into the theory, to modify the propositions, or to contradict them and to suggest something new.

An example of this is the relationship between professionals (staff) and users, which prior to the fieldwork, I had assessed to be of much less importance than I did after the analysis of the questionnaires. The issue of the nature of these relationships unravelled in the context of my enquiry into respondents' perceived importance in relation to professional support. Here, significant material about the dynamics between clients and staff was gradually revealed.

The questionnaire was not piloted in Germany for economic reasons (timing), but the draft questionnaire was circulated for comments among service users to eliminate problems related to terminology or specific phrasing that may have been confusing or difficult to understand. Responses included a number of suggestions for better understanding, for example, concerning the difference between German self-help and user groups and the advice to keep the questionnaire fairly short.

3.3.2.3 THE SURVEY

The actual survey took place over a period of 3 months simultaneously in both countries. The questionnaires were posted to the agencies involved according to the required number of reported users.

The self-administered questionnaire was given to the respondents by a selected staff member, which was often the person I had been in contact with through the expert interview. Usually, this was someone in a managerial position like the senior social worker or the staff nurse etc.

The purpose of the inquiry was explained to every individual respondent in an accompanying letter (User Information Sheet, see Appendix), and the

respondent was then to be left alone to complete the questionnaire. Respondents had the opportunity to post their questionnaire individually or hand it back to the staff member involved in the survey in a sealed envelope, which was provided with the questionnaire. Staff was clearly advised not to influence or advice respondents in any way other than technical.

This method of data collection should ensure a fairly high response rate (Oppenheim, 1966:36), accurate sampling, and a minimum of interviewer bias, while permitting interviewer assessments, providing necessary explanations (but not the interpretation of questions), and giving the benefit of a degree of personal contact.

In this comparative study members of staff were used as contact persons but not as interviewers, and what has been called interviewer bias above may be called staff bias in the context of this study. However, although perhaps relatively limited, staff bias cannot be entirely excluded and related problems are outlined further below.

3.3.2.4 A NOTE ON SCALES AND CHECKLISTS

The assessment of the mental state and behaviour of psychiatric patients or service users is often part of the research proceedings when user views and attitudes are explored. Therefore, the use of rating scales and other checklists is a widespread methodological tool in mental health research, usually applied to assess a client's current performance or functioning. This is often seen as a necessary precondition in order to determine whether a client is able to participate in an interview or a survey. Among the most well-known and accepted tools are the Rehabilitation Hall and Baker Scale (REHAB) and the Krawiecka Rating Scale (KRS). REHAB is an attempt to measure the rehabilitation status of psychiatric patients whilst the KRS provides an objective rating assessment of the mental state of chronic psychotic populations.

The use of rating scales and/or checklists, however, requires additional time and resources from both, staff and clients; even more important, it requires skilled staff to carry out an assessment by using one of the recognised scales. These resources, most notably time and skills, were simply not available to consider the use of one of the recognised scales or checklists across all the services that were supposed to participate in the survey.

Research by Barry and Crosby (1996:215) has indicated, however, that the relationship between quality of life and ratings of client functioning suggest that these are quite separate constructs which rely on different sources of information and which have distinct contributions to make to the evaluation process. Therefore, researchers should be cautious about using ratings of client functioning as a substitute for direct measures of client assessed quality of life. Barry and Crosby (ibid.) further concluded that it may be, as suggested by other studies (Champney and Dzurec 1992) that the quality of life of people with long-term psychiatric disorders in the community may be influenced more significantly by factors other than the psychiatric state.

3.3.3 ETHICAL ISSUES

Research involving human subjects requires the consideration of the ethics of a proposed research project. Most research undertaken in clinical settings needs ethical approval before any data can be collected. In Britain each health authority or Trust has an Ethical Committee that is responsible for protecting the moral and ethical welfare of their patients. Thus, anybody wishing to conduct research involving patients must apply to them for ethical approval. Ethical approval was necessary for my proposed research project since it involved using questionnaires with both patients

and staff at the Royal Edinburgh Hospital, which is part of the Edinburgh Health Care Trust.

Adelman (1981) acknowledges the need for rules when generating case study data to control the acquisition and use of information. The Ethics Committee is a body to ensure that such rules are appropriately selected and accepted. I submitted my application to the Ethics Committee of Lothian Health Board including the research proposal and the questionnaires. The Ethics Committee also required a procedure to ensure that clients or patients are fully informed and also independent in their decision to participate in the questionnaire survey.

In order to obtain informed consent, I offered an explanation of the research, and the nature of, and reasons for, the study in the User Information Sheet, which was attached to each individual questionnaire. In addition, I provided a phone number for further enquiries. Participants were clearly given the option to withdraw at any time. The application was successful at the first attempt, provided that I made a number of minor changes.

Ethical approval to approach mental health service users in the German case study locality was not required. It was considered sufficient that I provided written information to the potential respondents on the aims and objectives of the research study, especially why I wanted to include mental health service users. This was done by a client information sheet in German language (*Information fuer Klienten,* see Appendix) Principally I was granted permission and access to service users by senior staff in the respective organisation (e.g. housing agency, day care centre etc.).

The use of staff as gatekeepers can be seen as a specific methodological feature of this research. In both countries, staff was used as the first port of call to gain access to the field, to relevant information and to service users. This approach, however, has positive as well as negative implications. It is, for example, positive for the researcher in an economic sense to access service users via staff and channel relevant information in this way. The access to service users is easier if a well known contact

person (usually a member of staff) functions as transmitter concerning research relevant questions, i.e. participation in a group discussion or questionnaire survey. Whether this information is transmitted objectively remains crucial. Negative aspects therefore include the fact that staff is in a powerful position to decide whether information and access is granted in the first place, rather than service users. Although staff was advised not to interfere in any subjective way and written information was provided to each individual service user at a later stage, initial access was granted or denied by staff. Other possible ways to contact mental health service users, i. e. advertise in local newspapers, were considered less satisfactory for a number of reasons: more time consuming, no guarantee that advertisement are noticed, perhaps very little response as this approach requires considerable initiative by service users.

Research with vulnerable groups is a difficult area of research. It is a general question and matter of ethical conduct how and to what extent vulnerable groups like people with mental health problems should be exposed to public and scientific scrutiny. Although it is anticipated that the results of surveys and interviews can be helpful for further development, i.e. concerning the provision of services in mental health care, the exposure of vulnerable groups and individuals remains crucial. It requires clarity and sensitivity concerning, for example, the extent of the questions and whether sensitive issues are covered or not, the phrasing and design of questions, and the presentation of data. Clarity and transparency also requires that potential respondents receive relevant information (i.e. reasons for the study, confidentiality) beforehand, so that informed consent is possible. However, with regard to sensitive issues another problem arises as people may not share the same view. For example, the questionnaire developed for this study contained a section on finances and while the majority of respondents indicated no apparent reluctance concerning this issue, at least one respondent made clear that this was a 'private matter', where the person did not want to provide any information. While this example indicates that sensitive issues are dependent on personal attitude it is also important to recognise that particular themes

require a more careful approach than others, like, for example, sexuality or death.

The careful consideration of ethical issues is important in any research, but particular aspects may need specific recognition when case studies are conducted. For example, in a case study the individual person (or organisation) is perhaps more exposed to public focus which may require specific attention and careful handling of (individual) data. A case study may damage people, organisations and reputations (Nisbett and Watt 1978 in Thomson 1997:26) and therefore requires what has been phrased an 'ethical code of conduct' (Thomson 1997:28). In a similar context Walker (1980) stresses that confidentiality must be a continuous methodological concern, an aspect which has specific significance when conducting case studies and publishing case study material.

In this study caution was mainly required concerning the qualitative data, while quantitative data did not expose individuals to external scrutiny. However, caution was required concerning the answers to open questions and specific strategies were adopted to protect respondents from exposure. For example, answers where service users referred to support services or staff by their names were made anonymous or left out. Principally, when data were presented or material was published every attempt was made to reduce the potential harm that an incident in isolation might cause.

3.4   SAMPLING AND SELECTION CRITERIA

3.4.1   LOCATION OF THE STUDY

Great Britain with its comparatively radical approach to the closure of mental hospitals and a more ambitious mental health care policy seemed a challenging option as a location for this study, especially in comparison

to Germany where care in the community for people with mental health problems started many years later in policy and practice. German mental health professionals have often referred to the British example with great enthusiasm during the last decade, and it was an interesting task to compare the current situation in both countries. Furthermore, my professional background and prior involvement in community mental health care in Germany has also influenced the selection of the two countries.

The choice of Edinburgh in Scotland, and Offenbach in Germany, as the two specific locations of research interest was mainly influenced by practical considerations. During the first part of the study I was located at the University of Stirling, where the Human Capital and Mobility Programme, which had funded my research, was based. The Department of Applied Social Science entertains good links with organisations and authorities in Edinburgh, which was helpful in establishing contacts. Furthermore, staff was involved in research on other community care themes, including research in Edinburgh, and could provide valuable academic advice. The link to Offenbach had been established through former professional contacts, which were helpful to gain access to organisations and authorities.

In addition, I was looking for case study localities with a good level of community-based care and a multiple variety of support services. Edinburgh and Offenbach conformed to this criterion as both were considered relatively advanced in community care service provision (Bauer, Berger 1990, Simic et al. 1992).

3.4.2 THE SAMPLE

For the evaluation of the views and experiences of service users a sample was selected in each country. Before the selection procedure is detailed below, some theoretical considerations are examined first.

According to Rogers et al. (1993:193) there are few existing criteria of methodological adequacy in relation to the sampling frames for users' views of mental health services. There is, particularly, the definition problem as to who constitutes a 'user' of psychiatric services ? Is it the patient who requires a one-off treatment of minor tranquillisers from the psychiatrist or some sort of therapeutic advice[17], or is it the mentally disordered offender who has severe periods of disfunctioning ?

As I wanted to cover the mental health population with support needs in general I decided to approach the major support services in each case study locality. Although it was clear that I was not interested in what has been termed the 'worried well-being', I regarded the severity of the psychiatric problem and the severity of need as a problematic area; difficult to assess as the severity of need may vary over time and from individual to individual. However, all the support services that were included in the survey had identified the mental health problems of their clientele as severe and persistent.[18]

The sample was thus selected via major support agencies and organisations who offer support in the field of mental health care in the two selected regions. The sample was selected according to the reported number of users, i.e. every person using the service within a certain time (4weeks) was supposed to be asked whether he/she wanted to participate in the survey.

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[17] The term 'worried well being' is a phrase which has been repeatedly mentioned in Edinburgh (by professionals), apparently to distinguish clients' with more severe psychiatric needs from those with a merely neurotic disposition. For example, when I introduced myself and the study to various organisations in Edinburgh I was asked whether I was interested in the 'worried well being' or whether I was interested in people with more serious psychiatric problems.

[18] This information was based on staff judgement

3.4.3 THE SAMPLING PROCESS

It has been mentioned above that major support services in each case study locality were contacted in order to generate a sample. The sampling thus ranged across the field of different support services in both localities covering the priority areas: housing or supported accommodation, sheltered employment and day care centres, psychiatric hospitals, counselling services and user groups, according to the reported number of supported clients (for details see table 3.1 below).

To generate a sample in each country a total number of 9 different support agencies in Germany and 11 in Scotland was selected from the major support areas. These agencies were involved in three different ways: first in providing information about the service and its policy, second in providing information about the actual number of service users, and third in distributing the questionnaires among their clientele. The direct partner for this co-operation was usually a member of staff, often the manager or director of the service.

In both countries, Scotland and Germany, one agency respectively apologised that they were unable to generate a sample. In both cases the reason given was related to the agency's particular policy to refuse any kind of involvement in matters considered irrelevant and potentially disturbing to the relationship with their clients.

The table below (table 3.1) shows the distribution of the questionnaires in each case-study locality. For service agency details see Appendix.

Agency/Edinburgh	Total of user questionnaires	Agency/ Offenbach	Total of user questionnaires
Stafford Centre	50	Diakonisches Werk/Betreutes Wohnen	40
Edinburgh Community Trust	10	Gemeindepsychiatrische s Zentrum-West	25
Edinburgh Association for Mental Health	25	Gemeindepsychiatrische s Zentrum-Ost	56
Home Care Team	50	Psychosoziales Zentrum Offenbach	56
Scottish Association for Mental Health	66	Wohnheim Offenbach	38
Craigmillar Day Centre	30	Werkstatt fuer Seelisch Behinderte	96
Penumbra Housing Association	70	Philippshospital Riedstadt	16
Consultation and Advocacy Promotion Service	20	Stadtkrankenhaus Offenbach/Psychiatrisch e Klinik und Tagesklinik	32
Royal Edinburgh Hospital	25	Sozialpsychiatrischer Dienst	60
Occupational Therapy and Rehabilitation Unit	30		
Ballandan House	40		
Total	**416**	Total	**419**

Table 3-1: Agencies participating in the survey/number of questionnaires

The empirical work of this study is based on a total of 238 user questionnaires, 165 from Offenbach and 73 from Edinburgh. Interestingly, the response rate in Germany is considerably higher than the response rate in Scotland as shown in table 3.2 below:

	users/clients
Edinburgh	17.5%
Offenbach	39.3%

Table 3-2: Response rate of questionnaire survey

It is important to assess the representativeness of these proportions. Clearly, the proportion of those who participated in the survey must be seen in relation to the general number of people with severe and chronic mental health problems in both case study localities. There are obviously difficulties with defining the severity of mental health problems in order to receive objective estimates. However, Scottish Office (The Scottish Office 1996c) estimates in relation to a specific community care scheme, the Care Programme Approach (see Chapter 4 for details), range around 0.7 people in every 1000, which corresponds with a number of just over 300

individuals in Edinburgh. Estimates in Hesse, however, still centre around psychiatric beds (concentrating on a continuing need for short-term admission), and the current calculation focuses on a total of 0.8 per 1000 population with the aim of further reduction to 0.6 per 1000 population within the next two decades (HMJFG 1993b). Based on such estimates it could be assumed that the questionnaire survey in Edinburgh covered around 24 % of the estimated population with severe mental health problems, while the questionnaire survey in Offenbach covered around 47 % of the estimated population with severe mental health problems.

However, neither the British Care Programme Approach nor the German bed calculation are reliable estimates to assess the representativeness of the current sample as in both cases it is very likely that more people are affected by severe and chronic mental illness. The CPA in Britain may not cover all people with severe mental health problems in one region and besides, not everyone may use the programme despite a perhaps serious condition. The German bed estimates cannot accurately reflect the number of individuals suffering from severe and chronic mental health problems in need of community based support as beds only focus on people in need for acute care and treatment.

Estimates that centre around the number of people who have actually used in-patient care or are estimated as in need of in-patient care can thus only provide a partial picture. The Lothian Mental Health Strategy (Lothian Health 1995:22) estimates that a total of 1470 people in Edinburgh are in need of in-patient hospital care, which makes 0,3 % of the total population. The Psychiatric Clinic in Offenbach has a constant number of about 1000 admissions per year (Bauer 1995:2) with an average re-admission rate of 1.7 per patient, while the Mental Hospital in Riedstadt registered 2485 admissions in 1995 (Hessischer Landtag 1996), but provided no re-admission estimates. However, based on the assumption that the annual re-admission rate in Riedstadt is similar to the one from the City's Psychiatric Clinic both clinics together had provided in-patient care for an average number of about 1500 individual patients in 1995. While the Lothian Mental Health Strategy (Lothian Health 1995) talks about a total of

1470 people in need of in-patient hospital care in Edinburgh, Offenbach had registered a similar number of people who had used in-patient hospital care in 1995. This number of people may also be estimated as the number of people with severe and chronic mental health problems in both case study localities. It may now be suggested that people with severe and chronic mental health problems are the main clientele of continuing community based support, but clearly, not all of those people use community based mental health services. It is very likely that the numbers presented above may not be identical to number of people actually using community based services except hospital provision. For example, individuals who do not respond to community based service provision or reject the services for different reasons.

However, related to the present survey the proportion of the sample may be assessed in relation to the estimated population of people with severe and chronic mental health problems in both case study localities. This means that the actual sample approached for the survey in each case study locality represents about one third (28%) of the mental health population considered as being suffering from severe and chronic mental health problems. However, the proportion of those who responded to the survey is naturally smaller covering only about 4.9% in Edinburgh and about 11.2% in Offenbach. Compared with the number of people considered as suffering from severe and chronic mental health problems the sample only covers a rather small proportion. The sample was accessed via the major services in both case study localities, an approach, however, excluding those people with severe and chronic mental health problems who had no contact with community based support services during the time the survey was being conducted.

Principally, the sample was not designed to be representative – it was a purposive sample rather than a probability sample which was seen appropriate to this group as there are no adequate sampling frameworks. The results are nevertheless an indication of users' views, experiences and preferences.

There is no evidence to explain the considerable disparities in relation to the response rates in Germany and Scotland. It is possible that the higher response rate in Germany is due to the relatively new approach of a questionnaire survey among users of psychiatric services. It has been mentioned elsewhere, that user involvement and user participation is still fairly uncommon and a rather unique matter in the mental health field in Germany, and surveys of this kind are just starting to become more widespread. German users are therefore perhaps more motivated and not yet burdened with frequent surveys. This conclusion seems admissible as Scottish users and professionals indeed appeared to be more wearied with this sort of thing. For example, when I initially approached support services in Edinburgh I was notified - usually with some kind of ironic remark - that the frequency of surveys was indeed a bit of a nuisance, and that generally most of them had very little effect anyway.

In general, it has to be acknowledged that a rather low response rate as is the case in this study may have implications for the study's findings. An element of caution is thus needed when findings are presented and interpreted.

However, some may argue that research is of no value unless it is acted upon, but this would be to deny to the researcher the importance of publications as against the practitioner, who may be looking for more tangible outcomes (Barnes 1979 in Atkinson and Elliott 1994:155). However, these concerns show that not only is it significant to listen to the users, just as important is to take their word seriously and to accept user participation as a vital element in theory, policy and practice.

It is important to emphasise again, that the view of individuals who refuse contact with community support services could not be included in this study, because this group - though presumably a minority - could not be covered through the approach via support agencies.

3.5 GENERAL DATA COLLECTION PROBLEMS

If concern for user evaluation is to be taken seriously some account must be taken of methodological limitations. In the context of this study a number of points are important to acknowledge, for example, the exclusion

of specific minorities of the mental health population, and a possible bias between staff and clients.

Generally, all users of the services I had approached in both countries were to be asked whether they wanted to participate in the survey or not. Staff was to inquire about this willingness. The staff involvement at this stage has implications difficult to assess and staff bias cannot be excluded. For example, some individuals with significant symptomatology may not be able to tolerate long concentration or have difficulty completing self-report measures. Therefore, staff may insist less vigilantly to participate in a survey, while this might be less significant in relation to more 'able' clients.

However, with regard to the sampling procedures an attempt was made to ensure that research findings can be generalised. Staff was informed in writing not to intervene and influence clients with regard to participation. Furthermore, with regard to questionnaire completion it was explicitly banned to influence client opinion.

Certain groups of individuals with psychiatric diagnosis have been inaccessible, as has been pointed out before. This particularly includes populations not willing to respond to support services who refuse contact, but also those in prisons where access is highly restricted and those of certain ethnicity with a generally limited contact to support services due to cultural and/or language difficulties. Obviously these are minorities, except, perhaps, the growing group of clients from different ethical backgrounds (Bauer 1995)

Such methodological problems are neither unusual nor uncommon, however, they cannot simply be ignored. Clearly, at every stage of the process biases influence both the form the evaluation takes, the way it is interpreted and the use to which it is put (Corrigan 1990), yet every possible attempt was made to keep them at minimum. The specific problems related to comparative research have been outlined above.

3.6   DATA ANALYSIS

Once the research data was collected data analysis was organised according to the methods employed. Documentary analysis included the comparative examination of official documents such as policy guidelines, legislation, statistics etc. and was carried out on the basis of two major subjects. Firstly, according to relevant theoretical themes and concepts such as quality of life and the role of the service users and secondly, according to general availability of community based support services. The quantitative methods, i.e. the self completion questionnaire as the primary research instrument clearly required most of the time for analysis, while qualitative instruments like expert interviews and group discussions were few and mainly required the coding of fieldnotes. This coding procedure focused on frequency counts, for example, in relation to perceived problems with housing or general community support. Data on the setting (observation of the setting) was also based on fieldnotes and the analysis concentrated on the extraction of particular features that are seen relevant to care in the community; relevance was defined through themes identified in the literature or in policy guidelines, for example, the setting of a mental hospital, or aspects raised by users and staff in the discussions.

Following the return of the questionnaires the data material was coded and especially a number of 'other' categories that were included in the questionnaire needed particular consideration and coding. This also included a number of open questions at the end of the questionnaire. The coding of the open questions was to some extent qualitative coding (similar to the coding of interview transcripts), and preliminary analysis of the open questions in this study focussed on quantitative methods as frequency counts of occurrences of certain phrases or words. Pfaffenberger (1988) described some coding strategies for qualitative data, some of which apply well to open questions in a survey. As the open questions in my questionnaire in many cases included multiple responses, a coding scheme was required which would incorporate all relevant information. This involved designing a coding frame for the questionnaire

and trying to define theoretically relevant distinctions between responses. The open questions were coded by categorising the data, but only those that satisfied certain criteria were coded.

The fieldnotes concerning the observation of the setting, expert interviews and group discussions were coded using a similar strategy; data was divided and subdivided in categories.

The questionnaire data was then transferred to a computer for data cleaning and further statistical analysis.

Further data analysis mainly included frequency distributions and cross-tabulations. First a marginal frequency distribution was obtained to count the number of respondents who answered each question in each of the possible ways including the coded categories from the open questions. These frequencies were than compared between Scotland and Germany. For example, frequencies regarding the use of specific community care services such as sheltered employment, supported accommodation or day care. Frequencies were also compared in relation to the perceived importance of specific community support services as well as the satisfaction with (specific) community support services in both countries. The analysis also included a frequency count of occurrences of certain categories in order to give some notion of the representativeness of the data. This does not mean that those variables were ignored that occurred rarely, and which have run counter to the mainstream of opinions.

Data analysis continued with a number of cross-tabulations to examine variables in pairs or more complex relationships. This was done to look at the relationship between variables in order to explain differences on one variable in terms of differences on the other. For example, the relationship between the type of housing support and satisfaction with housing or the relationship between the financial situation and participation in social and community life. The examination of conditional contributions, that is the distribution of one variable under particular conditions of the other was thus possible.

The decision of what may be included and analysed as cross-tabulations was largely determined by the literature and other quality of life research focussing on issues that had been identified before (e.g. the role of employment in relation to satisfaction). Principally most of the questions were addressed by cross tabulating a satisfaction variable by one or more background factors, like finances, housing, employment or a importance variable by one or more background factors like support service provision in various areas. To some extent the decision on cross-tabulations was also influenced by the comparison of frequency distributions and the interest arising from stark differences which suggested it would be advisable to examine the relationship between variables in order to explore some national particulars (e.g. the role of user groups). The results from cross-tabulations were usually presented in percentages for increased clarity and the data (percentages) of both countries were thus compared. All computations were done using the SPSS (version 5.0/windows) computer package, as implemented at the University of Stirling.

3.7 SUMMARY AND CONCLUSION

This chapter has considered the methodologies and instruments selected for this study. The general study design was explained focussing on the selection of the case study approach as the major research method. This was followed by a look at comparative research and its implications in general and more particularly in relation to this study before quantitative and qualitative research methodologies and research instruments were introduced and explained.

A case study design appeared most effective providing a useful basis for comparative research into the effects of community care in two different countries. A case study has the potential to provide a consistent picture of particular localities on a relatively small scale; links and ties, connections

and dependencies are easier to identify and explain than on grand scale national basis.

Case studies are useful frameworks for comparative research provided that the localities selected are to some extent compatible. However, it has also been seen that comparative research poses certain problems such as language problems and terminological difficulties. In the field of mental health care specific problems for comparative analysis have been found to be the different variety of services in different countries, inconsistency concerning concepts and policy objectives and different statistical coverage.

User participation is part of the methodological approach in this study. Cahill (1994) argues, that social policy research needs to be in touch with the ordinary concerns of people, especially those who use services. Service users need to be given the opportunity, freedom and help to voice and define their concerns, and in doing so take the ownership of the research process as an integral part of being empowered. This raises methodological issues, which some consider to be part of new research paradigms in work with people who are disabled or disadvantaged (Rioux and Bach 1994). However, it was important to this study to ensure user participation at various stages of the research process, especially concerning the design of questionnaires and the identification of potentially important issues. A number of qualitative methods (expert interviews, group discussions, observation of the setting) were used to gain access to the field and obtain data to prepare the major research instrument: a questionnaire survey.

The Bangor Quality of Life Schedule developed by Barry and Crosby (1993) in Britain was taken as a basis to develop the profile for this study. The schedule developed for this study provides a framework for the comparative evaluation of the living circumstances of mental health service users in the community including an assessment of the use of support services. The schedule captures quality of life as a sense of well-being closely linked to a situational context. Barry and Crosby have used professionals as interviewers to ask the questions and complete the form,

while the schedule for this study was especially designed with the aim to develop a tool appropriate for self-completion. Therefore the schedule developed for this study was shorter than Barry and Crosby's original profile as it had to be fairly simple yet concise and easy to complete. The modified version also covers objective and subjective indices, but only in six significant life domains compared to originally nine, together with indices of satisfaction. Furthermore, as it was planned to apply the same schedule in two countries with different languages and a different policy framework, the schedule needed to cover similar areas appropriate for straight translation and comparison.

The critical aspects raised before in relation to quality of life as a concept and, more particular, the inherent implications regarding the subjectivity of satisfaction ratings (see also Chapter 2), could not have been completely eliminated in the schedule developed for this study. The apparent risk of producing a schedule too lengthy for self-completion has determined my ambition to develop a fairly short profile suitable for use in two countries and for a population usually unaccustomed to such tasks. This difficulty is considered at times when findings are presented in the following chapters.

This chapter has also addressed important ethical issues generally involved in research where people are exposed to external scrutiny. General data collection problems have been pointed out such as the difficulties related to accessing service users before data analysis was finally considered. Overall, the principal methodological approach as presented in this chapter points to a number of positive as well as negative aspects in relation to this study. First, a case study has been appropriate to provide a consistent picture of selected regions and the user perspective in relation to this. Second, the approach of service users via agencies is on the one hand a straightforward and relatively fast track, but it must be recognised that the use of staff as gatekeepers remains a crucial element despite all efforts to prevent potential bias. The approach had nevertheless the potential to access larger numbers of service users directly and furthermore with the advantage that the research process was not disturbed by hostility or rejection. This may have been related to the

potentially familiar environment (e.g. day care centre, sheltered work place etc.) in which the contact with the researcher and/or the questionnaire survey took place.

Third, the combination of qualitative and quantitative methods has generally been useful to obtain a holistic picture of community mental health care in the case study localities. While qualitative methods (expert interviews, group discussions, observation) were useful for gaining access to the field and for identifying issues of interest and/or examples of 'good practice', quantitative methods were useful to access larger numbers of service users and evaluate and compare their satisfaction with 'community life' and support services. However, what the survey gains in numbers it may lose in depth and it must be recognised that more in-depth information and more differentiated material concerning user views and perceptions cannot be drawn out of the rather short and concise questionnaire. Generally, the methodological approach applied in this study provides a good overview on community mental health care in policy and practice and identifies respective national tendencies and dispositions. For more in-depth information on users' individual views and perceptions, however, it may be more appropriate to apply qualitative methods, i.e. interviews with service users. This study can provide a useful basis and an effective framework for more in-depth evaluation and follow-up studies.

This study was undertaken by a German researcher based at a British university, and personal experience, language skills and contextual knowledge could be drawn on from living and studying in both countries. However, cultural and language barriers remain. They are recognised as necessary elements of the cross-national research process and are discussed whenever relevant in the study.

The following chapters address the specific aims of this study as outlined in Chapter 1 starting with the analysis of respective national community care policies and general policy foundations.

CHAPTER 4

SOCIAL AND HEALTH CARE POLICY

FOUNDATIONS IN COMPARISON

4.1 INTRODUCTION

In recent years outcome evaluation has become increasingly popular in measuring the general success and progress of a policy such as community care from a variety of perspectives, for example, from the perspective of policy makers or service users. A most significant perspective for policy makers is to assess outcome in terms of financial and operational efficiency (i.e. health economics)[19] while more significant from a perspective of service users may be the improvement of living circumstances and a better quality of life. Whilst the theoretical implications in relation to outcome evaluation and especially the concept quality of life and its application in the mental health field have been examined before (Chapter 2), the wider policy context is considered here. The examination of the respective national policy background is necessary to provide the basis for understanding the national differences concerning community care outcomes in relation to policy objectives on the one hand, and the perceptions of service users in relation to these policies (that are influencing the case study material presented in later chapters) on the other.

The first section examines community care policy in relation to outcome focussing on the concept 'quality of life', including an examination of governmental plans and programmes to monitor outcome. It will be seen

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[19] Economic evaluation and how economists define concepts of efficiency is considered in more detail in Mooney G H Russell M and Weir R D. 1986 or McGuire A Henderson J and Mooney G. 1992

that quality of life has become a most significant policy objective, especially in Britain, fleshed out in governmental documents and official planning papers. Attention will than be drawn to the role of the service user. It has been stated earlier that mental health service users are central to this study, thus, it is important to examine their role in policy and legislation, for example, how users of community care services are perceived and dealt with in policy documents. This section highlights some fundamental national differences concerning user involvement and participation in policy planning and practice development. Finally, the third section compares some of the foundations of health care and social care in Britain and Germany - including an examination of the individual type of welfare regime – that potentially affect community mental health care policy and practice development.

4.2 COMMUNITY CARE, OUTCOME EVALUATION AND QUALITY OF LIFE

4.2.1 QUALITY OF LIFE AND THE POLICY CONTEXT

It has been shown before that the concept of quality of life has become increasingly common in the mental health field over the last few years. It is often used as a catch-phrase rather than a concept, usually without any clear reference as to what it actually refers. While policy in Germany is generally less rhetorical but more technical and the phrase does not appear regularly in relevant documents, it is frequently used in Britain and in Scotland.

In Britain, the broad objectives of the community care reforms that focus upon quality of life are set out in the Governmental White Paper *Caring for People* (DoH 1989), the initial basis for legislative changes in Britain

proceeding the NHS and Community Care Act 1990. With regard to the new arrangements it was stated that

"a new style of service (which) offers a much higher quality of life for people with mental illness and a service more appreciated by their families than is possible in the traditional large and often remote mental hospital. The Government reaffirms its support of the policy as a civilised and humanitarian one" (DoH 1989:55)

With particular emphasis on the social dimension it was also made explicit that social care "will improve the quality of life enjoyed by a person with care needs" (DoH 1989:10), with social services departments being required to test and promote ways of "improving the quality of life for people in residential care" (DoH 1989:44).

The Key Area Handbook Mental Illness (DoH 1994:para 2.2) placed emphasis on health promotion and asserted that increasing awareness will "improve the quality of life of people with long standing, recurrent or acute mental health problems...".

The Scottish Office followed the national rhetoric and stated that "the aim of the reforms is to allow vulnerable people to live as independently as possible in their own homes or in a homely setting in the community so that the quality of their lives is improved" (The Scottish Office1993:2). The Mental Health Strategy for Lothian (Lothian Health 1995) also refers to the concept as a policy aim and promises "to provide services to users and carers that enable them to have a good quality of life" (ibid:5).

In Germany quality of life as a concept appears rarely in current policy documents. For example, the regional state guidelines for Hesse do not refer to the concept at all, and rather talk about the improvement of living circumstances or more independence, often in relation to the development of community based support arrangements (LWV 1994). Generally, the concept quality of life appears rather in academic quarters than in policy making and is often related to studies concerning the de-hospitalisation of long-term patients (Franz 1995, Priebe 1997) which increasingly focus on

the concept to investigate the de-hospitalisation process (*Enthospitalisierung*) from the quality of life perspective.

In order to see whether an intended outcome such as 'a good quality of life' is being achieved, it is necessary to consider what the (policy) objectives are, and how these objectives might be translated into specific measurements. But while the measurement of abstract concepts such as quality of life is generally crucial, which has been shown in Chapter 2, it is even more difficult if the objectives of that measurement also lack clarity. For example, policy objectives in Scotland contain a lot of rhetoric and only limited 'measurable' material. Furthermore, accurate data concerning current availability and future need are often scarce. This is different in Germany, where on regional state level objectives in terms of place numbers (current availability and future need) can be clearly monitored over time (see Chapter 5). Provided that more housing support or more day care does increase the individual quality of life of service users, which is usually implicated in the policy documents, it is necessary to rely on concrete data in relation to these policy objectives, otherwise progress is difficult to assess.

In general comparison it is evident that quality of life as a policy objective currently appears frequently in British and Scottish policy documents, but is rarely found in German equivalents. In Britain the concept is fleshed out as a statement of intention and a kind of vision concerning community life and all aspects of community care, including, for example, different life domains such as accommodation and day care, while in German policy the concept is hardly mentioned at all and neither appears in a general context nor in relation to major life domains. This difference is difficult to explain. The concept as such is almost as popular in Germany as it is in Britain and as a topic quality of life is increasingly common, for example, in the literature and in research. Perhaps it is more helpful to look at the difference from a hermeneutic perspective. In this sense, German mental health care policy texts tend to be rather technocratic, usually concentrating on numbers and figures, while British mental health care policy generally seems to include more prose. The interpretation of

German policy is thus rather straightforward and provides only little scope for speculation in relation to the aspects covered, while British policy documents seem to open a wide field of opportunity for interpretation. This is especially crucial when concepts like quality of life - that require a definition in any context - are subject to interpretation. British policy documents usually refer to the concept without any definition and therefore it is difficult to rely on policy objectives or take them as points of reference concerning assessment and evaluation.

In both cases, however, it is hardly possible to assess the concept quality of life against stated objectives. Whilst the German policy does not refer to the concept, the British policy tends to avoid clear definitions but uses the concept –or rather the phrase - extensively.

4.2.2 GOVERNMENTAL SCHEMES FOR MONITORING AND EVALUATION

According to respective national policy objectives and relevant legislation changes particular plans and programmes have been developed to monitor change and evaluate outcome from the perspective of service providers, particularly on the level of service operation. In Britain the NHS and Community Care Act 1990 has provided a basis for the development of general and specific systems for monitoring and evaluating community care. For example, regularly devised community care plans are now part of the local planning procedure - a policy requirement which will be explained in more detail further below - and locally administered inspection and registration units and complaints procedures were set up. A more specific system is the Care Programme Approach (CPA) - introduced in Scotland in 1992 – a scheme for people with mental health problems discharged from hospital or treated in the community. It was set up to monitor community based support schemes and provide good networked care outside hospital according to individual need. The CPA is treated as

an important and fundamental element of community based care and a focal point for networking services in an area, but has been criticised as not working effectively lacking, for example, more widespread utilisation. The Social Services Inspectorate found that only one in five areas inspected was using the care programme approach in Britain (Strong 1995:20).

Other, more general but regular systems for monitoring and evaluation in health and social care include quality assurance schemes and consumer or patient satisfaction surveys, set up or carried out to make the National Health Service and other bodies work more efficiently on the one hand and consumer friendly on the other. For example, independent inspection units (as part of local authority social services departments) are required to assess the standards of care in residential homes on a regular basis since 1991 and make sure that 'services are cost effective' (DHSSI 1991, para 4.5) and 'the quality of life of users meets agreed standards' (ibid). The views of the service users are particularly important for setting standards of care and users are considered as important participants in any assessment. In addition, surveys assess satisfaction and living situation, like for example the 1991 Mind survey where 500 people who use the services of local Mind branches (Mind is the largest British not-for-profit mental health organisation) were asked about their living circumstances.

The market oriented approach that has influenced the British health care system significantly in the last couple of decades, which will be seen later in the chapter, has also fuelled the debate focussing on consumerism and quality assurance and has influenced the development of schemes and programmes for monitoring and evaluation. It has been pointed out before that this development may have influenced the rise of what has earlier been phrased a 'user-movement' in Britain (see also Chapter 2 on user involvement), especially the approach to treat service users as customers.

German policy approaches to monitor the progress of de-institutionalisation concentrates on a succession of de-hospitalisation programmes (*Enthospitalisierungsprogramme*) administered by the regional states. The focus is particularly on the resettlement of long term

patients into community settings. The programmes aim to speed up the de-institutionalisation progress on the one hand, and to monitor and evaluate the process scientifically on the other. Therefore university departments have been involved, for example in Berlin (Priebe 1997) and in Hesse (Franz 1995). The de-institutionalisation programme is often part of other co-ordinative measures on a regional state level, for example, the *Landeskoordination* in Hesse (1994). Evaluation according to the programme often concentrates on the collation of numbers of patients resettled into the community, but further evaluation, for example, regarding the living situation in the community is usually not covered or included in other studies, some of which have been examined in the previous chapter.

A regularly required procedure for monitoring and evaluation such as the production of community care plans is not existent on national basis in Germany and most regional states have developed individual procedures and models for monitoring and evaluation such as the Landeskoordination in Hesse. Other measures designed for quality assurance in community mental health care include a documentation system developed in 1995 (see Cording et al. 1995) known as the Psychiatric Basic Documentation *(BADO, Basisdokumentation)*. This system was mainly developed by clinicians for use in clinical settings with the aim to assess the quality of care *before, during* and *after* hospital admission based, for example, on the assessment of relapse concerning the frequency of re-admission rates. The system is hospital focussed, therefore of limited use in other, non-clinical community care settings and criticism includes the need for further development and extended variables, for example, concerning housing, work or social contacts (Meiners 1996:7).

In contrast, the Institute for Community Psychiatry *(Institut fuer Kommunale Psychiatry, IKP)* developed measures applicable for non-clinical areas of mental health service provision and a highly technical instrumentation for quality control and quality assessment. The instrument introduced (Nouvertne and Nouvertne 1996) is rather for consultation purposes, i.e. to assist organisations in the field of mental health care in developing innovations concerning internally and externally relevant

managerial and organisational structures. The instrument is not effective for evaluating mental health care from a perspective other than organisational, for example, from the perspective of users or carers.

In relation to monitoring and evaluating community mental health care it has generally been pointed out that the very vocabulary, i.e. 'quality assurance' (*Qualitaetssicherung*) and 'quality management' (*Qualitaetsmanagement*) emerge from a background of trade and economy, and that there is severe danger that parts of this vocabulary are used to justify resource cuttings unless the subjective dimension of quality of life is not taken into account in quality assessment procedures (Richartz 1996:47). This aspect may be applied to both of the countries compared in this study since the terminology at the centre of the debate surrounding quality assurance is rather similar in both cases. However, the main issues arising from the final aspects drawn out in this section lead us back to the concept quality of life and the importance of the subjective dimension concerning the evaluation of care. In this light the role of the service user is particularly important and how service users feature in the respective national policy context is examined below.

4.2.3   THE ROLE OF THE SERVICE USER

The emergence of a user perspective in mental health care has been examined in the previous chapter and influential factors that gave rise to the issue as well as specific national differences have been identified. Major policy documents also reflect the respective national emphasis.

A central theme in community care in Britain in the 1990s is the incorporation of users' views in policy and practice. Thus, the routine requirements to monitor users' views was a major feature of the new health and community care arrangements set out in different reports (DHSS 1983, Griffiths 1988) which preceded the legislative changes set out in the White Paper (DoH 1989).

The National Health Service (NHS) was requested to

"Ascertain how well the service is being delivered at local level by obtaining the experience and perceptions of patients and the community: these can be derived from community health councils and by other methods, including market research and from the experience of general practice and community health service" (DHSS 1983). The Griffiths Report similarly emphasised that social services authorities must take "account of the views and wishes of the person to be cared for" (Griffiths 1988 para 3.8). The reformed community care arrangements in Britain have included the centrality of users in identifying their own needs and specifying the services they require. This principle is set out in the White Paper (DoH 1989 1.8) as to "give people a greater individual say in how they live their lives and the services they need to help them do so".

Similarly, the Key Area Handbook Mental Illness (DoH 1994:para 4.5) pointed out that

"involving service users is particularly important in the mental health services".

In their report on the closure of psychiatric hospitals in Scotland the Scottish Affairs Committee nevertheless commented critically on the role of users: "The platform is there but we are not persuaded that this in itself will guarantee user consultation and believe that where user groups exist these should be consulted in the preparation of Community Care Plans" (House of Commons 1995:xii)

The emphasis on user involvement is also evident in local policy documents. A central feature of the Lothian Community Care Plan is the need to take account of users' and carers' own definitions of their needs and preferences and the services they require. Among a list of goals the Plan sets out "to continue to look for ways of bringing service providers and users together to plan for the future" (Lothian Health 1995:25) as one of the central policy aims.

Essentially, official documents in Britain show that a policy of user involvement is at the top of the community care agenda, evident at all levels of policy making and planning. Although policy documents can often be seen as very general statements lacking perhaps more detailed strategies about how to achieve this aim, the general emphasis upon user involvement must be seen as a positive step to begin with. In addition, useful (local) strategies need to be implemented in order to include the views of those concerned effectively such as regular participation and consultation schemes as pointed out by the House of Commons (ibid.)

The principles that underpin the role of the user in the reformed community care system are on the one hand theoretical concepts such as empowerment (see also Chapter 2) or normalisation[20], but policy objectives like user participation and user involvement require clear statements in which way users may be included. For example, the clear statement that service users or their representatives must be consulted when community care plans are drawn together (DoH 1989, para 46). Clearly, there is a major step between consulting the users and acting according to users' preferences rather than perhaps divergent political dispositions. And yet, the theoretical emphasis on user involvement as highlighted in Britain can provide a basis for further development in everyday practice, it is at least an important formal entitlement for participation, an entitlement German service users still do not have.

In Germany user involvement in policy planning is virtually non-existent and official documents completely lack any mention of the issue. While a small number of user groups have been established in recent years, especially in Berlin, their influence is still rather marginal. Encouraged by the activities in countries like Britain, presently a few small groups of active and interested users and professionals have taken a grip on the issue yet

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[20] 'Normalisation' is a phrase often used to describe the principles of care for people with learning disabilities or people with mental health problems. Because of their disability these people have become devalued in society; they are often segregated from other people and denied the most basic human rights. Normalisation suggests ways of offering services which support people in becoming valued members of society. It is not about *making people normal* – the most common misinterpretation of the principle (Wertheimer 1989, see also Ramon 1991)

still with little political influence. User involvement and participation in policy and planning is not officially acknowledged and therefore minimal in practice.

In comparison, the differences concerning user involvement in policy (and practice, as will be seen when case study results are presented) are striking and yet, reasons are not immediately apparent. The topic appears now and then in professional journals (Didier J Haase R 1996, Kaemmerer-Ruetten 1996), but is rarely debated more widely, for example, in policy making quarters and relevant committees or among users and professionals within services. It is possible that more recent developments such as the consumerist approach towards service provision in Britain (examined in more detail below) has influenced the role of the service user both in policy and practice, i.e. users being now more viewed as customers rather than patients. This has also been pointed out in relation to the concept of empowerment introduced in Chapter 2. In contrast to increasingly consumerist approaches in Britain, the principles that underpin the delivery of social and mental health care in Germany rest on rather traditional foundations as will be seen further below.

In conclusion, it would be too easy to suggest that proceedings in Britain can only be seen as positive since asking users to comment is one thing, but taking on their recommendations quite another. The British mental health organisation MIND, for example, has stated that "repeatedly users are asked and then ignored" (Strong 1995:21) and the Scottish user organisation SUN (Scottish User Network) talks about tough negotiations if users want their views included in strategic planning with local authorities (Scottish User Network 1995:conference notes). It is evident, therefore, that research on the practical consequences of user involvement in mental health policy and practice is increasingly important.

This section has examined both the concept quality of life and the role of the user in their current policy context. It has been seen that development in Britain including Scotland is quite different from the current situation in Germany, both in relation to the concept quality of life and also concerning the role of mental health service users. The role of the service user may

have an impact on the quality of life of individuals - which will be explored in later chapters - as it is likely that participation and involvement and the feeling of having a say may lead to a greater sense of self mastery and autonomy than the rather defensive role ascribed to mental health clients in Germany. However, for the comparative evaluation of community based mental health care from a user perspective and the interpretation of the case study material in later chapters, it is essential to know more about the different policy foundations in the countries of comparison set out below.

4.3 SOCIAL POLICY IN COMPARISON

4.3.1 THE WELFARE STATE CONTEXT

Most industrial societies witnessed a substantial reorganisation and expansion of their social and health care services during the immediate post-war years and today the various state systems reflect different varieties of government intervention due to political choices established over the decades. Different kinds of welfare regimes have emerged and today the national welfare systems cover a range of programmes for various areas including, for example, health and social care as envisaged in a policy of community care.

Before starting to compare the British and the German welfare systems in general and mental health care policies in particular, a look at a number of influential aspects such as welfare state categorisations (Titmuss 1974, Esping-Andersen 1990, Abrahamson 1991, Leibfried 1993) – and emerging criticism in relation to mainstream classifications - is useful. Different types of welfare regimes are characterised by specific features, which reflect the role and responsibility of the state, family and market in various areas, for example, regarding the provision of personal social services. According to these specific features, categories of welfare state models have been given by Titmuss (1974) and Esping-Andersen (1990),

who identified three largely corresponding models of welfare state operation: the 'residual' (Titmuss 1974:30-31) or 'liberal' welfare state (Esping-Andersen 1990:26-27), the 'industrial-achievement performance' (Titmuss ibid) or 'conservative-corporatist' welfare state (Esping-Andersen ibid) and the 'institutional-redistributive' (Titmuss ibid) or 'social democratic' welfare state model (Esping-Andersen ibid). According to their analyses Germany fits in the 'conservative-corporatist' or 'industrial achievement performance' model, the one which applies most strongly to the principle of subsidiarity[21]. In this type of welfare state the family is expected to play a central role in caring for their relatives and/or supporting them financially (see also Tester 1994, 1996, Hill 1996) thus limiting the responsibility of the state. The UK does not fit archetypically in one of these categories but features elements of the 'liberal' welfare state.

It has been stressed (Esping-Andersen 1990) that countries do not fall neatly into these categories, but generally tend to one type and combine elements of others. Other authors, although largely agreeing with Esping-Andersen's three main categories, extended them by creating others (Abrahamson 1991, Ginsburg 1992, Leibfried, 1993). For example the UK is classified as 'liberal-collectivist' by Ginsburg (1992), characterised by rolling back the boundaries of the welfare state, i.e. public services are contracted out to the independent sector, to voluntary or private providers, while the 'institutional' welfare state (Abrahamson 1991) or the 'social market economy' (Ginsburg 1992) is particularly linked to Germany.

The theoretical frameworks of welfare categorisations as introduced above have been criticised by comparative social policy analysts - including feminist scholars - as being inadequate for advanced capitalist countries (Dominelli 1991, Langan and Ostner 1991, Orloff 1993, O'Connor 1993, Spicker 1996, Taylor-Gooby 1991, Williams 1989). General criticism focuses on the notion that the categorisation of welfare states generates a

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[21] A basic definition has been provided by Tester (1994:252): According to the principle of subsidiarity, responsibility and decision making (in any field) is placed at the lowest level possible, ascending step by step through higher levels only when necessary.

rather inflexible typology suggesting that either one or another category should fit, while some countries, like for example France, do not fit neatly into any welfare regime type. Spicker (1996:70-2) thus highlights the limitation of conventional models in describing the current situation in social welfare systems adequately.

More specific criticism concerning conventional welfare state models focuses on the rather conservative approach to gender and ethnicity, and that the models –apart from being eurocentred - are largely based on a white, male and middle-class Western culture. Esping-Andersen (1990), for example, fails to acknowledge the extent to which women operate in the domestic sphere (unpaid) and the extent to which their involvement in that sphere is a necessary basis for the commodification of labour and existing 'patterns of access to and status in paid employment that, despite national variations, deny women equal opportunities in this sphere' (Taylor-Gooby 1991:101).

The neglect of gender differences is particularly relevant to community care, since it is women who are primarily involved in the care of people with dependency needs both paid and unpaid. In relation to the (usually unknown) proportion of women providing 'free' welfare services in the domestic economy Dominelli (1991:9) argues that it is necessary to move away from approaches which sharply distinguish between the public and private spheres like those inherent in existent models of welfare states. In response to Esping-Andersen's theoretical model grounded in the decommodification of labour power, Orloff (1993:303-28) and O' Connor (1993:501-518) suggest that the concept of 'decommodification' should be replaced with that of 'personal autonomy'. This they argue would open new perspectives for the comparative evaluation of social care.

It is evident that within the last decade the focus of comparative social policy has shifted from the comparison of welfare states based on the model categories introduced above to new concepts of welfare pluralism

and welfare mix[22], taking account of the shifting balance in different countries between the role of the state, the market, the family and voluntary sectors.

More recently new models and frameworks for comparison have emerged based on the notion that cross-national variations cannot be explained sufficiently by the conventional variables used in comparative welfare state research (Alber 1995, Anttonen and Sipilä 1996). Anttonen and Sipilä (ibid:97) argue for an integration of social care services into the ongoing discussion of welfare state regimes, but highlight the lack of commonly accepted mechanisms for data collection suitable for comparative analyses. In this light Tester (1999:151) similarly emphasises the importance of further development and of shifting the focus of welfare regime theory, especially concerning the specific area of long term care.

The implications for this study are diverse. While Esping-Andersen's typologies may still be useful for broad categorisations and comparisons based on significant characteristics, they appear limited for the analyses of increasingly complex systems of social care. Although welfare states like Britain or Germany show specific characteristics such as the principle of subsidiarity in Germany or the mixed economy of care in Britain, which may be useful indicators for the identification of broad trends, the increasing diversity concerning the welfare mix and new conceptual aspects such as the importance of outcomes for users and carers or user and carers as participants - not only recipients - cannot be theoretically conceptualised and empirically analysed within conventional categorisations. Therefore, different methodological approaches and new research strategies that take account of changing situations and perspectives are necessary (Tester 1999:151-152). This study partly draws on the methodological approach applied by Schunk (1996), who

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[22] Welfare mix is a concept developed through studies on innovative welfare mixes in care (Evers und Svetlik 1991, 1993, Evers and Winterberger 1990) and refers to the balance between the roles of the state, the market, the family and voluntary and private sectors concerning the provision of health and social care services.

focussed on case study localities and charted patterns of welfare mix using a variety of methods.

Community care as an area of long term social care includes care and support for people with severe and chronic conditions. The welfare mix pattern in mental health care - as will be seen from the case study material in later chapters - is complex and differentiated, and the comparison of community based care and support service provision as in this study (based on new concepts such as quality of life and from the perspective of service users as outlined in Chapter 2) includes more aspects than those that can be covered by the collation of social security data. Conventional models of welfare state typologisation may thus be used to describe and compare a broad situational context, but they are of limited use to open wider perspectives for empirical analyses. In the light of the continuing debate concerning the comparison of welfare states, an attempt is made to locate Germany and Britain in their respective national context below.

4.4   FOUNDATIONS OF CARE IN BRITAIN[23] AND GERMANY

4.4.1   BRITAIN

The period after the second world war was one of greater openness to new ideas in Britain and a series of social reforms of basic welfare services, particularly the Beveridge Plan of 1942 led to increasing availability of health services. Beveridge also became an advocate for the voluntary sector which already provided some grounding for the liberalistic approach of later governments to further encourage voluntary sector activity.

In Britain a comprehensive state National Health Service (NHS) was introduced in 1948 'in order to secure the provision of such health services

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[23] According to common practice I refer to relevant authorities in the British context as Social Services Departments (SSDs)and health authorities or trusts, and in the Scottish context to Social Work Departments (SWDs) and health boards or trusts.

to the whole of the population', which is regarded as the major feature of health policy in Britain (Alcock 1996:23). It has been criticised, however, that the NHS has traditionally been geared to the provision of acute services, while in many cases social services have failed to provide an appropriate pattern of complementary or alternative services to the client groups[24] later addressed by the community care reforms (Bagott 1994:219). Government policy in the 1960s gradually started to develop new patterns aiming "to shift resources from the acute sector towards the care of these groups, to improve the co-ordination of health services, social services and, more recently, private provision" and "to develop caring services for these groups in the community rather than in hospital" (Bagott 1994:219).

In the mental health field it is especially the last aspect – care in the community rather than in hospital – that has led to a large scale closure of mental hospitals, especially in England. Already in 1959 the Mental Health Act provided a basis to gradually reform the mental health system succeeded in the following decades by new legal schemes and programmes. The 1975 White Paper *Better Services for the Mentally Ill* (DHSS 1975) provided the basis for subsequent de-institutionalisation, hospital closure and care in the community. Review of the de-institutionalisation process in England during the 1980s however, pointed out that hospital closures had outrun community care provisions and local authorities had not been allocated the resources necessary to provide alternative forms of care (SSSC 1985, Audit Commission 1986). The Griffiths Report (1988) into community care provided recommendations for necessary legislative changes to meet the problem. Following Griffiths' proposed reforms to the system the shift towards a 'purchaser-provider model' and therefore also to a more decentralised system received particular emphasis in the White Paper *Caring for People* (DoH 1989) which provided the basis for the National Health Service and Community Care Act 1990. At organisational level the 1990 Act proposed that local

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[24] (e.g. people with: – mental health problems, - learning difficulties, - physical disabilities or - problems associated with ageing)

authority social service/social work departments should take the leading responsibility for assessing the needs of individuals in their local population as well as the provision and purchasing of services. Social security benefits, e.g. for board and lodging, and other community care funding are now channelled via the social services/social work departments.

The reformed community care system was implemented in stages from 1991 to 1993. At organisational level it was intended to improve co-operation, co-ordination and thus effectiveness and quality of services, while on an individual level it was intended to make services more responsive to individual needs and increase individual choice. New concepts like care management and programmes like the Care Programme Approach were introduced, geared to individual needs assessment and the development of personal care profiles including instruments for quality assurance as well as monitoring and evaluation.

While the policy of community care as such is not new in Britain, the reforms of the 1990s have placed new emphasis on structural and organisational aspects on the one hand, and on the role of the individual on the other. The emphasis on the individual is evident in many ways (e.g. plans and programmes concerning needs assessment, individual packages of care) but also reflected by the changing role of the service user concerning increasing participation and involvement, for example in policy panning and mental health care development.

Overall, the changes concerning health and social services provision for people with disabilities were both social and political in nature and occurred within a context that reflects the growing interest in community based alternatives to institutionalised settings on the one hand, and a politically motivated interest in reducing public expenditure on the other. It is therefore likely that changes in the welfare mix during the 1980s in Britain were less influenced by pragmatic considerations or considerations of efficiency and effectiveness than by a commitment to privatisation and

competition as one of the central concepts of new right politics[25]. Sharp criticism concerning new right policies include the suggestion that they have been designed to introduce "aggressive entrepreneurship, flexible labour, reduced state spending and social policies guided by the needs of the economy rather than ideals of social justice" (Hadley and Clough 1996:14). Alcock (1996:91) points out the commitment of successive conservative governments to reduce public expenditure and to 'roll back' the boundaries of state welfare provided a further incentive for the expansion of private and voluntary sector activity.

The present situation in Britain mirrors an increasingly market oriented approach concerning the provision of personal social services, reflected by a growing body of different service providers, that will be introduced in more detail further below.

4.4.2 GERMANY

The roots of the present German system of social security date back into the last century when the social reforms (enactment of sickness, accident, old age insurance) introduced by Bismarck at the end of the 19th century took place. The German example was followed in most European countries (though not until 1912 in Britain), not so much through direct emulation but as a common response to political and economic pressure. Many subsequent reforms have shaped the systems into what they are today, and while the German governments from the 1920s to the 1950s transformed their insurance-based arrangements into a corporate system, the British in the 1940s chose to have a national government assume direct responsibility for health care, thus creating a nationalised system (Heidenheimer et al. 1990).[26]

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[25] Right wing politics in Britain during the Thatcher years included the development of a mixed economy of care by extending the role of the market, non-profit organisations and informal sectors, while reducing the state's role in service provision

[26] for more detailed historical analysis of the German and the British system respectively see also Lorenz W 1994 and Alcock P. 1996.

In contrast to Britain, Germany as a Federal Republic with member states (Laender) cannot just impose major policy innovations from the centre on to the member states because the process of policy making requires consensus among the member states. This is a sometimes painstaking process of bargaining and compromise because it is the Laender who have prime responsibility for the delivery of health care and personal social services[27].

Basic funding structures for health care are different in both countries. While Britain funds health care largely from taxes collected by the central government, the German health care funding relies on compulsory insurance contributions (sickness insurance scheme) that workers and employers are obliged to make to designated health funds, which in turn pay the treatment costs of their members.

The German sickness insurance scheme maintains a sharp division between the state of acute ill health and long-term care needs. Non-clinical health and personal social services, such as supported accommodation or residential care for groups with 'special needs', are usually not covered by the sickness insurance scheme but by a locally administered means-tested social assistance scheme or by the long-term care insurance.[28]

Both the medicalisation of care on the one hand, in order to qualify for free health services, and the marginalisation of care dependency on the other

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[27] Germany is administratively divided according to its federal structure into 16 states. At federal level, the Federal Ministry of Health is responsible for matters relating to health. At state level health matters are undertaken by health ministers who are also responsible for non-health areas. The ministers oversee the implementation of federal legislation, prepare their own legislation, and undertake a wide range of administrative duties through a conference of ministers. At municipal level the health authorities occupy a relatively subordinate position being responsible only for health education and promotion.

[28] The long term care insurance was implemented in 1996 to cover for people with long term care needs. Principally, long term care should also include people with mental health problems, but in practice the assessment scheme to qualify for the long term care insurance is rather geared towards care needs that affect older people (i.e. declining physical ability concerning aspects like getting dressed, washed, fed....) rather than younger psychiatric clients *(Verein Pflege und Hilfe Daheim 2/2000:5)*. Long term psychiatric care usually varies over time and often covers more intangible aspects than those addressed by the long term care insurance, for example, a need for social care and support.

hand through the residual coverage of costs by the social assistance scheme may affect the individual entitlement for personal social care and have been subject to widespread criticism (Naegele 1992, Dieck 1994). It will be seen further below in this chapter and also when survey results are presented in later chapters, that the medicalisation of care seems to rest on solid foundations in Germany, for example, in relation to hospital provision and the requirements for acute psychiatric care.

In general comparison British community care policy now very much emphasises the role of the citizen as a consumer (George and Taylor-Gooby, 1996:111) and a mixed economy of care, while in Germany the traditionally strong idea of subsidiarity prevails. In Germany, public authorities will only be involved in the production of services when the abilities and resources of the family, the community and organisations to serve their members have been fully exhausted. This is especially relevant in relation to personal social services and can affect the variety of services as well as patients' or clients' entitlement to support and the use of services. It is a complex system, which influences not only the provision of care and support but also how caring responsibilities are perceived in public. The specific features of both systems, which have an impact on community based care, are set out below.

4.4.3 SERVICE PROVISION AND SUBSIDIARITY IN GERMANY

Pursuing the principle of subsidiarity Germany is the prime example of a non-profit organisation approach to service production. Non-profit or welfare organisations are responsible for an important share of health care and social services and they depend heavily on public subsidies. Based on the long tradition of the 'subsidiary' role of the state (Landwehr and Wolff 1993), the role of intermediary organisations as providers of social services and health care became legally approved.

Today in Germany the institutions of voluntary welfare work[29] are organised in six large bodies, the so called Central Associations (*Spitzenverbände*) serving also as 'umbrella' organisations. German Welfare Associations run more than 60.000 units providing health care and social services and this represents, according to a survey compiled in 1990, ninety per cent of all staff involved in caring for people with dependency needs (Seibel 1992). The important role of the non-statutory sector has to be seen in the context of subsidiarity, the principle which applies not only to the responsibilities of families for their needy members but also to the relationship between statutory and voluntary bodies. Conditional priority is given to voluntary non-profit organisations which wish to provide such social help, and public social assistance bodies are obliged to support the voluntary welfare organisations (Jarre 1991:212-217). Among the six major associations providing personal social services in Germany (see Lorenz 1994:160ff) those of the churches (the Catholic *Deutscher Caritasverband* and the Protestant *Diakonisches Werk der Evangelischen Kirche in Deutschland*) play a traditionally influential role. They share a major part as provider of social services among voluntary agencies, which has certain ideological consequences such as a corporate policy concerning service provision and staff selection. For example, a church run service usually requires that staff supports the church, at least as formal members. The requirement to support the church by active participation in religious activities is rather less widespread – although not unusual in some orthodox quarters. Principally, in church run services the criterion of church membership plays a dominant role concerning the selection of staff and is often considered before professional qualifications are taken into account. However, although these considerations may sometimes be more formal than ideological, they retain elements of control and repression, at least concerning the selection of personnel. Major conceptual differences, for example, between supported accommodation or a day care centre run by

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[29]In the present context the term 'voluntary' for German welfare organisations refers to non-governmental, non-profit making organisations, which operate as *freie Traeger* oder *private Vereine*. They are nowadays highly professional services and may or may not draw on the work of volunteers.

the churches or non-religious agencies are usually not apparent and evidence that would support an altogether different approach towards service provision has not been found when carrying out this study.

However, Christian values in conjunction with the principle of subsidiarity can retain strong moralising elements carrying conservative values of family responsibilities and duties, frequently overemphasising the role of the family and the caring duties particularly of the female family members.

The principle of subsidiarity as an appeal to citizens' solidarity may involve subtle moral implications and it is important to notice that subsidiarity often seems to emphasise peoples' duties and obligations more than citizens' rights. However, in conjunction with the more indirect cultural and traditional implications it is the German legislation that holds relatives formally responsible for the care of disabled family members, and together these factors may account for a determination among the German citizens to care for their kin; families are often reluctant to apply for welfare benefits and state support in either cash or care if one of their members needs support (see also Tester 1994:259). While the former relates to the fact that social benefits are often understood as highly stigmatising, the option for residential care is sometimes avoided because it may indicate that families are not capable of caring for their needy members or even neglect them by placing them outside their home into residential care. The principle of subsidiarity displays exceptionally moralising elements in such context.

What is peculiar to German Welfare Associations is their twofold character as service providing organisations and umbrella associations. While these umbrella organisations could be seen as potentially more powerful than a single service and therefore could demonstrate political pressure, they rarely appear as a political campaigner for the client group(s) their services target. They are politically powerful in quite a different sense: "rather than competing among themselves to develop a pluralistic diversity of approaches, an elaborate system of mutual consultation has been established on how areas of responsibility are to be divided" (Lorenz 1994:161). The central welfare associations are therefore powerful in the

sense that they present a united front as they negotiate with the state over allowances for their services. Negative aspects like underlying 'inefficiency and monopolistic structure' (Lorenz 1994:161) as well as conjoint selection of 'profitable' areas of work (Heinze and Olk 1991 cited in Lorenz 1994:161) have been pointed out, but the whole political setting seems to operate rather smoothly lacking any heated controversy and public attention. Seibel (1992:53ff) offers an interesting explanation: his analysis of the different patterns of government - non-profit relationship concluded that German parties and welfare associations as peak associations form a stable coalition to their mutual benefit through the integration of non-profit organisations in public policy making.

The underlying deficiency of these structures seems to point to a rather uniform network of service provision, for example in community based mental health care, with few possibilities for more innovative approaches and unconventional ideas of service provision. For example, the approach to involve service users in policy planning has not yet received particular attention in Germany, and the way services are shaped, organised and funded is negotiated solely among politicians and professionals, who form a stable coalition according to their own perceptions and preferences. In this light it does not seem surprising that the idea of user involvement is not more common in German policy making quarters.

4.4.4 THE MIXED ECONOMY OF CARE AND CONSUMERISM IN BRITAIN

In Britain, the voluntary sector has also played a significant role in the development of welfare provision, particularly in the mental health field. It has been pointed out that in many ways the services originated by voluntary organisations can be viewed as laying the foundations of welfare provision (Brown and Dixon 1996:131). Between 1960 and the 1980's the most common form of funding the services offered by the voluntary sector was the provision by local authorities of grants on a block basis which voluntary organisations took the initiative to apply for. This method was

increasingly seen as inefficient from a statutory point of view for various reasons: very little monitoring, an emphasis on inputs rather than on outputs, a lack of evaluations, very little accountability on the service providers, a general lack of planning, and a tendency towards short-term arrangements (Brown and Dixon 1996:136).

Over the last decade there has been a radical change in the relationship between the voluntary sector and statutory agencies. The political agenda (Griffiths Report 1988, Caring for People 1989 the NHS and Community Care Act 1990[30]) set the framework for a change in balance of the welfare mix: local authorities have a lead role and are required to assess need, decide what services are available, separate out purchaser and provider functions, reduce direct provision and commission services to meet the identified need on an individual and strategic level. The legislation has led to an increase in service provision by a variety of providers on the one hand, but the services and facilities often still appear rather scattered and isolated with little organisational structure. The implications for the voluntary sector are a high risk of fragmentation, unless structures to facilitate co-ordination, co-operation and joint working are not fully developed.

While Social Services/Social Work Departments now have the lead role for all community care groups in terms of the identification of need, individual need assessment and the creation of packages of care[31], the co-ordination

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[30] The Act also created 'specific grants' available for local authorities, money which could only be spent on new services for certain client groups or in particular areas, e.g. mental illness. Voluntary organisations, for example in the field of mental health care, were thus encouraged to offer special services and apply for funding from the Mental Illness Specific Grant (MISG) at local level (Social Work Department). In the first place the MISG was made available to help set up new services in the community and was due to run out in 1995, but was extended until 1997. It has meanwhile been recognised that further funding is vital to ensure the continuation of support work in the longer term.

[31] Case management is currently the most significant care package in Britain and is also receiving growing recognition in Germany. It is a system in which care is provided through the individually planned combination of different sources of care and the whole package is overseen by a single 'case manager', often a social worker (Huxley et al. 1990:197). A number of advantages, e.g. comprehensive care arrangements, but also critical aspects like a need for training and a wide range of skills necessary to carry out assessment and care planning, have been pointed out (ibid).

of services and the allocation of funding, health authorities continue to be responsible for medically required community health services with the responsibility for health care in a more narrowly defined sense. Effective collaboration, co-ordination and co-operation, between these major authorities and the service providing organisations has long been recognised as a prerequisite for the delivery of high quality services to individuals (DoH 1989), and has become a major objective in the current community care debate (Culhane 1996:39). The communication deficiencies especially in the field of mental health care have been brought into public vision through a number of events in Britain (Ritchie et al. 1994), where a breakdown of the information sharing system was identified to have had major influence (Hervey 1996:1). It was further pointed out that "it is only in the last few years that many social service departments have begun to communicate more effectively at a strategic level with other agencies" (Hervey 1996:1). A number of guidelines were developed for fostering multidisciplinary work in community care including, for example, measures to facilitate good quality relationships between different agencies (Lucas 1996:359ff), but the current situation is often far from being satisfactory.

Authorities in general are expected to plan well ahead to meet more of their community care needs in relation to particular client groups, which includes the regular presentation of Community Care Plans jointly developed by local Social Services/Social Work Departments and Health Authorities/Health Boards and other agencies e.g. housing. These plans are expected to set out strategic objectives and priorities sufficiently clearly to enable performance to be monitored and assessed, not least to monitor the de-institutionalisation process the White Paper *Caring for People* (1989 para 5.6) proposed, but also to implement means for joint working and planning. It will be seen in later chapters that plans and strategies are often too broad and unspecific lacking more definite criteria to monitor service provision and community care progress.

Overall, a change in the balance of the welfare mix, i.e. reduced state intervention and increasing consumerism in Britain, indicates that the

state's monopoly on service provision is undergoing major changes. It is still a mainly centralised system, but with a growing voluntary and private sector. This development has produced a situation difficult to oversee. "The voluntary sector in Britain is a vast and varied collection of organisations composed of different groups of people pursuing different aims at different levels of society" as Alcock (1996:86) has pointed out, and "the variety is so great that it is almost as difficult to identify any structure within the sector as it is to arrive at a consistent definition of it."

The problem is also evident in Scotland. In relation to mental health provision an extremely patchy organisational structure of service providers has been subject to criticism (Petch 1996:5ff), and the Scottish Association of Mental Health has stated that:

"there is no umbrella organisation in place which has the resources to allow them to collect information systematically" and "at present it is difficult to describe with any accuracy the work of this sector" (SAMH 1994:30).

In contrast to the relatively uniform German structures, where most services are attached to systematically organised umbrella organisations, voluntary organisations in Britain are often not members of a larger central body. Many of the services appear rather isolated with little organisational structure and are sometimes difficult to track down. The different organisational structures have both positive and negative implications. While systematically structured and organised services may be handled more efficiently, they are primarily mainstream type of services, which often lack the potential for more individual, diverse and innovative approaches. This is evident in Germany where services, e.g. in the field of mental health care, are largely similar with few individual features.

Overall, in contrast to Germany services in Britain appear more scattered, but also to some extent more independent in the sense that Britain seems to provide more scope for new and more innovative approaches, for example, user led services. But this general impression may also indicate a rather deceptive understanding of the consequences of a policy. Alcock

(1996:93) suggests that "in practice independence is in many cases only partial. Many agencies rely on state support and state funding either in terms of cash or kind; for many agencies it is the state, either locally or nationally, that is the main focus for their activity" (Alcock 1996:93). In this light, however, the situation is not very different between the two countries.

4.5   SUMMARY AND CONCLUSION

This chapter has examined major policy issues relevant to this study. First, the two dominant themes, the concept quality of life and the issue of user involvement were examined in their policy context before, second, the foundations and the administration of health care and social care was considered.

The first part has shown that the concept quality of life is widely used in the British as well as in the Scottish policy context, while this is not at all evident in Germany. British and Scottish policy documents frequently refer to quality of life and use it as a phrase or a kind of policy objective, however, often without being clear about what it refers to or giving it a distinct definition. In contrast, German documents rarely mention the concept. It has been pointed out that this may be due to a general feature of German policy planning and development identified as more technical than rhetoric. It has also been emphasised that it is difficult in both countries to assess the concept against stated policy objectives as these objectives are either not available (Germany) or remain equivocal (Britain).

The rather technical approach in German policy documents is also evident in relation to monitoring and evaluation. While the German approach to monitor the de-institutionalisation process concentrates on technical data concerning bed reduction and the collation of statistics, the British tend to incorporate consumer views on the one hand but focus on an economically orientated approach towards service provision (thus justifying resource cuttings) on the other. In both cases, as has been shown, subjective assessment and qualitative measures as, for example,

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incorporated in a concept such as quality of life are usually not included in general monitoring and evaluation schemes of community care, or are insufficiently addressed by using conceptual objectives as catch-phrases rather than benchmarks for evaluation.

This section has also made clear, that the role of the service user – especially in mental health care – is perceived quite differently in policy and planning in the countries of comparison. While the emphasis on user involvement is fleshed out in British policy papers on national, regional and local level, German policy documents rarely refer to service users as active participants involved in policy planning and development. Although it has been pointed out that relevant British documents contain a lot of rhetoric, which also affects the role attached to service users, British policy and legislation is providing at least a formal basis and therefore an entitlement for users to proceed as active participants. It has therefore been argued that the British policy guidelines can be seen as one possible way to empower users, for example, by providing a legally approved platform for structured participation. This is, after all, an entitlement German users still do not have.

The second part of the chapter started with a review of the debate focussing on welfare state categories and emerging criticism. It has been shown that conventional categorisations have been denounced for being too static, Euro-focussed and furthermore, based on a male breadwinner-model, however, increasingly seen inappropriate for the comparison of social systems. The current theoretical debate is therefore focussing on a more flexible approach towards the categorisation of welfare systems including more qualitative measures.

The comparison of the foundations of health care and personal social services in Britain and Germany has shown that there is still a divide between health care and social care, which appears to be even more accentuated in Germany. In Germany the sharp division between the state of acute ill health and long term care needs - rooted in the insurance based system of care - may have an impact that also maintains a strong medicalisation of care. This is particularly evident in mental health care

(see Chapter 5) – especially concerning the importance attached to psychiatric hospital provision, which has never been questioned in German mental health care policy. Alternatives such as crisis intervention services as debated in the US and to some extent also in Britain and in Scotland (Caps 1995) are not part of the German policy discussion.

The medicalisation of care is also supported by an example mentioned earlier in relation to research into mental health care, where it has been shown that studies are often carried out within the medical departments of German universities (see also Chapter 2). Those responsible for research and funding are often psychiatrists, even if researchers from other professional groups (psychologists, sociologists) may also be included. It seems as if a certain status quo is preserved in Germany, where the ultimate decision as to who has a say in mental health care soundly rests with professional quarters, often dominated by the medical profession, however. In this light it seems little surprising that what can be called a user movement in Britain has so far not received more recognition and publicity in Germany. Service users are treated as patients and recipients *of* care rather than participants *in* care.

In Germany the principle of subsidiarity has implications that may not be obvious at first sight, yet as a basis for the German non-profit approach to service provision prevalent organisational structures include a rather uniform network of services with relatively little diversity and flexibility. Despite the fact that the implementation of new models of care provision have apparently increased state responsibility on the one hand and introduced greater diversity into the range of provider organisations on the other (like, for example, the long term care insurance finally implemented in 1996), the hitherto close and non-competitive relationships between the provider organisations and the public funding authorities is based on rather traditional structures. This is evident in the way service delivery is planned, funded and administered, a transaction mainly arranged between public authorities and a body of six major welfare associations providing social services. In this setting, users of psychiatric services have no active role to play which is reflected by policy documents on all levels. The

chapter has thus highlighted that social services in Germany - as part of large central bodies - appear rather mainstreamed, however, often with little innovative potential.

In relation to Britain the chapter has addressed the changing balance concerning the welfare mix and increasing consumerism in Britain, which indicates that the state's monopoly on service provision is undergoing major changes. The mixed economy of state, market, voluntary and informal sector is increasingly characterised by a reduced role for the state and the development of non-state sectors. It is still a mainly centralised system, but with a growing voluntary and private sector. It has been pointed out that this development in Britain has led to a situation difficult to oversee. The services provided by voluntary and private organisations appear scattered with little organisational structure lacking, for example, regional or national umbrella organisations. But in comparison to Germany there seems to be more scope for diversity and unconventional forms of service provision such as user-led services or alternatives to hospital provision such as crisis services.

Community care services, especially in the mental health field, are mainly provided by voluntary organisations in Germany. This is increasingly similar in Britain, where the mixed economy of care requires the encouragement of voluntary and private sector activity based on market oriented structures. While increasing privatisation of social services in the UK might produce structures which superficially resemble the feature of German 'contracted out' services (Lorenz 1994:149), the German principle of subsidiarity and the increasingly market oriented approach towards service provision in Britain remain fundamental policy differences.

Overall, the chapter has highlighted the different conceptual, organisational and administrative structures of health care and social care – including an examination of the quality of life in its policy context - in the countries of comparison. While some of the differences are merely technical in nature, like funding sources, others appear to be more fundamental which may have an impact on the delivery of care and the way community care is perceived by different stakeholders. Different

administrative foundations concerning the delivery of social and health care as well as distinct policy emphasis can have an impact on the quality of life of mental health service user. For example, concerning the number and variety of services that are available or concerning legal rights for participation in policy planning and practice development. These aspects will be considered again in later chapters when the user perspective will be presented.

The following chapter examines – more narrowly – community mental health care policy in the countries of comparison.

CHAPTER 5

MENTAL HEALTH CARE POLICY IN COMPARISON

5.1 INTRODUCTION

This chapter builds upon the previous chapter that has focussed upon the analysis of social and health care foundations in Britain and in Germany, which provide the respective national framework for distinct mental health care policy and practice. The current chapter examines the policy basis relevant to the administration and practice of mental health care in Germany and in Britain[32]. The chapter includes an analyses of relevant national mental health care policies and legislation in Britain and Germany, but with a special emphasis on the proceedings in Scotland and Hesse as well as in the case study localities, Edinburgh and Offenbach. The case study level is rather generally presented here, more detailed examination is provided in the following chapter, when the local welfare mix will be examined and compared.

The chapter attempts to outline some of the foundations of mental health care policy in the countries of comparison, which are important to understand the respective national policy context in general, and the comparative analysis of outcome in community mental health care from a user perspective in particular. The chapter addresses the second specific aim of this study: to analyse national community mental health care policy

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[32] Mental health care policy is embodied within the wider field of 'community care' in Britain and more narrowly defined as *Gemeindepsychiatrie* in Germany, both marking the move away from care in large institutions.

in Britain, especially Scotland and Germany. Therefore, the chapter identifies major components of community mental health care policy in both countries and furthermore provides the immediate policy framework relevant to the interpretation of survey results presented in subsequent chapters. While the two major themes of this study, the concept quality of life and the role of the service user and their relevance in community care policy have been examined in the previous chapter, this chapter concentrates on major mental health care components. It will be seen that distinct policy objectives affect both, the profile of support services and their general availability, while later chapters will address the effect of policy objectives and general availability on the quality of life of service users.

In this chapter mental health care policies are examined in general, but also in relation to major areas of support service provision, identified as *health, housing or accommodation* and *employment or day care*. These areas can be seen as the most dominant components of community mental health care within which policy development and service provision has taken place over the years in the countries of comparison. While the first area, health, refers to acute services (i. e. psychiatric hospital provision) and the scheduled reduction of hospital beds, the two other areas refer to increased service provision and the creation of places (i.e. housing or supported accommodation, day care or sheltered employment). Other components - or life domains as they have been called earlier - that have been identified as important in relation to this research include *finances, formal and informal support and social contacts*. The identification of altogether six life domains is to some extent based on other quality of life research and evolves from the theoretical framework developed for this study and introduced in Chapter 2.

In this chapter principal policy development in community mental health care is set out on national, regional level and case study level below, before policy development in relation to the three most dominant components is considered. While more general policy development is

examined on national level (i.e. Britain/Germany), the more detailed comparison of mental health care policies and especially current availability such as place numbers is provided on regional state level (i.e. Scotland/Hesse).

The data provided for Scotland and Hesse refer to rather similar population numbers focussing on a population of 5. 525 033 (The Scottish Office 1995:89) in Scotland in 1994, and a population of 5. 837 000 in Hesse in 1995 (Hessischer Landtag 1996). The numbers and figures presented refer either to the total population or to population estimates of 150 000 or both.

It is important to recognise the principal difficulty in comparing national entities on the one hand, and federal structures on the other, especially since compatibility is not always possible. While German mental health care policy development is rather similar on both national and regional levels[33], differences between the British policy framework and the proceedings in Scotland are more distinct. In the present case Germany and Scotland seem to have more in common than perhaps Germany and Britain, for example, concerning the closure of mental hospitals or the initial implementation of community based mental health care. General mental health care policy development is thus compared first between Scotland and Germany (including Hesse), before more detailed analysis concentrates mainly on Scotland and the regional state of Hesse, but refers to the wider national context when necessary.

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[33] Considerable differences rather appear between urban and rural areas

5.2 COMMUNITY MENTAL HEALTH CARE POLICY

5.2.1 SCOTLAND

A great deal of public policy for Scotland is identical with that of the rest of the UK (e.g. income tax rate, foreign policy) and until 1999 Scottish administration was controlled by The Scottish Office, a territorial department of the UK Government that allowed for some measure of distinctiveness in policy making for Scotland, for example, concerning community care. Managing and implementing community care policy was a corporate responsibility of The Scottish Office until the new Labour Government in Britain set up the Scottish Parliament with distinct legal powers. While the Scottish Office's role was to lead the implementation of community care, to create the framework for its success, provide guidance on key aspects, develop specific implementation mechanisms (such as Resource Transfer, Bridging Finance and Mental Illness Specific Grant) and to monitor and evaluate progress against stated objectives, this is now the responsibility of the Scottish Parliament. The responsibility of implementing the policy locally rests with local authority Social Work Departments, Health Boards and Trusts, Housing Departments and Scottish Homes, the Governmental Housing Association.

The implementation of community care policies happened later and more slowly in Scotland[34] than, for example, in England. The historically high provision of psychiatric hospital beds which Scotland had compared to England, seemed to be largely accepted for a long time and numbers fell only slowly between 1970 and the late 1980s.

Despite a general policy of care in the community in Britain, the Scottish health policy document Shape Report (SHHD 1980) did not substantially

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[34] Differences in mental health care policy and practice can be found in Hunter and Wistow 1987 and Titterton 1991

alter the balance of care between long stay hospitals and community services. In 1984 there were still 31565 available staffed beds in the long stay sector (House of Commons 1995:vi). The subsequent document, the Sharpen Report (SHHD 1988) began to change this when community care was made a priority and attention was drawn to the historic problem of the long-stay hospitals and the need to move care progressively out into the community. The pressure for this came from a wide range of sources - professionals and voluntary organisations - as experience grew of alternative models of care. In addition, it became evident over the years that it was not sufficient to provide only domiciliary care and support at home, clearly a variety of other support services for people with mental health problems was also needed.

Interestingly, despite the significance the Sharpen Report had attached to the issue, the Scottish health document, 'Scotlands Health. A challenge to us all' (The Scottish Office 1992) only briefly refers to mental health care - in contrast to Governmental Strategy for Health in England 'Health of the Nation' (Department of Health 1992) and neglects issues such as the importance of community based support services. For example, indication as to whether services and support needed for people with mental health problems should be extended or improved is limited, let alone decisive referrals to increasing need in the future. The document notes that "nowadays the long-term mentally ill are increasingly living in the community" and "the resident population in mental hospitals has fallen by 20 per cent over the past 20 years" (ibid:34) but the important role of support services in the community is not taken into account in more detail. It is evident that while independent professional organisations like, for example, the Scottish Association for Mental Health (SAMH), have taken a lead role in campaigning for the expansion of community based support services, official governmental documents in Scotland have remained rather superficial about concrete aims and objectives.

In a related context Simic et al. (1992) claimed that policy in Scotland is, despite rhetorical similarity, substantially different from that in England and

Wales. "The contrast is particularly stark in relation to policy on hospital closure. Whereas in England there is a desire to close all psychiatric hospitals by the year 2000, in Scotland there has only recently been any talk of planned closure on a hospital wide basis" (Simic et al. 1992:22).

Similarly, the Scottish Affairs Committee (1995:vi) pointed out that Scotland has relied more heavily than England and Wales on traditional patterns of care (Scottish Affairs Committee 1995:vi). Although there was a steady reduction in staffed bed numbers in the long stay sector from 1984 (31565 beds) to 1994 (23052 beds) in Scotland, it was pointed out that "there have been no significant hospital closures of the scale seen south of the border. Only now are plans for the complete closure of selected hospitals starting to emerge". (House of Commons 1995:vi).

The Scottish Association for Mental Health (SAMH 1994) identified a lack of central direction from the Scottish Office as a major reason for the slow development in Scotland, for example, concerning the establishment of targets for the reduction of mental health beds and the closure of named psychiatric hospitals. This point was also raised by the Scottish Affairs Committee (House of Commons 1995:v) in their review of the closure of mental hospitals in Scotland. In response to the Scottish Affairs Committee's report the Scottish Office produced "a statement of aims and points which we would expect to be covered in local strategies" (The Scottish Office1996a). The Framework for Mental Health Services in Scotland (The Scottish Office 1997) is the current Scottish guideline intended to promote the implementation of existing policy and build upon initiatives already in existence. In order to monitor the de-institutionalisation process and progressive bed reduction the Scottish Office also asked local authorities to provide greater detail in their community care plans about their broad view of the needs of the area and the actions by which they intend to work towards meeting them. In practice, however, the problem is that community care plans often focus on general goals and descriptions and also statements of principle rather than specifying clear objectives that could be monitored over time.

5.2.2 GERMANY

Similar to Scotland, innovations in psychiatric care took more time to establish themselves in Germany compared to England. There was at first little interest in community psychiatry in Germany, and with university departments and mental hospitals going their separate ways (Mangen 1985b) the debate was rather restricted to separate professional quarters. *Gemeindepsychiatrie* (community psychiatry) only gradually started in the 1970s, after the Federal Government had appointed a Commission of Enquiry to investigate psychiatric care in the Federal Republic of Germany. Their report, commonly known as the *Psychiatrie Enquete* (1975), was said by Mangen (1985b) to make 'depressing reading' with accounts of how patients were living in impoverished and inhumane conditions. The Commission required immediate action to improve the situation for mental health patients, who were until then living in appalling and intolerable conditions in large psychiatric hospitals. While the *Psychiatrie Enquete* launched a new era in mental health care in Germany on the one hand, the Commission's recommendations have also been accused of being 'a perfect technocratic solution' (Degkwitz 1978:53), largely lacking therapeutic and practical concepts for the new services (see also Bauer, 1975).

The two central areas for community based service development were identified as housing and employment (Psychiatrie Enquete 1975:223-232), and provision expanded gradually during the 1980s. Another major theme of the psychiatric reforms set out in the Psychiatrie Enquete (1975:160ff) was to equate patients suffering from a psychiatric illness with those suffering from a physical illness. Therefore it was suggested that psychiatric units for acute inpatient care should be attached to general hospitals. The latter was seen as one of the core elements of the German mental health reform: the development of psychiatric units as part of general hospitals for a maximum population of 150 000. While this was meant to commensurate the status of people suffering with a mental

illness with those suffering from a physical illness, the reforms also underpinned the medicalisation of care (see also Chapter 4). Under the auspicious label of 'reform' it was thus possible to preserve a certain status quo and keep the hospital at the centre of community based mental health care both as a place for acute in-patient care and treatment and as a last resort in times of any psychiatric crisis. In contrast to other countries like England, Italy or the US, where the need for hospital provision is sporadically questioned and debated from various angles, for example, in comparison to crisis-centres (Stein and Test 1985, Hoult 1986, Mosher und Burti 1994:175ff) this has never been part of the policy debate in Germany.

In comparison, it is evident that in contrast to the much more explicit British policy of hospital closure (a policy followed by Scotland much more slowly), the *Enquete*-Report was reticent about the future of mental hospitals only recommending that they should have a maximum size. In-patient hospital care, although now often in small psychiatric units rather than large institutions, is a central feature of community based care in Germany. In 1992, 120 of these hospital units had been established across the country and while the German Government positively emphasised the progress of this development, criticism had been raised about the slow pace and a deficit of still around 400 units in relation to the total population (Bauer 1993:45).

At national level progress was reviewed in 1988 (Expertenkommission 1988), when a great number of community based services had been established. The new guidelines *Empfehlungen der Expertenkommission* (1988) were as technocratic as previous documents, highlighting facts and figures of achievement and targets for the future. Little was said regarding statements of principle or concepts for the future, for example concerning the role of users and carers as being more than recipients of services.

Instead, the review set out strategies for further progress at operational level based on professional and political preferences. For example, a new focus was upon measures to network already existent services and on

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quality assurance. In addition to housing and employment as core areas for service provision other complementary mental health services were introduced as significant 'building blocks' *(Bausteine)* for a community based mental health network (*Gemeindepsychiatrischer Verbund*) such as community mental health centres (*Gemeindepsychiatrische Zentren*) or psychosocial meeting and advice centres (*Psychosoziale Kontakt-und Beratungszentren*). The need for networking and collaboration was increasingly seen as vital for successful further development. To oversee community based care locally and network the services effectively, the policy document recommended structural units on the basis of a model community care network (*Gemeindepsychiatrischer Verbund*), i.e. sectors comprising of a population of 150 000 (Expertenkommission 1988:136). The 1988 guidelines were drawn together on the basis of prospective staff expenditure for the major support areas, but did not assess need in terms of place numbers for clients. The document is the most recent national policy framework for community based mental health care, successively supplemented by the German regional states' individual mental health policies and strategies.

5.2.2.1 HESSE

In 1996, the regional state of Hesse published its own planning document for progressive community mental health care. The document (*Landeskoordination*) attempts to set the agenda for community based mental health care in the regional state until the year 2000 especially concerning service provision in the major areas of support defined as housing, day care and employment. The document mainly concentrates on current availability and future need, i.e. place numbers to be created by the year 2000. Future requirements are estimated at regional state level, but also in relation to 24 designated 'planning regions'; the case study locality (Stadt und Kreis Offenbach) is one of them. Overall, the document is rather technical in nature offering only little community care rhetoric, but

records achievements in terms of availability and place numbers in the major areas of service provision as well figures concerning future requirements.

Community based mental health care services are mainly funded by the regional state and its administrative bodies, in relation to Hesse this is the *Landeswohlfahrtsverband (LWV) Hesse.*

5.2.3 EDINBURGH AND OFFENBACH

The relevant documents concerning the Scottish case study locality show a recurring broadness regarding their aims and objectives, which has already been pointed out in relation to other British and Scottish policy documents. Similar to the Lothian Community Care Plan 1995-1998 (Lothian Regional Council 1995), the Strategy for Mental Health Services 1995-2000 issued by Lothian Health (1995) only provides broad and comprehensive statements regarding the major policy aims and objectives, lacking more concrete measures for progressive development.

The most recent strategic document is the Joint Mental Health Plan for the City of Edinburgh, jointly prepared by Lothian Health and the City of Edinburgh Council (1998). According to national policy requirements the plan has been developed including representatives from the local authorities, voluntary organisations, users and carers. It draws together the mental health aspects of the existing plans mentioned above, and highlights the key points for further development for the years 1998-2004. In contrast to existing plans like the Community Care Plan 1995-1998 (Lothian Regional Council 1995) and the Strategy for Mental Health Services 1995-2000, the new document systematically identifies specific gaps at various levels. For example, at operational level a need for more effective interactions between agencies or more awareness for mental health issues through better mental health promotion. In relation to support

services the plan identified a specific gap in the availability and range of employment opportunities (Lothian Health/City of Edinburgh Council 1998:14) and in relation to housing a need for high levels of support and more flexibility (ibid:15) based on the recognition that housing demand far outstrips availability (ibid:18). The most detailed measures as to how the identified needs should be met concentrate on the development of plans and review schemes, for example, an implementation plan to underpin and support the joint mental health plan and regular reviews of the progress (ibid:2) and the setting up of groups such as an advocacy tasks group (ibid:20) or a crisis task group (ibid:23).

Overall, the new plan appears to be more decisive concerning the identification of gaps and the necessary action to close them, but many statements remain broad and unspecific. However, not included in the new document is a more detailed overview on existing services and place numbers, for example, in significant areas such as housing or day care and employment, which would allow for a more systematic overview on what has been achieved in the past in relation to what needs to be done in the future. While some broad figures are presented occasionally such as the recognition that "there are currently over 200 registered residential places" (ibid:15), a more specific account of particular types of accommodation or the range of support options according to different levels of need remains elusive. The connection of current availability, identified gaps and future need is thus difficult to oversee.

The most recent strategic document concerning mental health care in the City and District of Offenbach is a joint paper developed by major stakeholders in 1994. These stakeholders constitute a Board *(Psychiatriebeirat)* that meets regularly to facilitate planning, networking and development in mental health care throughout the region. The board includes representatives from City and District Council as well as major service providers, but as yet no service users.

The policy guidelines *'Fortschreibung der "Empfehlungen zur Weiterentwicklung der Psychiatrischen Versorgung von Stadt und Kreis*

Offenbach" (1994) provide information concerning the availability of different kinds of services as well as current place numbers. The document also contains planning targets for the future including a list of priorities, but remains reluctant in the way of timing, for example, concerning a distinct time scale. The document makes clear, however, that service provision in mental health care is more advanced in the City of Offenbach, while provision in the District has generally started to develop later and is lagging behind the City's current standard; it is therefore pointed out that service expansion needs to concentrate primarily on District regions.

5.3 HEALTH: PSYCHIATRIC HOSPITAL PROVISION

Fundamental reforms of psychiatric care from hospital based care towards care in the community took place in many Western countries albeit the shifting of resources occurred at a different pace. It has been pointed out elsewhere that the considerable pace of hospital closure in England has not occurred concurrently in Germany and its respective regional states and neither in Scotland, where this development had started later and more cautiously.

5.3.1 PSYCHIATRIC HOSPITAL PROVISION AT REGIONAL STATE LEVEL

Since 1981 there has been a steady shift away from hospital beds towards residential care homes in Scotland, and yet the number of residents in hospitals fell by only 11 per cent between 1981 and 1995, with still more than 13.000 beds in psychiatric hospitals in 1995 (The Scottish Office 1996b:50, SAMH 1994:1). These figures show that the number of people

resident in mental hospital is indeed still very high in Scotland. It has been pointed out that, traditionally, Scotland has relied more heavily than England and Wales on institutional patterns of care, and several arguments have been put forward to explain this variation, including greater professional conservatism, a lack of proven alternatives and an absence of a central directive from The Scottish Office (Scottish Affairs Committee 1995:v). For the first time in Scotland, however, broad targets have been set for the reduction of mental health beds and for the closure of named psychiatric hospitals in 1994 (SAMH 1994:1), when the Scottish Office announced a significant shift in the provision of care away from institutions and the reduction of the number of long stay mental health beds by 8000 by the year 2000 (ibid.). Until 1995 Scotland had a total of 26 psychiatric hospitals, of which in 1995/96 two of the six hospitals scheduled for closure were completely closed down (Gartloch in Glasgow -350 beds and Kingsseat in Grampian - 312 beds).

In its response to the Scottish Affairs Committee's report on 'The Closure of Psychiatric Hospitals in Scotland', the Scottish Office committed itself to produce a statement of aims and points which would be expected to be covered in local strategies. While the draft framework for Mental Health Services in Scotland issued in 1996 covers a wide field of potential development in all areas of community based provision, the future role of psychiatric hospitals remains rather unspecific. It has been stated that the traditional wards must not be closed until satisfactory alternative facilities are in place in the community (The Scottish Office 1996d:28), but a clear statement for the eventual closure of hospitals and wards has not been made explicit.

The development towards the closure of hospital beds is supposed to continue according to national policy requirements and more structured Scottish Office guidance, but at the same time there is serious concern that provision outside hospital remains fragmented and uncoordinated. While in some areas service provision is entirely underdeveloped, for example, sheltered employment, many of the valuable but small initiatives

developed in the field of community based care are jeopardised by insecure funding (SAMH ibid:2).

The number of beds in psychiatric hospitals has been generally smaller in Hesse compared to Scotland. Bed reduction in Hesse slowly started after 1975 from a number of 9543 psychiatric beds to 6629 psychiatric beds in 1984, which was once more reduced by almost 50 per cent to 3181 psychiatric beds in 1996 (Hessischer Landtag 1996:4). Predominantly, bed reduction took place in the old style asylums, of which none has been completely closed down to date[35].

According to a central recommendation of the Enquete Commission (Deutscher Bundestag 1975) the number of special psychiatric units attached to general hospitals has risen during the last two decades, and since 1978 a total of six psychiatric units have been attached to general hospitals across the region state of Hesse (Hessischer Landtag 1996:1). Most of the units provide an average number of 80 beds for a population of 150.000 according to the most recent Governmental guidelines (Expertenkommission 1988:291).

Psychiatric units have not yet been established everywhere and many sectors still rely on psychiatric beds in large mental hospitals often far away from the geographical community they serve. Hospital provision in one part of our case study locality (Offenbach District), for example, is one of those archetypical settings which will be seen in the following chapter. However, almost 20 of the old style mental hospitals are still used for in-patient care in Hesse, and development concerning the proposed replacement of the traditional mental hospital by psychiatric units and community based services seems slow, although progressive bed reduction appears relatively favourable in comparison with Scotland.

The table below shows the total number of psychiatric beds available on Scottish and on Hesse state level in 1995 and 1996 respectively.

Scotland 1995	13.000 beds	361 beds per 150.000 pop.
Hesse 1996	3.181 beds	88 beds per 150.000 pop

Table 5-1: Mental hospitals beds in Scotland (1995) and Hesse (1996)

The numbers above show a remarkable difference between available beds in Hesse and in Scotland which needs to be explained.

In comparison, the most striking differences concerning in-patient mental health care in mental hospitals and/or specific wards must be interpreted on the grounds of particular national policy objectives on the one hand and their transfer into practice on the other. There are two major aspects which potentially influence national developments in the countries under comparison: different general policy objectives and basic guidelines, but also the action undertaken to transfer them into practice. British community care policy has focussed upon the closure of mental hospitals more radical than the German mental health care reforms. In contrast, the German policy has remained reticent about such principles and rather focussed on bed reduction but with a principal emphasis on hospital care as a central element to community care (Psychiatrie Enquete 1975). The German mental health reforms thus concentrated on bed reduction but on a clearly structured basis according to regionally devised plans. The numbers provided above on regional state level reflect that development has taken place, which mirrors almost exactly the planning directives (Expertenkommission 1988:291). In contrast to the radical closure of mental hospitals in England, but also in apparent contrast to the rather technically structured bed reduction over the years in Germany, Scotland's policy concerning mental hospital care and especially bed reduction appears rather ambivalent. On the one hand policy guidelines require the shifting of resources into the community according to national directives, but on the other hand bed reduction has happened comparatively cautious and slow. It seems as if Scotland's position towards the closure of mental hospitals has remained rather unspecific at least until the Sharpen report (SHHD 1988) required more action. But even then, more detailed plans or

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[35] This is similar in most other regional states. Nationwide, only one mental hospital had been closed down completely by 1996, Kloster Blankenburg in Bremen

guidelines for scheduled bed reduction have not been provided in sufficient detail on Scottish level, which has also been criticised as being a lack of guidance from The Scottish Office (Scottish Affairs Committee 1995). However, since there is no other indication that would perhaps explain a particular need for the current number of 13000 psychiatric beds in Scotland, for example, based on policy objectives diverging from those proposed by national policy guidelines, it is likely that other aspects such as a lack of planning directives explain the remarkable differences in the number of hospital beds as shown above. Other indicators for the comparatively slow development in Scotland in contrast to England have been pointed out to include greater professional conservatism in Scotland (Scottish Affairs Committee 1995, SAMH 1995). Professional conservatism and a rather traditional attitude towards care in mental hospitals highlighting a need for substantial hospital provision is also reflected by early Scottish studies into community care, a tendency which has gradually been refuted by other studies (see also Chapter 2). However, since current Scottish policy objectives generally conform to national guidelines with little divergence concerning major issues, the influence of conservative tendencies may be more subtle. Provided that such tendencies are prevalent in Scotland, this may also influence political decisions and the absence of more detailed planning directives.

In general comparison, however, further bed reduction is still on the agenda in both regional entities, Scotland and Hesse. While the regional state of Hesse seems to conform to successive national planning requirements at least from the point of bed numbers (not necessarily concerning other aspects, i.e. geographical access, as will be seen on case study level), Scotland has apparently been more reticent to follow national directives. In any case, however, Scotland and Germany appear reluctant to follow, for instance, the English example of entire hospital closure or the US example of establishing alternatives to hospital provision such as crisis intervention services (Stein and Test 1978, 1980, 1985). This tendency is also evident on local i.e. case study level as shown and discussed in more detail in later chapters.

5.4 HOUSING AND ACCOMMODATION

The fundamental reforms of psychiatric care during the last couple of decades have brought about a variety of different housing options to accommodate people with mental health problems in the community, not least those discharged from traditional mental hospitals according to respective national de-institutionalisation and de-hospitalisation policies. Residential care consequently concentrated on the provision of care and support in a variety of sheltered settings in the community. A review of research into different types of residential care in Britain showed that during the 1970s and early 1980s (National Institute for Social Work 1988) a clear tendency towards hostel provision for people with mental health problems prevailed, but housing provision has meanwhile changed. While initially hospital hostels, staffed hostels and group homes were among the most common alternatives in Britain and in Germany, more individual living arrangements in individual flats and houses - now commonly referred to as supported accommodation - have become more widespread. This development is especially noticeable in Britain including Scotland, while in Germany hostels still play a more significant role in community based housing, along with supported accommodation.

The term supported accommodation is currently used for any form of housing especially provided for people in need of care and support. It is, however, intermediate between conventional institutional care, and fully independent living, while support can be temporary or permanent.

Supported accommodation is a generic term and requires a definition especially as different forms of supported accommodation are necessary to meet the diverse and varying needs of individuals. Generally, the national housing agency Scottish Homes (1995:1) talks about "dwellings dedicated for the specific purpose of accommodating individuals requiring some form of support in order to live independently in the community" and yet, supported accommodation covers an array of possibilities and options. More precise definitions of various types of supported

accommodation are hard to pin down, as many of the terms are used interchangeably by the organisations and agencies providing housing and support.

5.4.1   SPECIFIC HOUSING POLICIES IN COMPARISON

In Britain the housing element is enshrined in the Governmental intention that 'suitable good quality housing' (DoH 1989:9) should be available, as community care policy is based on the belief that nearly everyone prefers to live in ordinary housing rather than in institutions, because institutions often lack the capacity to be a real home.

The White Paper *Caring for People* (Department of Health, 1989) stated that people with mental health problems

"...need to be able to live as independently as possible in their own homes, or in 'homely' settings in the community" (DoH 1989:1.8)

It is further suggested that social services authorities will need to work closely with housing authorities, housing associations and other providers of housing of all types in developing plans for a full and flexible range of housing (DoH 1989: 25). The White Paper provides the national theoretical framework for community care planning and development, but it has been criticised that housing merits only four paragraphs, whereas entire chapters are devoted to the roles and responsibilities of social services authorities and of the health service (Petch 1994:76).

Most governmental publications focus on broad theoretical statements, and while the essential nature of the housing contribution is often recognised, more reliable directives to encourage and support progressive development are often lacking. For example, a Scottish Office publication states that

"Housing has a particular and crucial role to play in the success of community care. The availability of a range of suitable housing for those who need community care is essential if their needs are to be properly met" (The Scottish Office 1991:para 1.4.1)

but little is said concerning the successive transfer into practice. Furthermore, governmental rhetoric does not seem to match with practical development.

The successive transfer of broad national policy guidelines into practice is usually set out at local level, for example, in Community Care Plans, which are regularly produced by local authorities. In relation to the Scottish case study locality, plans and strategies continue to be relatively unspecific, although in 1994 the Scottish Office asked local authorities to provide greater detail in their community care plans about their view of the needs of the area and the actions by which they intend to work towards meeting them.

The central policy aims concerning housing as presented in Community Care Plan 1995-1998 for the former Lothian Region in relation to housing broadly intend to "support people at home by creating realistic alternatives to hospital, or residential care...and ...support the expansion of supported accommodation services" (Lothian Regional Council 1995:18) but the entire document offers no benchmarks to assess the current situation or estimate a calculated need for future provision.

The Mental Health Strategy (Lothian Health 1995) provides somewhat more specific material, but still remains relatively unspecific with regard to future need. The Strategy, jointly prepared by Lothian Health and Social Work Department in order to improve the range and quality of services for people who have a mental illness, aims to ensure that appropriate services are provided in the community before any individual is transferred from hospital to the community. Although the Strategy provides more detailed information on supported accommodation than on any other community care area, i.e. place numbers and future need, figures for the

City of Edinburgh are few. Except for the present level of accommodation places in 1995, estimates for future requirements only broadly cover the entire Lothian region without any further distinction or definition, for example, in relation to geographical priority areas or in relation to different options or different levels of support.

The German housing policy is similarly broad in promoting 'better living conditions' and 'the continuing development of community based support services' (Psychiatrie Enquete 1975:15ff, Expertenkommission 1988) on a fairly comprehensive basis. In contrast to the British or Scottish policy documents, however, printed policy matters in German generally appear more technical and less rhetoric which has also been shown in the previous chapter.

Housing for people with mental health problems has basically two domains in Germany: first, 'supported accommodation' in a more general sense, i.e. users live in individual dwellings (flats and houses) with varying extent of support provided by professional supporters, and second, in hostels (*Wohnheime*) usually with a larger population between 12 and 40 inhabitants, often even more.

It is in fact surprising that hostel provision is not viewed more critically in Germany, although the institutional character of such housing is hard to deny. In contrast to Britain and Scotland, where hostel accommodation is rather outdated in favour of more individualised forms of housing, the official course as evident in German policy documents continues to focus on hostel provision as a central element of community based mental health care and the extension of places in the future. While Germany has embarked on reforming the mental health care system in the late 1970s with a clear emphasis on community based housing as an important area for activity, it seems also evident that what has been a progressive step at the time (i.e. hostel provision rather than care in mental hospitals) has remained 'status quo' up until now and progress takes place very slowly. Although supported accommodation has become more widespread

especially during the 1980s, hostel provision remains a significant housing component (Expertenkommission 1988).

A number of reasons may sustain the German policy focus on hostel provision. It may be possible that care in larger institution is deemed cheaper by those responsible for planning and decision making than more individual forms of housing, especially for people with a need for more intensive support. A possible explanation may also emerge from particular organisational structures that have been examined in the previous chapter, especially, that the organisations providing services in the field of mental health care – as parts of larger bodies (i.e. welfare associations) – are less flexible and innovative in developing, establishing and financing 'new' ideas. There seems to be a general tendency to preserve institutional forms of care in contemporary German mental health care. This includes in-patient hospital care as well as care in hostel type of settings both of which are central elements to community care policy. Policy documents reflect a strong reliance on such forms of care evident on national, regional and local level. In comparison, one could conclude that the British market mechanisms of the mixed economy of care provide more potential, for example, concerning larger numbers of different service providers including small initiatives. This leads to more scope for 'new' ideas and therefore more differentiated options of care and support.

However, while German mental health care policies principally rely on institutional housing structures, the more recent professional debate reflects emerging criticism. Thus, it has been suggested that de-institutionalisation needs to include homes and hostels as well, and not only focus on mental hospitals of the old style, in favour of more ordinary living alternatives (Zechert 1996, Zechert and Suhre 1997, Steinhart 1997). In 1996 the national housing situation was reviewed (Zechert 1996, 1997). Data material on discharge numbers and housing alternatives after discharge were requested from all German regional states (16) of which 41% did not provide any data material. One of the central questions, however, was related to the size of the home or hostel patients were

discharged to. The 1993 figures from 5 region states showed that a remarkably small proportion (only 4.7%) had been discharged into individual flats, while 15.6% were discharged into homes up to 24 places and 84.4% into hostels with more than 25 places (Zechert 1996:28). These figures underline the remarkable importance of hostel provision compared to other forms of housing support in contemporary German mental health care.

In contrast to the Scottish documents, the German policy material provides little rhetoric with regard to policy aims and objectives, but figures on current provision and future requirements are clearly formulated. In relation to housing the emphasis in relevant German policy documents is upon the expansion of 'supported accommodation' in individual dwellings, but - as has been pointed out above – also on hostel accommodation. The 'Landeskoordination 1994' highlights supported accommodation as the conceptual focus of the future, and yet the expansion of hostel provision is also seen as essential, and an estimated rise of around 15% by the year 2000 is suggested (Landeskordination 1994:30). The general availability of places in the area of housing is reviewed below.

5.4.2 HOUSING SUPPORT AT REGIONAL STATE LEVEL

It is worth noting at the beginning of this section that the direct comparison of place numbers concerning housing support in relation to both regional entities, Scotland and Hesse as well as the case study localities are affected by limited statistical compatibility as well as by differing conceptual approaches in the two countries. For example, while hostel provision is much more common in German policy and practice - and therefore relevant for the statistics – this is not the case in Scotland. Furthermore, while in Scotland supported accommodation in individual

dwellings is widespread, the Scottish statistics offer limited data material. This may be influenced by the greater variety of different providers and varying conceptual approaches difficult to oversee in Scotland. However, Scottish mental health statistics, i.e. the Community Care Bulletin produced by the Scottish Office, focus on what is called residential care, but do not distinguish between residential care places and supported accommodation places. In contrast, the mental health statistics for Hesse clearly distinguish between places in hostels and supported accommodation places.

Most residential care in Scotland takes place in what is called small group homes with an average home size of 7 residents, while residential care in homes or hostels in Germany usually takes place in homes with 25 places or more. This is important to note when looking at the figures (see table 5.2 below).

Research commissioned by Scottish Homes stated that by March 1994 5768 supported accommodation places (754 projects) existed across Scotland providing about 922 places for people with mental health problems (Scottish Homes 1995). In 1996 the amount had increased to 7936 bedspaces of supported accommodation (Edgar et al. 1996:3) across Scotland, while the percentage assigned to mental illness remained largely constant and has risen to about 1341 places (Edgar et al. 1996:4).

Similar numbers (1105 beds) were registered in residential care homes across Scotland, providing a number of 30 places per 150 000 population, however, with varying density (The Scottish Office 1996b:52). With a total of 2500 places Hesse provides a much higher proportion of hostel places (69 places per 150 000 population) which is not surprising given the high importance of hostel provision in German mental health care policies (LWV 1996:8). While official Scottish statistics focus on residential care and do not offer additional figures in relation to other forms of housing (i.e. supported accommodation) the figures provided by Scottish Homes have been used as basis for comparison in the table below. Hesse identified a

number of 2354 places for supported accommodation in 1996 (*Hessischer Landtag* 1996:10).

The planning document for Hesse (*Landeskoordination* 1994) also provides figures for future need based on a calculation of 0.48 places per 1000 population. According to these estimates another 750 supported accommodation places will be required in Hesse by the year 2000 (LWV 1996).

The table below shows the situation in relation to housing/accommodation for people with mental health problems on Scottish and Hesse level.

	Scotland	Hesse
Residential care/hostel	1105 places	2500 places
	30 places per 150 000 population	69 places per 150 000 population
Supported Accommodation	1341 places	2354 places
	36 places per 150 000	65 places per 150 000 population

Table 5-2: Availability of housing support in Scotland and Hesse in 1994/1995/1996

The comparison of place numbers in the area of housing shows different availability in Scotland and in Hesse. This difference affects the provision of residential care and the provision of supported accommodation places both of which are provided in larger numbers in Hesse. It needs to be stressed that the interpretation of the data is affected by different national particulars, especially that residential care in Scotland takes place in much smaller settings (that may also be referred to as supported accommodation in a different context) than in Germany, where residential care takes place in homes with often more than 25 inhabitants. The explanation of this difference may be similar to what has been pointed out before: a strong reliance on institutional forms of care in Germany on the one hand, and a policy emphasis on planning procedures rather than rhetorical objectives focussing on scheduled development and planning targets on the other. As has been shown before, the procedure to turn policy objectives into practice has started more slowly and comparatively late in Scotland, which may be reflected by less availability in the area of housing on Scottish level. It will be seen in the following chapter, however,

that the local situation differs remarkably from the Scottish situation, reflecting a different pattern of availability.

However, housing or accommodation is only one component of comprehensive community mental health care, also important are other supporting measures such as opportunity for daily activity and work. The most common options in the countries of comparison are examined below.

5.5   EMPLOYMENT AND DAY CARE

In Scotland day care in day hospitals or day care centres is much more common than employment support and sheltered employment. Although the Disability Discrimination Act in Britain makes it unlawful for employers to treat a disabled person less favourably than anyone else because of their disability and specialist services run by local authorities and voluntary organisations should be available to people with disabilities, the reality appears different. The availability of employment support is still limited in Scotland and only marginally included in community care policies[36], while the German mental health reforms (Psychiatrie Enquete 1975:408-410) highlighted employment as one of the priority areas and created specific services. The specific national approaches concerning day care and employment are already evident at policy level and affect current availability as will be seen from the data presented below. Before policy differences and practical availability are examined more closely, a look at different care options in this area of service provision is useful.

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[36] Employment related issues are dealt with in different policy guidelines and legislation (Disability Discrimination Act) which may also influence the marginal role of such issues in community care policy and practice

5.5.1 DAY CARE AND EMPLOYMENT AT REGIONAL STATE LEVEL

Day hospitals were established rapidly during the 1960s in England and some time later also in Scotland and in Germany, but even today the number of day hospitals in Germany appears to be rather insignificant compared to Britain. For example, in 1984 England had 350 day hospitals compared to only 40 day hospitals in Germany (Doerner, Plog 1984:446), a relation which has to date not changed greatly. A reason for the comparatively small number of day hospitals in Germany may be related to the strong emphasis on other forms of day care emphasised in German mental health policy (Psychiatrie Enquete 1975), particularly sheltered work. While day hospitals were seen as an important measure to avoid or shorten psychiatric in-patient treatment in Germany (Doerner, Plog ibid) on the one hand, they were never highlighted as a priority. Instead, the Germany policy focussed on the provision of work-related opportunities in two major settings: day care centres (*Tagesstaetten*) or sheltered workplaces (*Werkstaetten fuer Behinderte*) as explained in more detail further below.

In Scotland about 2000 places were available in day hospitals in 1995, used by approximately 4000 people usually on part-time basis (SWSI 1995:10). In contrast, Hesse provides a relatively small number of 275 places in day hospitals across the regional state (HMFJFS 1996:12) but places more emphasis on other forms of day care.

Day care centres in Britain are defined to cater for clients' long term needs for shelter, occupation and support and to provide respite for families (DHSS 1975), while day care centres in Germany are a relatively new support option (Expertenkommission 1988) offered in *Tagesstaetten* with the aim to provide flexible, work oriented support in addition to the more traditional sheltered work places (Psychiatrie Enquete 1975).

There are difficulties in getting reliable figures for the number of actual day care centres run by voluntary organisations and local authorities in

Scotland. This has also been confirmed by a report issued by the Social Work Services Inspectorate for Scotland (SWSI 1995:2).

Day care services across Scotland were inspected by the SWSI and it was concluded that 'the number of services has increased greatly in the last four years' but "it is still not sufficient to meet needs" (SWSI 1995:4). Figures released by the Scottish Office show a similar situation. Although there has been a substantial rise of places in day care centres across Scotland, from none in 1980 to 469 in 1995, the proportion of 1.1 per 10.000 population is comparatively small. However, the number of day care places is not equivalent to the number of persons on the registers, which were considerably higher, mounting up to 1405 in 1995 in Scotland (Scottish Office 1996b:50), indicating that places are used on a part-time basis rather than a full-time one.

In 1994 day care centres in Hesse provided 431 places for people with mental health problems. Because of their specific focus on work-related activities on the basis of small remuneration, which will be examined in more detail further below, the comparison of place numbers between Scotland and Hesse is difficult: However, for the interpretation of the data presented here and in later chapters it is important to be aware of the conceptual differences between a day care centre in the British and the German context.

Looking at employment services or sheltered work in a comparative context shows striking differences, both in relation to the national and regional situation as well as in relation to the case study localities. While Scotland has comparatively little to offer for the mental health population, Hesse provides a diverse network of opportunities, including *Tagesstaetten* and *Werkstaetten* as major facilities providing day care focussing primarily on occupational and vocational measures.

At state level, community care statistics in Scotland provide only poor coverage for work-related activities. The Statistical Bulletin on Community Care in Scotland provides no figures at all on sheltered employment or

any work-related service, only day care services are recorded (The Scottish Office 1995, 1996b).

In contrast, the situation in Hesse appears relatively good. In 1994 Hesse provided a total of 1479 sheltered workplaces for people with mental health problems (LWV 1996:10), and planning estimates require an increase of another 1150 places to make up a total of 2629 sheltered workplaces by the year 2000, based on a calculation of 0.44 places per 1000 population. Places in Hesse are currently unequally distributed and while some regions already fulfil the requirements, others, like Offenbach, need to stock up their provision (LWV 1996:11).

The table below summarises the provision of day care and employment at regional state level.

	Scotland	Hesse
Day hospital	2000 places/=55places per 150 000 population	275 places/=7 places per 150 000 population
Day care centres	469 places /=13 places per 150 000 population	431 places/=12 places per 150 000 population
Sheltered employment	n/a	1479 places/=41 places per 150 000 population

Table 5-3: Day care and employment places in Scotland and Hesse 1994/1995

5.5.2 A POLICY OF WORK-ORIENTED DAY CARE IN GERMANY

In general comparison to Britain including Scotland, Germany pursues a policy of work-oriented day care more actively and a number of alternatives have been developed over the years. The Psychiatry Enquete (1975) had emphasised the significance of work and work-related activities as an important element of community based care and the implementation of appropriate services was recommended. Consequently, sheltered work places for people with mental health problems started to emerge (*Werkstaetten fuer seelisch Behinderte, WfB*) first, while day care centres (*Tagesstaetten*) developed in addition especially during the 1980s. The

national and regional planning documents similarly focus upon these alternatives.

The significance of work is still a central feature of community care development and reflected by the expected increase in *Tagesstaetten* and *Werkstaetten* estimated for Hesse (LWV 1996) by the year 2000 rising to altogether 1495 places based on planning estimates of 0.25 per 1000 population.

Conceptually, the *Tagesstaette* is a day-care centre especially for people with severe and chronic mental illness, with a strong emphasis on a therapeutic concept focussing upon work-related activities in a supportive environment. The type and variety of work provided is largely dependent on successful acquisition, i.e. industrial tasks are subcontracted from local companies and businesses. If feasible and affordable, small machinery is bought, leased or rented to carry out particular work.

The *Tagesstaette* can be seen as some sort of sheltered workplace, but with the intention to provide a more flexible and principally unrestricted environment in terms of working hours and stress of performance. *Tagesstaetten* have developed with the aim to provide a more flexible working environment - especially for people with chronic and most severe conditions - in contrast to the original sheltered workplaces (*Werkstaetten fuer Behinderte*) introduced below, which are often organised according to rather strict funding and attendance regulations.

However, although the concept of the *Tagesstaette* highlights maximum flexibility and low pressure for its users, the registration policy often requires that users sign up for a certain working pattern such as 2 or 4 hours per day to provide a basis for structured planning and acquisition. In addition to the major feature of work, *Tagesstaetten* also offer social support as well as various group and leisure activities, which is similar to the Scottish day care centres.

Sheltered work places started to develop especially during the late 1970s and 1980s in German mental health care according to specific policy

recommendations (Psychiatrie Enquete 1975). Dependent on the size of the service, sheltered work-places for people with mental health problems *(Werkstaetten fuer seelisch Behinderte)* offer different types of work in different units, from rather monotonous, plain (industrial) tasks to more complex duties like, for example, offset printing with professional equipment and machinery. The workload as well as the variety of work is very much dependent on local circumstances. Similar to the *Tagesstaetten*, sheltered work places perform on a local level and are dependent on acquisition and subcontracting from local companies and businesses.

The *Werkstaetten* often use a model of rehabilitation stages to support clients to adapt to more demanding tasks if they wish. While initially the concept of rehabilitation into open employment was promoted as a central objective and funding regulations initially concentrated on rehabilitation schemes ranging from one to three years, these principles were increasingly considered as being unrealistic. The issue of transition to employment after a period of stabilisation and training is one aim of the rehabilitation process, and only in 1996 has it been stated that rehabilitation into open labour market employment is first (policy) priority (Hessischer Landtag 1996:10). But while services aim to assist people back into employment on the one hand, the barriers often preventing such a transition must be recognised. In an environment of high unemployment the insecurity of the competitive labour market does pose great stress on a great number of workers and people with severe and chronic mental health problems are particularly vulnerable; in reality, only a small number of those working in sheltered workplaces can successfully make the transition into open labour market employment. Although the Hesse Government still highlights these priorities, there is no statistical evidence available on the number of people who have successfully transferred or been rehabilitated into the open labour market. The meagre results would perhaps undermine Governmental priorities. However, the aim to create and maintain 'safe corners' within the competitive labour market should

not be hampered by the acceptance of a gloomy economic reality, which may even justify the exclusion of marginally functional employers.

A relatively new service in the German mental health field is the *Berufsbegleitender Dienst (BBD)*, which is a job assistance service providing employment support to those who have a job in the competitive labour market. Thus, the service supports clients in their working environment in order to sustain those experiencing difficulties in their jobs, to prevent breakdowns and the threat of unemployment. In the job assistance scheme the client may receive supervision and counselling according to personal circumstances, for example, weekly, monthly or on request, however, to keep the job and maintain a stable relationship with employers and colleagues. The BBD offers a consistent contact person to the client, and if required to the employer. In times of need the service can provide close attention, increasing clients' chances of productivity and success. Immediate counselling can reduce stress and symptoms and decrease the probability that the client will leave or be fired. Employers generally welcome the opportunity to co-operate with the service and are more likely to tolerate temporary instability of employees (fieldnotes 1996). In addition, the service offers courses on work and psychiatric problems or diagnoses for employers.

The development to set up job assistance teams started in the late 1980s in Germany, and by 1993 a total of 150 services had been established across the country (Beule et al. 1993:12).

It should be recognised however, that while open labour market employment may be useful for some, it may not be feasible for others, mainly those who need more protection and the secure environment of a sheltered workplace. Both alternatives, open labour market opportunities and sheltered workplaces, but also continuing employment support are complementary elements in a comprehensive community-based network of mental health care services in the area of employment support.

5.5.3 DAILY OCCUPATION IN COMPARISON

The central role of day care was set out in the British White Paper *Better Services for the Mentally Ill* (DHSS 1975) and in addition to day care centres the comparatively high proportion of day hospitals characterises the present situation in Britain. While day hospitals are usually attached to the health care sector and run by Health Care Trusts, day-care centres are generally provided by voluntary organisations, usually funded by local Social Services/Social Work Departments.

A number of problems are related to this pattern of day care in Britain, especially since different authorities are responsible for the provision of day-care services. In 1989 the White Paper *Caring for People* (DoH 1989) stated that health authorities were responsible for 'health' aspects while the social services were responsible for more social aspects, which is often the bulk of community care. In relation to day care this separation is problematic because day-care services are difficult to place as they usually do not fall neatly on either side of the artificial health/social care divide. In effect, day-care centres and day hospitals often cater for the same client group, people with long-term mental health problems, who have similar needs with regard to health and social care. Furthermore, confusion seems to remain as to what day care actually is, what its legitimate functions are and how these functions are best carried out. The policy documents do not distinguish by definition between day-hospitals and other day-care services except for the diffuse health/social care divide. Other related services, for example training projects or sheltered employment are, while mentioned under the heading of day care and employment, neither particularly highlighted in policy nor actually being put into practice.

The situation in Scotland is similar to the rest of Britain and features a relatively small number of employment services mainly provided by the voluntary sector or private providers. The examination of policy documents indicates the marginal role attached to employment or related support

services in relation to community care policy and therefore Scottish community care statistics provide only poor coverage for work-related support.

In Germany the recommendation to provide sheltered workplaces for people with severe and chronic mental health problems was firmly embedded in the major national policy documents (Psychiatrie Enquete 1975, Expertenkommission 1988). While figures for a progressive development were not included in the Enquete's recommendations, the follow-up Commission (Expertenkommission 1988) focussed on progressive planning for catchment areas of 150.000 population.

According to policy guidelines, training and employment are usually provided in special working places (commonly referred to as *Werkstaetten fuer Behinderte-WfB* or *Tagesstaetten*) on full-time or part-time basis; while other labour market oriented activities include a service to support clients in open employment or approach the labour market through various strategies.

It is surprising that in Britain sheltered employment or other labour market oriented activities are less common. Although the history of psychiatric rehabilitation strongly emphasises the value of work for people with a severe mental illness, in Britain "the integration of work into systems that treat severe mental illness is limited, sporadic and inadequately addressed" (Harding et al. 1987:317ff). While studies and reviews of community care development in Britain also point out issues around the protective nature of work (Carson et al. 1991) or highlight users preferences for structured daily activities (Rogers et al. 1993:91ff), policy documents often remain rather superficial, lacking more concrete recommendations.

Although a range of employment activities have been created in Europe during the 1980s and the 1990s, not least because European Union anti-poverty programmes and the Social Fund have enabled the channelling of resources into mental health services for this purpose only, the differences

between Britain and Germany are remarkable. While various forms of day care are generally common in both countries, it is especially employment support that is more widespread in Germany. Various reasons may explain these differences. For example, the basis for the general notion that work has a central role to play in state policy may be influenced by historical determinants dating back to the Bismarckian model on which the German insurance based system is firmly grounded, that embodies assumptions about the centrality of work. Furthermore, specific structural elements embodied in the German legislation also emphasise the centrality of work. The German legislation offers a measure of positive discrimination to people with a disability entering employment both for a quota reserved for them in larger work-places and through a system of support workers (*Berufsbegleitender Dienst*) whose task it is to acquire employment (i.e. jobs) and support clients in employment. Such measures, however, may work to the benefit of a small number of people with disabilities, but is not to say that the legislation is generally sufficient to keep people with disabilities in employment. Rather, companies are often more inclined to pay money to the state in order to avoid their legal obligations. The state in turn is than forced to provide alternatives, otherwise the legal system would not run smoothly. On the one hand Germany provides legislation that appears to offer the protection of the employment status of people with disabilities as a fundamental principle, but the state needs to provide alternatives since open-labour market employment is often not available for people with disabilities, in spite of legally based commitments. On the grounds of historical determinations it is perhaps not surprising that the German mental health reforms (Psychiatrie Enquete 1975) highlighted both housing *and* employment as the two core components where community based support is needed, while British documents generally highlight housing as a core element, and either neglect employment support as a significant area of service provision or rather tend to treat it as being included in day care activities (fieldnotes 1996).

However, it is certainly to the benefit of people with mental health problems if community care policy provides the basis for a variety of

options concerning day care *and* employment. Ideally, options may range from open labour market opportunities to sheltered workplaces, self-help companies and different initiatives that are helpful to provide support concerning meaningful daily occupation, preferably with adequate financial incentives. Potential and limitations of employment support and especially the financial remuneration are considered in more detail and in specific relation to quality of life in later chapters.

5.6 SUMMARY AND CONCLUSIONS

This chapter has examined community mental health care policy and practice in Britain and Germany with special reference to significant components of community mental health care identified as including health, housing or accommodation and employment or day care. While more general aspects concerning the national and regional mental health care policy development were considered first, significant components - or major areas of service provision – were examined and compared in addition. The examination included both policy objectives and practical availability on Scottish and regional state level (Hesse).

A number of similarities and differences have been highlighted in this chapter that affect community based mental health care, especially concerning the general provision of services, but also concerning the availability of places. Differences arise from distinct national policy objectives, but also from different strategies in turning policy objectives into practice. In general comparison, policy differences appear in all major areas of service provision and affect service provision more or less fundamentally. While a similar policy approach between Britain including Scotland and Germany may be seen in the general tendency to shift mental health care provision from care in large mental hospitals into

community based settings, major differences are evident in the number of mental hospital beds currently available in the countries under comparison. While generally mental hospitals or specific wards appear to be still rather central in the Scottish as well as in the German mental health care context (thus contrasting principally to England), the comparison of bed numbers shows remarkable differences. It has been shown in this chapter that Germany has gradually started to shift acute psychiatric care from large mental hospitals into small units attached to general hospitals during the Eighties according to regional planning schedules based on national directives. In contrast, structured bed-reduction on a larger scale has not taken place in Scotland until relatively recently. Compared to Hesse, Scotland still provided three times as many acute psychiatric beds in mental hospitals in 1995/1996. Reasons for the relatively slow Scottish development have been identified as being influenced by limited official guidance from the Scottish Office and a lack of plans and strategies for structured bed reduction or hospital closure over the years. More recent criticism in response to Scotland's reluctant approach towards the closure of mental hospitals thus revealed considerable shortages concerning structured planning procedures (House of Commons 1995, SAMH 1995). While Scotland was thus hesitant to follow the national guidelines of a more radical hospital closure policy, the German regional states such as Hesse largely followed the national directives and implemented schemes for structured bed reduction in response to the Enquete Commissions (1975) recommendations . The chapter has also shown that the German approach to care in the community is nevertheless backed up by a principally strong reliance on care in mental hospitals both in policy and in practice. This is evident in all policy documents on national and regional level which propound a general need for 80-120 mental hospital beds for a population of 150 000. While in contrast to German guidelines Scottish policy documents provide no particular measures concerning actual bed -need in mental hospitals or structured reduction, evidence suggests a principle reliance on hospital care/beds in both countries.

The comparison of housing policies has highlighted that support options in Scotland and Hesse appear rather similar to some extent, but with an apparent focus on more institutional forms of housing support in Germany. The data from Hesse indicate that although supported accommodation has become more important in recent years, other more institutional forms of housing such as care in homes or hostels also feature centrally in German mental health care policy and practice. Housing options in Germany are characterised by larger homes or hostels which are perhaps less individual than current housing options in Britain including Scotland where individual living arrangements in supported accommodation or smaller residential settings are prevailing.

It has been shown in this chapter that the German policy recommendations feature employment and work-oriented services as central elements to community mental health care. This is perceived to be of equal importance as are housing options. The focus on employment in policy documents is also reflected by the comparatively high number of places compared to Scotland. The situation in Hesse is characterised by a variety of options concerning daily occupation of which the most common alternatives are sheltered work places and *Tagesstaetten.* In comparison, it has been seen that in Scotland day hospitals and day care centres are more common than employment or other work-related alternatives.

The following chapter examines the specific situation in the case study localities and compares the local welfare mix, before subsequent chapters particularly address the perspective of service users concerning the effects of community based mental health care policy and practice on their quality of   life.

CHAPTER 6

THE WELFARE MIX IN THE CASE STUDY

LOCALITIES

6.1 INTRODUCTION

In many Western countries "moving from institutional to community settings has triggered a whole new mental health enterprise" (Rogers and Pilgrim 1996:183) with a variety of distinct approaches in relation to community based support and service provision. This chapter draws on developments in community mental health care in Scotland and Germany, using the case study format as a framework for comparative evaluation. While the previous chapter has analysed and compared the principal mental health care policy framework including general availability in the countries of comparison, the focus of this chapter is to provide an overview of community based mental health care in the case study localities, Edinburgh and Offenbach; especially concerning support service provision and care arrangements in two different national settings. Similar to a study into elderly care (Schunk 1996:88-89) a 'mapping' of major services is considered useful to provide a coherent picture of community based mental health care.

In this chapter an attempt is made to show how community mental health services feature in practice. Therefore the 'welfare mix pattern' (Schunk 1996:89) in terms of a comprehensive overview of community based mental health services is presented by charting the available range of services in each locality. This service mapping concentrates primarily on major support areas previously defined as including health, housing or accommodation as well as day care and employment, but also includes

other services and smaller individual projects in areas less common yet important such as respite care. The services are described and availability is examined. The examination focuses on the comparative analysis of local particulars such as plans, policies and place numbers including a critical investigation of limitations and potential of individual national or local variations. The examination includes an assessment of the current local situation in the case study localities on the one hand, as well as an examination of relevant policy objectives in relation to current issues and future development on the other. The tables presented provide both: total bed or place numbers concerning the case study localities (based on a similar population totals of approx. 450 000) and figures per 150 000 population.

This chapter primarily addresses the third specific aim of the study: to evaluate compare the range of community support options in both countries (on case study level) and explain major differences in service provision. The chapter first introduces the two case study localities, Edinburgh in Scotland and Offenbach in Germany. The major part of the chapter then concentrates upon the evaluation of community based mental health care in the two case study localities. The chapter is organised according to major components of community care identified earlier as including health, housing/accommodation and day care/employment, but also covers other relevant support services in the case study localities such as community mental health care centres or user groups.

The evaluation of community mental health care and especially support service provision starts with an examination of the health component. The current role of the mental hospital will be examined and it will be shown that generally the provision of mental hospital beds is a central feature of community mental health care in both case study localities. Development in this area, i.e. scheduled bed reduction, has essentially informed increasing activity in other areas especially housing. The hospital dimension is followed by an examination of housing and accommodation support before day care and employment options are considered. Both

housing and day care or employment are areas in which significant activity has taken place in the past, however, with different national priorities. A number of differences have already been highlighted in the policy context in the previous chapter, some of which appear again on local level. Finally, other relevant community support services are examined and compared.

6.2 THE CASE STUDY LOCALITIES

Edinburgh in Scotland and Offenbach in the German regional state of Hesse are both part of specific administrative entities in their respective national country. Edinburgh is the capital of Scotland with the Scottish Office providing national guidelines in relation to mental health care[37], while Offenbach is in the regional state of Hesse, has its own parliament and develops its own mental health policy according to national directives. While the development of the respective national and regional mental health policy and legislation has been outlined earlier, local particulars will be examined here.

6.2.1 EDINBURGH

Edinburgh is the capital of Scotland and in 1995 had a population of 442 000. Administratively, the City had been part of Lothian Regional Council until April 1996, when Governmental reorganisation was due to affect local governments nationwide. The newly created City of Edinburgh Council has now the responsibility for making sure that the full range of community care services is provided to meet the needs of its population. This chapter partly draws on material which was initially produced for the 'old administration', for example, the Lothian Community Care Plan 1995-1998

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[37] The political and administrative situation may be different in the future since Scottish Parlament has been opened in 1999

(Lothian Regional Council 1995) and the Lothian Mental Health Strategy (Lothian Health 1996).

Research by Rogerson et al. (1989:12) into quality of life in Britain's intermediate cities, ranked Edinburgh as the best city in the country in terms of health provision and sports and leisure facilities as well as being highly ranked for education provision and short travel to work times. Similarly, community based mental health provision has been considered as being relatively advanced in Edinburgh in comparison to other Scottish regions (Simic et al. 1992)

The City of Edinburgh is administratively divided in four sectors: Northwest (NW), Northeast (NE), Southeast (SE) and Southwest (SW). Mental health care planning and service provision is organised and administered accordingly. For example, the Community Care Plan 1995-1998 for the former Lothian Region has included individual community care statements of the four Edinburgh planning regions. While certain themes are common throughout the City, individual statements cover priorities in the light of the needs of the local population.

A number of mental health services are provided by the local authority (City of Edinburgh Council), while the majority is provided by many different voluntary organisations.[38]

Edinburgh provides an innovative mental health information resource, the data base 'In Touch'. The data-base is supposed to list major mental health resources that are available across the City, providing information on individual services, place numbers and details for contact. It does not, however, distinguish between services for people with more severe and chronic mental health problems and services for people with milder problems. Therefore it may be difficult to select the most appropriate service, for example, in relation to day care, where a great number of addresses are listed, of which some only offer a two-hours counselling service every fortnight.

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[38] Common terminology is also non-profit organisations (NGOs)

The data-base was developed by a team of experts attached to the Royal Edinburgh Hospital and should ideally be accessible by professionals, users and carers. Professionals, organisations and agencies can obtain the data base for their professional use, while users and carers should themselves be able to access it in libraries, community resource centres etc. In practice, there are obviously problems to make full use of the resource. Information technology not only requires equipment, which is usually available in most organisations, but also the competence to use it. The survey in Edinburgh indicated that many professionals were indeed aware of the existence of the data-base, but only 2 organisations (out of ten) confirmed to have it available, while most of the users I spoke to did not even know about it. Clearly, the potential to use a particular tool is a precondition for effective utilisation, but often information is not directly accessible. This is certainly a key issue in community care and relevant for future development not least because the problems arising may be wide ranging (lack of information = lack of access to service provision) and should therefore be addressed by policy-makers and service providers.

6.2.2 OFFENBACH

The City and District of Offenbach (Kreis Offenbach) is in the South of the regional state (*Land*) of Hesse, one of the sixteen regional states (*Laender*) comprising the unified German Republic. Hesse has its own parliament and legislative powers, for example, with regard to mental health care provision. Hesse is to date the only regional state without a specific Psychiatric Law (*Psychiatrie Gesetz*), while all other regional states have implemented the law during the last few years.

Offenbach is a city in the shadow of its bigger neighbour Frankfurt being at maximum 10 km away. The whole region is highly industrialised and densely populated. Offenbach's closeness to Frankfurt compensates for

the lack of metropolitan urbanity in comparison to the City of Edinburgh. In 1995 the City and District of Offenbach taken together had a population of 450 000.

It has already been pointed out elsewhere that the Federal Government does not provide health services, but provides the legal and economic framework within which local and regional authorities contract with voluntary and private organisations to provide the whole range of mental health services.

With regard to mental health service provision the City and District of Offenbach has been divided into four regions: The City of Offenbach, the Western District, the Middle District and the Eastern District. While community based mental health care has initially started in the City, the more recent development during the last 5 years has particularly concentrated on setting up services in the different parts of the District.

Three major independent sector service providers[39], all attached to either one of the six state welfare organisations, mainly participate in the provision of community based mental health care in the City and District of Offenbach: *Diakonisches Werk/DW, Lebensräume e.V.* and *Arbeiterwohlfahrt/AWO* (see also Chapter 3). These three provide most of the community based mental health services in the case study localities, with the exception of two major areas: first, (mental) hospitals provided by the regional state and second, the Socialpsychiatric Service (*Sozialpsychiatrischer Dienst*), a statutory service attached to the local Health Departments. Except for the regionally-changing configuration of welfare organisations involved in the provision of mental health care, the basic structure is similar all over the country.

It is important to note that Offenbach City and Offenbach District are administered by two different (local) authorities. The City itself has its own administration (*Stadtverwaltung*) and so has the District (*Kreisverwaltung*), while the municipalities constituting the District also have their own

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[39] They are also referred to as non-governmental organisations-NGOs or voluntary organisations

administration. For example, City and District have own departments for health (*Gesundheitsamt*) or social welfare (*Sozialamt*). The complexity of relationships and responsibilities between the various local, state and federal levels is difficult to oversee and often produces tensions rather than co-operation[40].

In contrast to Edinburgh, Offenbach does not provide an information resource like the data-base 'In Touch'. A register of services and addresses is contained in the documentation on psychiatric care in Offenbach City and District (Kreis Offenbach 1994), but the list does not provide any more detailed information on particular services and is rather an address guide for professionals than an information source for users. While the three major service providers in Offenbach provide leaflets on their individual range of services, a comprehensive information resource for the City and/or the District is not available.

The following sections present the welfare mix in the case study localities starting with the examination of psychiatric hospital provision.

6.3 HEALTH: PSYCHIATRIC HOSPITAL PROVISION AND CRISIS INTERVENTION

Psychiatric hospitals or wards and crisis services can be seen as services providing immediate care and treatment for people with a mental health problem displaying acute symptoms. It is often difficult to distinguish between the two, as usually psychiatric hospitals refer to themselves as a form of crisis service which will be seen further below in relation to the case study localities.

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[40] for more information see Lorenz W. 1994.

6.3.1 EDINBURGH

The Royal Edinburgh Hospital (REH) is the psychiatric hospital responsible for the Edinburgh population providing a total number of 629 psychiatric beds in 1996. It is a major urban hospital centrally located on the fringes of the city centre. The location is perfectly convenient from a community care point of view[41] and patients have easy access to shops and other amenities nearby or can travel by bus into the city centre within short time. The hospital site is in an area called Morningside, an area with a most attractive atmosphere with little shops, galleries, pubs and restaurants.

The REH is currently responsible for a population of 460.000 covering the entire City of Edinburgh (fieldnotes 1996). It is made up of three major units: the acute psychiatric unit, a unit for long-stay psycho-geriatric cases and forensic psychiatry, all based on one site.

The hospital provides 145 acute psychiatric beds, 250-300 care of the elderly beds, 103 continuing care beds and 81 rehabilitation beds (fieldnotes 01/96). There are 6 acute wards with average 25 beds, 6 continued care wards and 1 rehabilitation ward with 17 beds. The care of the elderly beds include those patients who are the old long-stay patients whose resettlement into the community is deemed difficult or impossible; the sites recognised as being long-stay wards have average ages ranging from 61-73 years while a more active rehabilitation ward, for example, has an average age range of 42 years.

The REH hospital promotes having a long-established tradition of rehabilitative work with long stay patients (fieldnotes 1996) and the Lothian District has indeed a 23 per cent lower hospital resident population than Scotland as a whole (Lothian Health Board 1988, Simic et al. 1992:66). This may be related to a relatively advanced network of support services available in Edinburgh compared to the rest of Scotland. The REH

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[41] see Chapter 3 for details on observation of the setting

operates medium-stay and long-stay rehabilitation wards for patients who may need lengthier periods of treatment readjustment or rehabilitation.

Attached to the main hospital is a system of hostels (5 units/54 beds) near the main hospital site. Two of the hostel units (13 beds) are intended as more independent hostels with movement out of hospital a clear aspiration; they are referred to as transitional units. The other hostel beds are longer-term or permanent beds. The longer-stay wards and hostels all have a mixed population of patients; that means patients may be undergoing rehabilitation geared towards resettlement, geared towards preventing deterioration, or receiving maintenance care.

In 1992 the REH had some 2.500 admissions and discharges per annum (Simic et al. 1992:65), nearly half of which come from the acute wards. The overall trend in Scotland, as in England, is for shorter admissions and increasing numbers of re-admissions (Simic et al. 1992:66). The (all) admission rates per 100 000 increased by 34 per cent from 1970-1989 across Scotland while resident rates decreased by 24 per cent over the same period (Simic et al. 1992:66).

Inside the hospital, basic daily activities are similar to any other long-stay institution. In addition to the daily round of medical rituals, patients have access to various educational and occupational activities. The normal standard and everyday routine on the wards left some rather bleak impressions, however. The acute ward I was visiting had very little appeal to visitors and - most likely - patients alike. The atmosphere and the ward environment was far from being 'homely: there were no plants and scarcely any pictures either in the corridors or in the bed-rooms, and the only sort of 'common room' that was available for patients was the one for smokers. The dining room was locked up and I was informed that it was only opened at meal times. The reason for this and the generally limited amenities, it was pointed out, was to 'protect patients from hurting themselves', for example, 'with hot water from the kettle' (fieldnotes 1996). There was no opportunity for the patients to communicate with friends or visitors in a more pleasant environment than the corridor, bedroom or smokers room, or prepare coffee or tea. While the bedrooms were only

sparcely furnished, there was no other alternative place to sit and have a chat. The entire setting, however, completely lacked a warm atmosphere.

These observations contrast quite sharply with the surroundings on the German wards I visited during the course of my research. Although the hospital character was also evident on German wards, the environment generally appeared more homely, and patients were always able to prepare coffee, tea or snacks. Hospital provision in the German case study locality, however, has other negative features as will be seen below.

6.3.2 OFFENBACH

The provision of in-patient mental hospital care in the City and District of Offenbach appears more complicated than in Edinburgh. This is partly because two different hospitals are responsible for the local mental health population, one in the City and for the Cities' population (116 5000) and one for the District population (329 000), the latter geographically far away from the District. While the Cities' population is provided for by the Psychiatric Clinic in Offenbach (which is part of the General Hospital) with a total of 98 beds including 18 day hospital beds/places, patients from the District have to travel more than 60 km to the 'next' mental hospital (*Philippshospital*) in Riedstadt. The mental hospital in Riedstadt[42] is responsible for the District's population of almost 329.000 providing a number of 157 beds, while the Psychiatric Clinic in the City of Offenbach is responsible for a population of 116 533 providing 80 beds.

The Psychiatric Clinic in Offenbach was established in 1981 following the recommendation of the Enquete Commission (Deutscher Bundestag

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[42] The mental hospital in Riedstadt had once been one of the biggest institutions in the regional state Hesse with more than 1000 beds in the Seventies. The hospital is currently not only responsible for the Offenbach District, but also for another catchment area (Kreis Gross-Gerau) and a total population of 605.000. In 1995 the hospital provided a total number of 309 psychiatric beds.

1975) to establish small psychiatric units in general hospitals. The clinical provision of 80 beds relates to a bed estimation rate (*Bettenmessziffer*) of 0,66‰, but when the 18 day-hospital beds are added the rate amounts to 0,81‰. That means a number of 0,6-0,8 beds per 1000 population, a proportion in line with official guidelines and Governmental requirements regarding psychiatric hospital provision as provided by the year 2000 (Hessischer Landtag 1996:5).

The average distribution of the available number of beds in the City of Offenbach is: 70% for general psychiatry, 20% for patients with drug related conditions and 10 % geriatric beds.

The annual admission rate for the psychiatric clinic and day clinic ranges around 1100 to 1200 patients.

The psychiatric clinic is located on the premises of the General Hospital (*Staedtische Kliniken Offenbach*) and centrally located with good access to transport, shopping and other community facilities. The clinic is divided into 7 wards, 5 of which provide 11 or 12 beds, and one ward with 15 beds. One of the 7 wards provides an intensive psychiatric care unit with 5 beds, two of which are always accessible for emergency or compulsory treatment; yet with an annual bed utilisation average of more than 95% the odd 'corridor-bed' is inevitable at times. The rooms are supplied with three beds, which does not always account for privacy, apart from the one and two-bedded rooms of the intensive psychiatric care unit. Every ward has a common room and a separate dining-room for patients, a small kitchen, a staff-room and a room for meetings, counselling and similar purposes. In contrast to the Royal Edinburgh Hospital, the common room, dining room and also a small kitchenette in Offenbach are always accessible for patients (and their guests). Generally, compared to the Royal Edinburgh Hospital, the wards in Offenbach appear more friendly and homely, mainly perhaps because plants and pictures provide a sociable and pleasant atmosphere.

The *Philippshospital* in Riedstadt is the mental hospital responsible for the District of Offenbach. It is one of the old-style asylums, and after

considerable bed reduction during the last couple of decades the hospital currently provides 343 beds of which 157 are allocated to patients from the Offenbach District. Ironically, the mental hospital in Riedstadt exhibits all the traditional geographic and architectural features deemed to contradict community based care. The mental hospital is remotely located in a beautiful yet isolated area and patients in need of hospital care (as well as their friends and relatives) have to travel great distances to get there. For all that can be said about the objective requirements related to care in the community such as centrally located support close to peoples living environment it is contradictory to provide hospital provision far away from peoples homes. While plans to change the situation according to community care policy objectives have been around for a long time, in fact almost for the last 20 years, the situation has remained largely unchanged ever since. While the Psychiatric Clinic for the City of Offenbach was established in 1981, the need to set up new wards for the District's population in the two District General Hospitals has been repeatedly confirmed (Bauer et al. 1987, Bauer, Berger 1988, LWV 1994), but to date without any result.

The Ministry for Social Affairs in Hesse (HMJFG 1996:13), for example, has recommended to set up new psychiatric wards attached to General Hospitals especially in those regions where in-patient hospital care is currently only available far away from peoples homes. While the planning paper 'Psychiatrische Krankenversorgung in Hessen' includes actual bed numbers as well as future estimates for most catchment areas[43] within Hesse up until the year 2001, there is little information concerning Offenbach and no details for the District (ibid:7).

The table below shows the total number of hospital beds in the case study localities in 1996.

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[43] Psychiatric hospital provision is provided for defined catchment areas (Sektoren) and according to policy recommendations a catchment area covers an average population of 150 000. Mental hospitals or psychiatric wards are thus responsible for the provision of psychiatric beds for the population of their specific catchment area (Sektor).

Edinburgh	629 beds	210 beds per 150.000 population
Offenbach	80 beds (City) 157 beds (District) =237 beds	80 beds per 150.000 population

Table 6-1: Mental hospital beds in the case study localities in 1996

It has been shown in the previous chapter that Scotland still provided far more hospital beds than Hesse in 1995/1996. This situation is similarly reflected by the case study data. Reasons for this apparent difference have been identified before as including, for example, a lack of guidance from relevant authorities in Scotland. This can also be said in relation to local authorities since relevant policy documents in Edinburgh lack clear benchmarks for progressive bed reduction. Although community care plans should provide a basis for further development concerning their particular region, structured planning remains superficial in the documents available for the Edinburgh case study locality. The relevant documents (Community Care Plan, Mental Health Strategy) are both not detailed enough to provide reliable estimates for monitoring and evaluation or further development. Only more recently in response to the criticism raised by the Scottish Affairs Committee (1995) has the issue been addressed again in a Stakeholders Discussion Document for a Joint Mental Health Plan for the City of Edinburgh (Lothian Health and Edinburgh City Council 1998) in an attempt to provide more definite measures for the future. In contrast, it can be seen that the actual situation concerning metal hospital beds in Offenbach conforms to the most recent policy requirements in Hesse to provide a number of 80-120 beds per 150 000 population (Hessischer Landtag 1996:5).

In general comparison, however, the principal approach to provide acute mental health care in psychiatric hospitals or wards reflects that hospital beds are important elements of the community-based service network in both countries, a principal tendency that does not seem to differ widely between Scotland and Germany. Although it has been shown that the total number of available beds in mental hospitals differs considerably between the two countries both on regional state and on local level, the basic understanding that acute psychiatric care requires in-patient hospital treatment seems to be prevailing in policy and practice. Respective

planning requirements are thus based on the notion that psychiatric hospital care is an essential element of care in the community. The major difference concerning the actual number of beds in mental hospitals suggests that the policy requirements have been met in the Offenbach case study locality, while in Edinburgh successive bed reduction is still continuing.

The comparison of principal policy objectives on the one hand and the comparison of practical availability in the area of acute psychiatric care has shown that it is predominantly hospital beds that are at the centre of planning and funding in the countries under comparison. Thus it seems obvious that a more critical attitude towards hospital provision or even the issue of entire hospital closure is not on the policy agenda in both countries. This can also be concluded from general policy objectives concerning the current and future provision of in-patient psychiatric care as examined before (Chapter 5). Alternatives to hospital provision such as crisis-intervention services are more common in the US (Stein and Test 1980, 1985), but are currently not available in the case study localities although the issue is receiving recognition in Edinburgh. Paradoxically, however, the current form of hospital care is generally promoted as crisis intervention in the case study localities. This requires a closer examination of the situation in the case study localities as presented below.

6.3.3 CRISIS INTERVENTION IN THE CASE STUDY LOCALITIES

Edinburgh has no particular crisis intervention service in the sense of a 24 hour/7days a week coverage in a non-hospital setting, but offers two services which aim to deal with psychiatric crisis. The 'Psychiatric Emergency Team', for example, is a service at the Royal Edinburgh Hospital established in 1991. It is essentially a complementary service available from 5pm to midnight during the week, and from 9am to midnight

at the weekend. The aim of the service is to ensure that people turning up at the hospital receive an assessment as quickly as possible and have the opportunity to build up a relationship with specific nurses and doctors. Over the year 1995 some 2500 individuals approached the service, indicating that there is substantial need for psychiatric emergency services. However, what is offered is basically extended opening hours of the psychiatric hospital rather than an altogether different service.

Research into Mental health crisis services for Lothian (Caps 1995) refers to another service, also set up by the Royal Edinburgh Hospital. The Home Care Team, a team of workers responsible for one area of the city (SE District) was set up in 1995 with the particular aim to see whether domiciliary support could be effective in reducing bed usage. The service is available from 9am to 9pm and aims to provide service users with the degree of support they need. In 1996, the team included 7 home care workers, each with a caseload of ten individuals, who are usually long-term users of mental health services. Although it is admitted that this service is not a crisis service as such, it is suggested that it may help to avoid the development of situations which lead to individuals experiencing crisis (Caps 1995:13). However, it is important to recognise that the availability of good domiciliary support is *one* central element in a comprehensive community care network, while the availability of crisis support is yet *another* important element; both may overlap or ideally link into each other.

The situation in Offenbach is similar to Edinburgh. Across the City and the District a special crisis service is not available, but the emergency unit of the General Hospital is presented as a crisis intervention service (Bauer 1995). While officially there is little debate on the issue of alternatives to hospital provision, mental health guidelines and official documents tend to suggest that the (regional) clinical provision can provide adequate crisis intervention (Kreis Offenbach 1994:30). The Psychiatric Clinic in Offenbach even exercises a policy as if crisis intervention was part of their clinical support profile. For example, the Psychiatric Clinic in Offenbach suggests in their information brochure that a 24- hours crisis intervention

service is covered by the Emergency Admission Unit of the general hospital (Bauer 1995). This is indeed possible for anyone with any kind of medical problem requiring clinical treatment, but this can be hardly seen as a crisis service especially relevant, appropriate and useful to provide adequate support in an acute psychiatric crisis.

The central role of the hospital is evident and strengthened by powerful professional stakeholders. In a 1988 publication the clinical administration in Offenbach pointed out that "statistical evaluation and practical experiences indicate, that an independent 24-hour crisis service is not required in Offenbach" (Bauer, Berger 1988:120), although they admit that a social worker 'on call' could be helpful at times (ibid.). It is thus obvious that professional stakeholders in both case study localities have a profound interest in showing that crisis intervention is provided by mental hospitals thus strengthening the role of hospital provision in community mental health care.

In conclusion it is evident that, in both case study localities crisis intervention is only provided by out of hour casualty departments or mental hospitals and psychiatric wards without any other relevant alternative. A number of reasons may count for this: in contrast to the United States, where more unconventional ideas concerning personal freedom and individuality are perhaps accepted more readily, European standards may have remained more influenced by conservative values and the preservation of traditional structures. In some ways, especially concerning mental hospital provision, this may be applied to the German and the Scottish context, but it must be explained why the English mental health care policy has so radically emphasised hospital closure. It is perhaps legitimate to speculate that financial considerations may have played a significant role, especially since bed reduction was for a long time only marginally accompanied by setting up an adequate amount of community based services, which has led to increasing criticism (House of Commons Health Committee 1994) and a number of tragic events in England (Ritchie et al. 1994).

The current situation has been critically examined in Edinburgh and the need for a specific service has been identified (Caps 1995). The issue has not yet received any major attention in the German mental health care debate. Therefore it is not surprising that in the German case study locality no evidence was found that crisis services as alternatives to hospital provision are part of the policy discussion.

Alternatives to hospital care depend on the availability of services for acute intervention on the one hand and a comprehensive community based support network on the other. The services available in both case study localities in addition to the current form of acute care, i.e. hospital provision, will be examined in the following sections starting with a look at the housing dimension.

6.4 HOUSING AND ACCOMMODATION

The statistics available for the case study localities provide material on supported accommodation in general, while material on particular forms of residential care such as hostel provision are only available for the Offenbach region. According to the Mental Health Strategy (Lothian Health1996:29) Edinburgh provided total of 175 supported accommodation places for people with mental health problems in 1995 plus an additional number of 70 places offering more limited support.

In the Mental Health Strategy housing seems to be generally summarised as 'supported accommodation' and a distinction regarding particular forms of housing or different forms of support, for example, more intensive support according to different levels of need, is difficult to draw out of the strategic paper. However, according to the results of this survey, hostels or group homes for more than 8 people were not found in Edinburgh.

The following table illustrates the housing provision in the case study localities in 1995.

	Edinburgh	Offenbach
Residential Care/Hostel	none	47[44]places/=16 places per 150 000 population
Supported Accommodation	175 places/=58 places per 150 000 population	79 places/=26 places per 150 000 population

Table 6-2: Availability of housing support in the case study localities in 1995

The national comparison of 'supported accommodation' is as difficult as the comparison of residential care, since there is no accurate way to compare different conceptual approaches and practices. Supported accommodation may cover a variety of support options from 24-hour staffing to more limited forms of staff support. The relevant documents in both countries offer only little detail regarding specific types of supported accommodation. While the Mental Health Strategy (Lothian Health 1995) at least distinguishes between high level of support, and medium and low levels of support yet without further specification, the Landeskoordination 1994 (LWV 1996) does not make any distinction other than 'hostels' and 'supported accommodation'. The Lothian Mental Health Strategy talks about 175 supported accommodation places and 70 additional places with more 'limited support' for Edinburgh (Lothian Health 1995:29), but it remains unclear what limited support may include. For example, it may only include being visited by a health visitor once a month without any opportunity of increasing the support in times of need.

The comparison of future developments in the area of housing is difficult as figures on case study level are not available in similar detail. The Lothian Mental Health Strategy broadly promotes an overall increase of supported accommodation (Lothian Health 1995:13), while figures for Edinburgh are not specified. In contrast, the planning documents from Offenbach indicate a growth of supported accommodation in Offenbach's City and District by the year 2000, estimated to require an additional 134 places summing up to a total of 213 places; but while the document also expects a growth in hostel places it provides no target figures for Offenbach (LWV 1996:25).

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[44] The number of hostel places rose by 12 in 1996 as a new hostel opened in one of the district regions

6.4.1 PROVIDERS AND CONCEPTS OF HOUSING SUPPORT

Housing or supported accommodation in Edinburgh is mainly provided in small flats for one to perhaps 3 or 4 people and the provision is offered by voluntary organisations like Penumbra or the Edinburgh Association for Mental Health (E.A.M.H.) or housing agencies like Edinvar. These three are among the major providers of accommodation services in the City and while the two voluntary organisations focus upon the mental health clientele, Edinvar offers supported accommodation to all client groups in need of community-based support.

The way accommodation support is organised may vary from provider to provider, but principally major concepts are similar. For example, support is provided by support workers and may range from every day support to less frequent provision including everything from "organising the house accounts, to facilitating house meetings, from looking at benefit forms with tenants, to enjoy a few laughs with people in their local" (Penumbra 1995:8). Penumbra also provides a number of special accommodation services, for example, one house for women only as this was specially requested, a particular accommodation place for young people up to the age of 25, and an 24-hour support service in one of their houses (for 6 people), i.e. a support worker is always available (fieldnotes 1996).

Housing in Offenbach is differently structured including supported accommodation and hostel provision, both major resources. The hostels in the case study locality are mainly run by two provider organisations (*Verein Lebensraeume, Diakonisches Werk*), who usually offer places for at least 12 residents, the largest hostel in the City of Offenbach has 32 places. Clients in the city's hostel live in flats of four to six people, have their own room and share kitchen and bathroom, while the hostels in the District feature even more as an institution as they do not provide the flat-type of setting but one single dwelling for 12 clients with a shared common room, kitchen and bathroom together with individual rooms for clients. Staff is available 24 hours a day and offices are also located in the

dwellings. Although, for example, the hostel in the City is conveniently located among other public housing in the city centre and residential life is arranged in small groups of four to six, there is no denying the institutionalising character of the entire setting. Users as well as staff have critically questioned the therapeutic and social benefit of hostels and especially the continuation of setting up new hostels for the clientele (fieldnotes 1996). Nevertheless, hostels remain a major policy objective and planning target for the future (LWV 1996:30) not only locally but also on regional state level as has been seen before (Chapter 5).

In comparison, supported accommodation according to the definition provided before is similarly available in both case study regions, conceptually based on the notion of providing various levels of support according to individual need. It has been shown, however, that Edinburgh provides more places for supported accommodation, while in Offenbach hostel provision also plays a significant role, which has a number of critical implications. They will be examined in more detail in Chapter 7 drawing on the user perspective and quality of life issues.

6.5   EMPLOYMENT AND DAY CARE

6.5.1   DAY HOSPITALS AND DAY CARE CENTRES

Day care in Edinburgh is characterised by a combination of day hospitals (one in each sector of the City), and a number of day-care centres scattered across the City. The day hospitals are run by the health authorities, while a rather uncoordinated number of day-care and drop-in centres are mainly provided by different voluntary organisations.

The Mental Health Strategy (Lothian Health 1995) registers 900 half-day places in the city's day hospitals (ibid 1995:33) which is a comparatively

high level of availability in a hospital type of setting. In contrast, Offenbach offers only a small number of 20 places in the local day hospital, which is attached to the psychiatric clinic in the city. Day hospitals in both case study localities offer mainly therapeutic services such as occupational therapy and various group activities (e.g. conversation groups, cooking groups etc) with the aim to train patients' communication and social skills on the one hand and provide organised daily structure on the other. The day hospitals also oversee the medical treatment of their patients and arrange regular consultations with psychiatrists or therapists.

In general comparison, the local situation reflects the respective national indicating that day hospitals are much more widespread in Britain than in Germany.

In addition to day hospitals day care centres have become increasingly common in community mental health care. The specific national differences concerning the conceptual basis of day care in the countries under comparison (e.g. the German emphasis on work and work related activities) have been outlined in the previous chapter.

The Mental Health Strategy (Lothian Health 1995) does not provide current numbers for day- care centres or places in day-care centres in Edinburgh. With regard to different forms of day care (e. g. from regular full-time options and training centres to different irregular support groups) the Strategy does not provide any more detailed information or even future estimates apart from relatively broad statements. For example, one of the main points noted about current day care services in Edinburgh is that "there are a large number of relatively small projects, many funded by the Social Work Department" (Lothian Health 1995:35).

The Social Work Department in Edinburgh registers the day-care services supported by the Mental Illness Specific Grant, and yet the current number of places in day care centres or an estimated future need in terms of accessible place numbers are not officially available. While the general development is reviewed positively in the Strategy, with a clear pledge to

increase the number of places in the future, current availability and future need in accessible numbers is lacking.

Since day hospitals and day-care centres are both significant mental health resources in Edinburgh, another problem became evident during the course of this research: the potential role of the different services. The major documents (Lothian Health 1995 and Lothian Regional Council 1995) do not provide any guidelines or definitions to distinguish between the role of day hospitals and other day services like day-care or – as they are also called - drop-in centres. It is not possible to identify a particular pattern of individual responsibility or specific characteristics perhaps related to different needs or different rehabilitation schemes. All that can be said in relation to survey results from Edinburgh is that day-care centres are often characterised by a less rigid daily structure in terms of therapeutic and rehabilitative measures. Day-care centres function predominantly as open door and drop-in facilities, while day hospitals appear to be more strictly organised and with stronger emphasis on medical therapy. The medical orientation of day hospitals is also evident in relation to staffing, with more personnel from medical professions than in day care centres.

While the daily structure in a day hospital seems to be rather similar in both case study localities featuring primarily therapeutic and medical measures, it is the principally different conceptual basis of day care that is the major contrast between Germany and Britain including Scotland. The specific difference is characterised by an explicit policy of work-oriented day care in Germany, which has led to increasing activity in recent years concerning the area of day care and employment, which has been shown in the previous chapter.

This is also reflected by the case study data (see table 6.3 below).

In 1996 the number of places in day care centres (*Tagesstaetten*[45]) had risen to 82 provided in 5 *Tagesstaetten* across the German case study

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[45] for further explanation see Chapter 5

locality, one in each sector of the Offenbach District and one in the city. The expected increase until the year 2000 is relatively small (111 total places by 2000) as daily occupation is also provided by other support services such as sheltered employment.

6.5.2   SHELTERED WORK

The comparison of employment opportunities and especially sheltered workplaces shows remarkable differences between Edinburgh and Offenbach, with relatively little opportunity in Edinburgh. The level of available options in Edinburgh such as training in advanced technology and small service industry is very low, featuring very few places together with time restrictions that are serious limitations for continuing care clients. In comparison to Offenbach there is little opportunity for people with long-term mental health problems for secure and continuing sheltered employment.

Statistical material on employment support is not available, and official figures for Edinburgh are difficult to obtain from local sources. For example, local authorities can only provide the names and addresses of the (two) major providers in the city, but place numbers or a calculation for future need are not available. The limited scope of employment support appears relatively unstructured and a consistent concept concerning this area of community care service provision is not available.

The survey has identified a small number of providers offering training and employment schemes in Edinburgh. For example, 'Atlantic Text' is an employment training service run by the Scottish Association for Mental Health (SAMH). The training project provides 20 training places for individuals with mental health problems and offers an advanced office technology programme, focusing on IT and computer training courses. Training includes general office skills like word processing, type-writing

and computer applications and trainees have access to PC's and tutors. Although the organisation is trying to arrange placements in local companies and businesses it is relatively difficult to secure a job after the one year training period and integrate clients into the mainstream labour market (fieldnotes 1996). The problems concerning rehabilitation and especially integration into the mainstream occupation are similar to the problems German users face when approaching the labour market. The difference is that users in Edinburgh have more limited alternatives after their training programme has finished. Open labour market employment is difficult to secure and sheltered work places are rare. Therefore people often pass the training programme only to realise that there is no serious employment prospect afterwards. This is often frustrating, a fact which has been pointed out by users and staff (fieldnotes 1996)

SAMH also runs a horticultural project providing a total of around 20 part time sheltered work places in gardening and maintenance. Clients are employed on therapeutic earnings[46] and usually work between 2 and 12 hours per week without any time restrictions regarding the length of their working period in sheltered employment.

The Edinburgh Community Trust (ECT) is another provider of employment support for people with mental health problems in Edinburgh and offers a variety of different work projects for clients. At the time of the survey three major services were operated by the Trust: a catering service 'Rolls on Wheels', a Guesthouse (B&B) with eight bedrooms and conference facilities in the city centre of Edinburgh, and a garden service for landscaping and garden maintenance. The Trust employs people with mental health problems to work in these three service areas, the majority on therapeutic earnings. In 1995 the Trust provided opportunity for about 50 people to work part time, and employed seventeen people on a full-time basis. Those on therapeutic earnings participate in a part-time scheme with individual working hours from 2 to 10 hours per week, while

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[46] Therapeutic earnings refers to the money paid to clients for part-time or full-time work in day care centres, training projects or sheltered work places, for more details see also Chapter 7

the seventeen full time places seem to be all that is available on full time basis for people with mental health problems in Edinburgh.

Sheltered work for people with mental health problems *(Werkstatt fuer seelisch Behinderte, WfB)* in Offenbach is comparatively well developed. In 1994 City and District provided 100 sheltered work places for people with mental health problems on either full time or part time basis (LWV1996:11) for whom a completely new purpose built facility was opened in the city in 1996. The new three-storey building is very bright and the working atmosphere appeared open and friendly. Users (as well as staff) appreciated the modern environment and expressed great satisfaction with their new surroundings (fieldnotes 1996).

Future need according to the calculation provided on regional state level is estimated to increase by almost 100 per cent until the year 2000 (LWV 1996:11) making a total of 195 places for the case study locality.

Currently users or workers can choose from different work options in the Offenbach *WfB*, mainly industrial tasks requiring different levels of ability and expertise. Work is usually organised in small groups supervised by a member of staff or a user with special expertise. The professional background of the supervising staff is often industrial rather than social and it was pointed out that this aspect supported an ordinary work-oriented focus and character of the setting as in any factory rather than featuring a social or therapeutic environment (fieldnotes 1996). Since 1982 when the first *Werkstatt* was established in Offenbach one of the major aims was the acquisition of work and the delivery of services. Over the years a number of local and regional companies and businesses have been recruited, and it has been pointed out that - despite occasional shortages - a consistent network of contractors has developed securing a fairly stable workload (fieldnotes 1996).

While the *WfB* is the major provider of sheltered work in Offenbach, a few smaller projects similar to self-help firms have been set up over the years, some of which have disappeared again, mainly for being too costly or for lack of funding. However, a small flower shop run by one of the voluntary

organisations has succeeded for more than ten years providing sheltered work places for 2-3 clients.

The table below (6.3) summarises the number of day care and employment services available in the case study localities on full-time basis if not stated otherwise and shows the differences as examined above:

	Edinburgh	Offenbach
Day hospital	900 (half-time) places/=300 places per 150.000 population	20 places/=7 places per 150.000 population
Day-care centre/*Tagesstaette*	n/a	66 places/=22 places per 150.000
Sheltered work/*Werkstatt*	17 places/=6 places per 150.000 population	166 places/=55 places per 150.000 population

Table 6-3: Day care and employment places in the case study localities in 1994/1995

This section has highlighted a number of major differences concerning the current situation in the area of day care and employment in the case study localities. These differences also reflect the general national tendencies as has been seen in the previous chapter. While on national Scottish level and also in Edinburgh day care mainly takes place in day hospitals as well as day care and drop in centres, work oriented day care and especially sheltered work places are more widespread in Germany on regional and also on case study level. Furthermore, German options for daily occupation appear comparatively heterogeneous in order to meet different levels of need, which has also become evident in the previous chapter when the specific profile of *Tagesstaetten* and *Werkstaetten* was explained.

In general comparison, Scotland offers very little opportunity for employment support or work oriented activities for people with mental health problems compared to Hesse, and the figures provided on case study level show similar disparities in terms of place numbers and general availability. Furthermore, respective local policy documents deal with the area of day care and employment with different emphasis. The Mental Health Strategy relevant for Edinburgh does not provide a more detailed account concerning the principal importance of work or future efforts (e.g.

concepts, place numbers etc) in the area of employment support. Progressive planning is only covered broadly without clear benchmarks for prospective development. In contrast, the initial German mental health guidelines (Psychiatrie Enquete 1975) highlighted the importance of (sheltered) employment services from the beginning of the community care debate, which has led to the implementation of a greater variety and more availability in this area of service provision.

6.6   OTHER COMMUNITY SUPPORT SERVICES

This section examines community based support services which do not fall neatly into one of the areas of service provision identified before, but they must be seen as additional support options more or less commonly available in the countries under comparison.

6.6.1   COMMUNITY MENTAL HEALTH CENTRES

Community mental health centres (CMHCs) can be seen as part of what is called primary health care in Britain. In the British policy context primary care usually refers to the settings to which people will turn first when seeking professional help such as the GP (General Practitioner), who may then refer patients to the CMHC for more specialised help[47]. In contrast to community mental health centres in Germany who also offer and network psychiatric services such as accommodation support or day care and employment, CMHCs in the British context function mainly as alternative reference places (in addition to the GP).

Currently, Edinburgh does not provide a community mental health centre addressing the specific needs of people with mental health problems, but

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[47] for more information on primary care and mental health care see also Sheppard M. 1996

a recent discussion document concerning a joint mental health plan for the City of Edinburgh includes setting up Community Mental Health Teams (CMHT) in each quadrant of the City as a priority service for the future (Lothian Health and City of Edinburgh Council 1998:2).

The City of Offenbach has established a Psychosocial Centre *(Psychosoziales Zentrum, PSZ)* in 1985, while the Eastern and the Western District have established Community Psychiatric Centres *(Gemeindepsychiatrisches Zentrum, GPZ)* during the early Nineties. All three centres have similar features based on concepts that focus upon offering and networking housing support, employment services and other mental health services in their respective sector. At the same time they function as open-door and drop-in facilities for users and carers.

One of the centres (East) also provides hostel accommodation on its premises with currently 12 places. This development must be viewed critically as it increases segregation rather than community integration. Especially the situation of working and living in the same place resembles the rather traditional features of old-style hospitals, where people had little opportunity and little need to leave the caring setting.

6.6.2 SOCIAL-PSYCHIATRIC SERVICE

The German case study locality comprises two local authorities, Offenbach City and Offenbach District, and it was a formal requirement of the Psychiatrie Enquete to set up a statutory mental health service as part of local authorities (Health or Social Work Departments) with the aim to facilitate co-ordination and co-operation between service providers and other relevant stakeholders. In Offenbach a Social-psychiatric Service Team *(Sozialpsychiatrischer Dienst, SPD)* is attached to each of both Health Departments. The staff team usually includes qualified professionals (mainly social workers, psychiatric nurses and psychiatrists) dependent on the size of the service, which is based on population

measures. In Offenbach both teams include one psychiatrist and about 4 full-time social workers. The services engage in duties similar to supported accommodation teams focussing on home visits and individual care and support. In addition, the concept of the Social-psychiatric Services in the City and District includes to encouraging self-help and contact groups, organising regular group meetings for clients (self-help groups) or carers, or otherwise refer clients to different providers offering appropriate services.

The SPD is perhaps the service most closely resembling the CMHCs in Britain.

6.6.3 RESPITE CARE

Respite care is an area with relatively limited availability in Scotland and none in Hesse. Scottish policy documents refer to respite care as an area of importance, while policy documents in Hesse do not refer to the area at all. The situation in the case study localities reflects this particular aspect. While the availability in the Edinburgh case-study locality is by no means satisfactory, there is at least a clear recognition of the issue as an important mental health support measure (Lothian Health 1995:47). A national respite care resource with 13 places is based in Edinburgh, but only 3 of those places are available to people in Lothian including the City of Edinburgh. This is an extremely low number given the general significance attributed to the issue (Lothian Health 1995:46-48). In 1995 the Scottish Affairs Committee also addressed the issue and stated that provision in Scotland is underdeveloped (Scottish Affairs Committee1995:viii).

However, the Edinburgh respite care service, Cairdeas House[48], was opened in 1992 by Penumbra. Cairdeas House provides short term breaks

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[48] Cairdeas is Gaelic for respite, fellowship and harmony

up to three weeks in guesthouse style accommodation for people with mental health problems and their carers; the service provides 24 hour staff cover on seven days a week (Penumbra 1995:14). It has been reported that the service is mostly booked out with long waiting lists for people interested. This indicates that the service is highly requested, but also that opportunity to take advantage of the resource at short notice, for example, in times of a crisis, is usually impossible. Although respite care is not a crisis service as such, the resource can help to avoid a psychiatric crisis, but if availability is lacking, it is usually the mental hospital that remains the last resort.

In general comparison there is a lack of respite services in both case-study localities, but while the service is at least available in small numbers in Edinburgh - albeit very limited – it is completely lacking in the Offenbach case study locality. The reason for this difference may be related to the significance attached to the service in policy terms. While the German mental health policy fails to address the issue completely, the British policy explicitly highlights the importance of respite care. However, it remains difficult to explain why German policy documents on national, regional and local level do not refer to respite care as a community care component and reasons are not entirely obvious. It is possible that the traditionally strong role of psychiatric hospital provision - as highlighted before - together with the influence of powerful stakeholders to preserve the hospital as a last resort are possible explanations for the specific situation. The ambition to preserve the psychiatric hospital or clinic as a last resort could explain why other services such as respite care or crisis services (see also Chapter 5) are playing such a marginal role. This has implications for further policy and practice development. While more widespread availability of services such as respite care or also crisis intervention could perhaps further reduce the need for hospital beds, the absence of such services rather confirms current German policy objectives focussing on a need of 80-120 beds per 150 000 population.

6.6.4 USER GROUPS

It has been shown before that user involvement and user participation are central elements to British and Scottish mental health care policy, but do not appear in the German policy context[49]. Thus, it is not surprising that the case study material reflects a similar pattern. A number of user groups are available in Edinburgh, most of them with a clear emphasis on political campaigning and related activities. For example, CAPS - the Consultation and Advocacy Promotion Service - is a user run service actively involved in policy planning at local level and campaigning for better services for users in Edinburgh. User representatives participate in meetings with Edinburgh Council and the service has been involved in research, for example, into the provision of crisis services in the City. CAPS was set up in 1993 and runs office and meeting facilities in the city centre. The service offers regular user meetings most of which have a certain focus addressing relevant themes ranging from illness related issues to service related and policy planning matters. The service is regularly involved in reflecting the user perspective to policy makers and local authorities on on-going mental health issues in the City.

A user group in the sense of CAPS described above does not exist in Offenbach. While a number of self-help groups provide support and to some extent counselling to mental health clients, these groups are neither campaigning in a political sense nor are they involved in any kind of policy planning, evaluation and service delivery. The potential impact of this difference on mental health service users is presented as part of the survey results in Chapter 7.

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[49] for more explanation see Chapter 4

6.7   SUMMARY AND CONCLUSION

In this chapter an attempt was made to provide an overview of major community mental health care services in the case-study localities as part of their wider national entities. A mapping of major services took place at case-study level and general availability was reviewed.

The case-study material presented in this chapter has confirmed some national differences identified in the previous chapter in the areas of health, housing and employment (see Chapter 5), but also highlighted differences concerning other support services such as respite care or user groups.

The comparison of acute psychiatric services has shown particular differences concerning bed numbers in the relevant psychiatric hospitals. While it has been generally pointed out that hospital provision is a central element in both case study localities, bed numbers in Edinburgh are higher than in Offenbach. Similar to the tendency evident in comparing numbers from Scotland and Hesse (see Chapter 5), bed numbers in Edinburgh are about three times as high as in Offenbach. Potential reasons for this difference have been pointed out earlier and include a lack of guidance from the Scottish Office and a comparatively slow progress concerning the development community based alternatives in Scotland. Professional conservatism and a traditionally strong influence of medical care may be applied to both countries and perhaps account for the general significance of hospital services in providing acute psychiatric care in the countries of comparison.

In both case-study localities housing is an area where significant activity has taken place in recent years. The case study material has shown that housing support appears similarly important in policy and planning in both countries, while major differences appear in relation to particular forms of housing support. In Edinburgh supported accommodation is the major form of housing support, while in Offenbach hostel provision also plays a significant role, along with supported accommodation. It has been pointed

out before that financial aspects together with a relatively strong reliance on institutional forms of care may have an influence on the German situation.

Overall, it seems that in both countries the general development concerning the areas of psychiatric hospital care and housing is rather less advanced than it may seem at a first glance: although the comparison of psychiatric bed numbers between Scotland and Hesse or similarly, Edinburgh and Offenbach, may suggest that German mental health care is more advanced[50], the strong reliance on other forms of institutional care in Germany such as hostels highlights a situation which is altogether not so different between the countries of comparison. While the Scottish situation is characterised by larger number of hospital beds, the German situation is characterised by a different, perhaps more subtle alternative of institutional care, i.e. care in hostels. Thus, the comparison concerning the two components of health and housing generally shows that institutional forms of care are still central to community based mental health care. Although housing support is increasingly provided through supported accommodation schemes it remains doubtful whether more institutional forms of care such as hostel provision are principally beneficial to enhance the quality of life of people with mental health problems, an aspect which will be more closely examined in the following chapter, when user views are presented.

Day care and employment is an area where differences appear more accentuated than in the area of housing support. Day care in Edinburgh, for example, is largely determined by care in day hospitals and, less frequently, in day-care centers. Both options focus upon therapeutic measures concerning the care and treatment of their clientele. In contrast, day hospital provision is small in Offenbach, while *Tagesstaetten* with a clearly work-oriented focus are major resources together with sheltered work places (*Werkstaetten*). Especially concerning sheltered work places, the local and regional differences are striking. Data from Edinburgh show

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[50] It is recognised though that bed reduction as such may not be a principal indicator for progress

that availability for sheltered employment is indeed very limited compared to Offenbach. This also reflects the wider national situation to a large extent. Reasons for these differences may be related to different policy objectives with more emphasis on employment and work oriented services in Germany than in Scotland. This specific policy emphasis is possibly influenced by national particulars such as the German insurance based system of care, which traditionally embodies assumptions about the centrallity work.

Major differences concerning other services on local level mainly appear in relation to respite care and user groups. While Offenbach neither offers a respite care facility nor any user groups that are involved in policy planning and service delivery, Edinburgh provides these facilities. Respite care is currently only available in small numbers in Edinburgh, while the availability of user groups is more widespread. In apparent contrast to national, regional and local policy guidelines in German mental health care, the involvement of service users – as has been shown in previous chapters – but also the availability of respite care are seen as important to comprehensive community mental health care policy and practice in the Britain and in Scotland.

It is obvious from the data presented that different national policy objectives and a different conceptual approach can affect the locally-available 'welfare mix'. The emphasis on work and work-related activities in initial German community mental health care policies (Psychiatrie Enquete 1975) have clearly informed practical outcome and availability. This, however, seems to have had an impact on greater variety in the area of day care and employment on the one hand, but also to more availability in terms of place numbers on the other. In contrast, user involvement is increasingly important in Britain and the policies provide a basis for user participation in policy planning and practice development. The case study material reflects that user groups are more widespread in Scotland, and Edinburgh has a number of smaller user led-projects but especially with Caps a service that is involved in local mental health care policy planning and practice development.

This chapter has considered the welfare mix in community based mental health care in Edinburgh and Offenbach and has examined the respective local particulars. Mental health service provision was examined in relation to conceptual profiles and availability in both case study localities and major similarities and differences concerning support service provision were highlighted. Generally, it is important to know what a service is providing, and also for whom and to what effect. Information systems must therefore be closely attuned to the policies being implemented. It follows from this that a combination of 'hard' statistical information like bed and place numbers - as presented in this chapter together with conceptual explanations or definitions - and 'softer' information on processes, perceived outcomes and users' views is essential. In her review of evaluative research on community mental health services Ramon (1996b:346) similarly highlighted that "it is useful to include users, carers and grassroot workers' views as an integral part of service evaluation".

The evaluation of community based mental health care from a user perspective is a central theme in this study and the following chapter presents the case-study material into the effects of community mental health care on the quality of life of service users in Scotland and in Germany. The chapter draws on data obtained from a survey in both countries, understood and interpreted within the context of theoretical and policy issues addressed in the context of this study.

CHAPTER 7

OUTCOMES IN COMMUNITY CARE: A USER PERSPECTIVE

7.1 INTRODUCTION

It has been shown in earlier chapters that the concept quality of life has become an increasingly popular concept, mental health outcome and outcome measure. The theoretical and conceptual background to quality of life as a concept which can refer "to the sense of well being and satisfaction experienced by people under their current life conditions" (Lehman 1983:143) has been examined in Chapter 2.

The previous chapter has compared the range of community support services for people with mental health problems in the case-study localities thus providing the respective local context for the presentation of user views in this chapter, while in earlier chapters basic national policy foundations were examined and compared. This context, the current welfare mix based on general policy development and respective guidelines, is important to the basis of our understanding of community based care in the case study localities and the perception of service users in relation to this.

The present chapter presents the views of mental health service users on their current life conditions; especially their satisfaction with community living in general and support arrangements in particular. The analysis is based on objective and subjective quality of life indicators concerning significant life domains as identified in Chapter 2. The measure for subjective well-being is the 'perceived' quality of life defined as an

individuals' appraisal of his or her level of satisfaction in various life domains.

The chapter has two major aims: first, the comparative evaluation of mental health service users' views concerning community living and support service provision in the two countries and secondly, based on this the analysis of potential effects on the individual quality of life of mental health service users. The analysis presented addresses the fourth aim of this study: to evaluate and compare users' satisfaction with community living and support services in both countries in relation to quality of life.

The user perspective analysed in this chapter is based on the results of a questionnaire survey among mental health service users in Edinburgh and Offenbach. With the aim to investigate the effects of community care on the quality of life of service users in Scotland and Germany the questionnaire survey obtained users' views on 'community living', for example, concerning living circumstances and/or support arrangements and especially users' satisfaction in relation to this. The present chapter is organised according to the most significant life domains as identified in Chapter 2 which also match with the sections of the user questionnaire:

Health, Housing and Accommodation (Living Situation)[51], Employment and Day Care (Daily Occupation), Finances, Support, Social Contacts.

The information provided in this chapter will be in both quantitative and qualitative form. First, using the information provided by 238 respondents, I can give a quantitative picture of a number of issues. For instance, this can tell us how many respondents in each region make use of supported accommodation and day care centres and sheltered employment or show the percentage of respondents dependent on welfare benefits in each of the two countries, thus highlighting their financial situation and dependencies. Second, by selecting out cases who answered open-ended questions, a qualitative view can be built up of the user's perspective.

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[51] The phrase in brackets refers to the expression used in the questionnaire

Whenever appropriate throughout the following sections, answers that were given to open questions are presented to illustrate particular issues and provide a more lively account of the user perspective.

Quantitative data will be offered in tables and figures while qualitative data include statements and quotations from group discussions and users' answers to open questions. Before the findings are presented further below general sample notes are provided first.

7.1.1 GENERAL SAMPLE NOTES

Most respondents had extensive experience of in-patient hospital care, which indicates that the majority of the sample can be considered as being part of the mental health population relevant to this study, i.e. those suffering from severe and chronic conditions (for more details concerning response rate and representativeness see Chapter 3).

A smaller percentage of 24% in Germany and 13% in Scotland had never been an in-patient in a mental hospital, while the majority (76% in Scotland and 87% in Germany) had frequent more or less enduring hospital periods. For example, 9.4% of the Scottish respondents reported their longest hospital period had lasted more than 8 years while none of the German respondents appeared in this group. 13 % of the Scottish respondents and 17% in Germany reported their longest hospital period as ranging between 13 months and 8 years. More than half of the respondents in both countries (53% in Scotland and 59% in Germany) reported their longest in-patient period as ranging somewhere between 3 and 12 months while almost one quarter (24% in Scotland and 23% in Germany) reported in patient admissions of 2 months or less. This admission pattern indicates that the majority of the sample in both countries seems to have had long-standing contact with mental health services.

A survey in the UK (Rogers et al. 1993:58) identified an admission pattern suggesting that the majority of their respondents were generally 'revolving door' patients: that is people who spend most of their time outside hospital with intermittent in-patient phases. Since hospital care seems to work as a form of acute emergency care – as has been highlighted in previous chapters - and crisis intervention services as an alternative are not available in the case-study localities it is very likely that this pattern can also be applied to the present sample.

7.1.2 DEMOGRAPHIC CHARACTERISTICS

Demographic characteristics of the sample in both countries show that gender composition was unequally distributed. While the percentage of male respondents almost doubled the rate of female respondents (64% male/36% female) in Scotland, the distribution was more balanced in Germany (47% male/53% female). This difference is difficult to explain. There is, for example, no evidence whether this is based on a lower female response rate in Scotland compared to Germany or whether this was influenced by generally smaller numbers of female clients or whether it was purely arbitrary.

There was no particular difference regarding the major age groups of respondents in both countries. The mean age of the entire sample was 41 years in Scotland (42 male, 37 years female) and 40 years in Germany (37 years male, 43 years female). Respondents were grouped into three age groups, ranging from 18 to 35 years, from 36 to 50 years and from 51 to 70 years. 33% of Scottish respondents and 40% of German respondents appeared in the first and youngest age group, and 37% of the Scottish respondents and 33% of the German respondents appeared in the second and middle age group, while finally, 23% Scottish respondents and 24% German respondents fell into the last category. The majority of respondents were in their middle years, yet almost 12% of the German

respondents and 8% of the Scottish respondents were at or beyond retirement age. The age structure also shows that chronic severe mental disorder is rare in people under 20 - only three individuals were under 20 in Germany, none in Scotland - because of the lengthy period (i.e. two years or more) for which individuals must have severe disorders before many clinicians will consider their condition as chronic or long-term. It is a common definition criterion that a time span of two years or more clearly indicates that a mental disorder is of long standing, which has also been pointed by a study in England (Oliver et al. 1996:135).

Oliver et al. have also pointed out that it is probable that the average age of onset of illness approximates age at first admission (ibid.). In this instance, average age of first admission in the present survey was 27,2 years in Scotland and 29,7 years in Germany.

The marital status of respondents showed, overall, a similar picture in both countries. The overwhelming majority of respondents in each country was single, however, with a slightly higher proportion of single people in Scotland than in Germany (73% in Scotland/59% in Germany); 11% of the Scottish and 16% of the German respondents were married, while 14% in Scotland and 20% in Germany were divorced. The number of widowed respondents was very small. The most striking aspect is the high level of individuals who are unmarried; and it has been pointed out elsewhere that the level is considerably higher in comparison with the general population, but typical of this particular client group (Oliver 1996:141). Oliver et al. (ibid.) implied that this was hardly surprising as prolonged periods of drug treatment with major tranquillisers, hospital confinement (for example, on single-sex wards) and the possible underlying rationales of management regimes to which individuals have been exposed have had an impact on their behaviour and consequently on relationships. However, the many social difficulties related to mental illness in spite of treatment (for example, burdening efforts to cope with the illness or psychotic episodes that can periodically affect relationships seriously) may also be counted as influential factors.

7.2 HEALTH

The issue of health (physical and mental) has a strong bearing on general living circumstances and the individual quality of life and in most quality of life research health is thus part of the assessment concerning individual living circumstances (Lehman et al. 1986, Barry and Crosby 1995, WHO 1991).

In this study the health dimension was assessed broadly notwithstanding the countless aspects that determine the personal conception of health and illness which may influence the individual perception. For example, data on the impact of general health services or the influence of medical substances on the personal perception of physical or mental health have not been directly obtained, but the qualitative data provided some indications as will be seen.

Service users in Scotland and Germany have not shown any extreme ratings concerning the state of their physical and mental health (ranging from excellent to poor). In relation to both physical and mental health average scores were fairly similar in both case-study localities with a clear tendency to rate the physical health more positive than mental health. Physical health was rated good or excellent by 23.7% of the Scottish respondents and 30.2% of the German respondents, while mental health was rated excellent by only 8.2% of the Scottish and 8.9% of the German respondents. On the other hand mental health was rated relatively poor by 22.6% in the Scottish case study locality and 15.2% in the German case study area. It shows that mental health is an issue of great concern to service users which became also evident in the open question section, where the issue appeared in relation to aspects considered most difficult in respondents' lives:

11% in Scotland and 13.3% in Germany considered coping with the illness as most difficult. Illness in this context was clearly related to mental health rather than physical health.

A number of remarks referred to the use of psychotropic substances and a very critical attitude was expressed:

"As you can see I have been damaged by psychiatric drugs which were given without my consent in the Royal Edinburgh Hospital and I have had no life whatsoever since their onset" (041)[52]

"Personally I have found it impossible to function on anti-psychotic medication. This has put a strain on my relationship with staff ..." (004)

"I've been lucky to avoid too much psychiatric intervention – I don't trust them. They see my depression as an illness rather than a way of dealing with problems/abuse etc." (029)

One remark made quite plain what was considered necessary in life, suggesting that good health was the basis to achieve other relevant things:

"Good health=work=bank account" (018)

Although psychotropic drug treatment is often seen as one of the cornerstones of modern post-war psychiatric care that has influenced patients' move into the community, the individual attitude towards drug treatment as expressed in the survey is not particularly positive: none of the respondents referred to psychiatric drug treatment as a positive experience, enhancing, for example, the quality of life or better functioning in everyday life. It will be seen later in the chapter that among the things most helpful for respondents were mainly other aspects such as social contacts and financial independence rather than help through psychotropic substances. This may be related to a generally sceptical attitude towards prescribed drugs and the dependency on medical treatment, but also to the negative side-affects of many of the psychotropic substances, which has been indicated by the following quotations:

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[52] The number in brackets refers to the code of individual questionnaires

"Shaky hands and shaky legs" (043)

"I think it's the medication that is difficult to cope with. It makes me fat and sleepy and I fear that I may never be able to function without the daily dose. Before I became patient here I was much more active. I like to play football and tennis." (067)

The health dimension as assessed in the survey obtained gross data providing broad indications about service users' general condition in relation to physical and mental health. However, the health dimension in the field of mental health care cannot be treated isolated from support service provision as some qualitative judgements show:

"Without the help of the Home Care Team I don't know where I'd be today...taking pills all day and feeling much worse I suppose" (028) or

"All I need is my work at the Stafford Centre – without it I would surely end up in the REH" (GDS)[53]

"I hate to go to hospital and usually I can cope all right with the help of my support worker, but sometimes I have no choice to fight the voices" (135)

7.2.1 PSYCHIATRIC HOSPITAL PROVISION

Principally, psychiatric hospital provision as currently provided in the countries of comparison can be seen as the form of support service provision that is most closely associated to health care, especially if health or health care is defined in the sense of medical treatment and professional expertise based on medical training rather than in the sense of social care. This is also evident in relation to common funding structures in the countries of comparison, where health care (e.g. hospital provision)

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[53] GDS-Group Discussion Scotland

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is funded by national health insurances or Health Boards, while social care is funded by Social Services Departments.

The table below (table 7.1) shows the importance of mental hospital provision to service users in Scotland and Germany:

Importance of hospital provision	user Scotland	user Germany
1=not important	26,3%	10,9%
2	8,8%	3,6%
3	3,5%	5,5%
4	7,0%	10,9%
5	14,0%	10,0%
6	15,8%	18,2%
7=very important	24,6%	40,9%

Table 7-1: Importance of mental hospital provision

The data above show that hospital care is to some extent important to service users in both countries, but even more so to German service users than to Scottish.

There are various possible reasons for this variance. On the one hand, quite a high proportion of the Scottish sample (23.9%) have never been an in-patient in a psychiatric hospital and consequently in-patient hospital treatment does not appear to be very important for them. On the other hand, it is likely that German respondents generally attach more importance to hospital provision, because a variety of aspects may influence this disposition. First, user groups who question and criticise institutional care and rather plead for other forms of acute in-patient treatment (i.e. crisis-centres) are less common in Germany, and second, the political and professional debate in Germany is also more careful in this respect, relying on - and therefore supporting - a national mental health policy that proposes a need for 80-100 mental hospital beds per 150 000 population without any question. The reliance on hospital care as the sole alternative for acute crisis intervention indicates a conservative attitude towards community-based mental health care in Germany, which may be reflected by a less critical viewpoint of service users towards hospital provision in particular and the psychiatric system in general. The emphasis on hospital care as a central element of community based care

in Germany has been examined earlier and also to some extent the role of the service user in relation to policy development and critical involvement (see Chapter 4). Altogether, it seems likely that the aspects raised earlier (i.e. little criticism concerning hospital care as a central element in community care policy and practice, no involvement of service users in policy and practice and consequently no political campaigning of service users) reflect a less critical attitude and a relatively strong reliance of German service users on institutional forms of care as evident in the importance attached to in-patient care in the German case study locality.

In general comparison the data indicate that in both countries hospital care is of general importance to service users, and that hospital care is apparently considered as a form of crisis-intervention service and a last resort as will become more clear below.

7.2.2 PSYCHIATRIC HOSPITAL PROVISION AND QUALITY OF LIFE

It has been shown in previous chapters that psychiatric hospital provision is one of the cornerstones of acute psychiatric care in the countries of comparison and consequently also in the case study localities. Taking into account the descriptive analyses of hospital provision presented in the previous chapter, and focussing on certain particularly negative aspects such as the rather hostile atmosphere in the REH or the remote clinical setting for District patients in Riedstadt, limitations are obvious. In the Scottish case-study locality these limitations affect individual independence (e.g. being able to prepare a cup of coffee) as well as choice and control over personal affairs such as entertaining friends or family. In the Offenbach case-study locality severe limitations affect patients' opportunity to keep in contact with their usual surroundings through the geographic isolation of the mental hospital for district patients, which may have an impact on relationships with friends, relatives and well-known surroundings.

The limitations concerning in-patient care in the case-study localities as summarised above seem to have – at first glance - little in common. While in Scotland the internal hospital structures evoke more criticism, criticism in Germany primarily concerns geographical problems, i.e. great distance between hospital and living environment.[54] However, a similar pattern is that both hospitals show particularly adverse features in terms of individual choice and personal freedom, aspects that can affect the individual quality of life in many ways as the following quotations indicate:

"They checked everything: my bed, my clothes, my wardrobe. There was no privacy. I felt so weak. Sometimes I had to be there for months. I'm lucky now. I have found a flat with the help of EAMH (Edinburgh Association of Mental Health)" (100)

"The way they forced you with injections whether you wanted it or not was what I liked least" (119)

"I wish I could see my partner more often, but she is far away and has no car and I've been here (Riedstadt) for more than two months now. " (159)

A sense of dependence and restrain concerning hospital provision has also been reported by users in a different study:

"It should only be attended short term, because there is a danger of becoming institutionalised"(Rogers et al. 1993:69)

"Very medicalised and patronising" (ibid.)

"...depressing surroundings" (ibid.)

However, being in a mental hospital might not mean a traditional hospital-type service, but the comments suggest that service delivery in mental hospitals still features typical structures.

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[54] This does not mean that internal hospital structures are altogether totally different in Germany. Typical institutional structures such as a more or less rigid care regime or generally limited privacy and autonomy are similar features in such settings.

Taking into account the comparison of hospital care in the case-study localities (Chapter 6) and the views of service users, it seems obvious that in both countries some adverse institutional structures have remained that were long ago accused of producing negative effects like social exclusion, hospitalisation or even suppression. But if things are still so negative, why have survey respondents attached relatively high priority to acute in-patient care and indicated that it is to some extent important to them ?

It is likely that the importance attached to in-patient care refers to a secure port in times of crisis rather than the hospital setting itself. This interpretation is supported by evidence from group discussions in Edinburgh, where clients attached high priority to the development of a crisis-centre as an alternative to the local hospital. There was a clear understanding that the availability of medical treatment as well as therapeutic support at any time was important to service users, but rather not in a conventional hospital type of setting like the REH. It is nevertheless obvious, that if alternatives are not available the hospital is the last resort to many of those in need. In turn, mental hospitals often refer to themselves as crisis-intervention services as has been shown in relation to in the case study localities (Chapter 6). The interpretation of user views (especially from Edinburgh) suggests that the current situation is not satisfactory, and that the general importance attached to hospital care indicates a lack of alternatives rather than a preference for hospital care.

Service users in Edinburgh have clearly expressed their preferences as has been shown by a research study into Mental Health Crisis Services for Lothian (Caps 1995). According to the study a crisis itself is seen as a highly individual matter and occurs at different levels of distress for different people, therefore help must be accessible and available quickly in order to prevent unhealthy resolutions to crisis. The study has thus found that service users clearly favour a multi-faceted form of crisis service:

"Having phoned the freephone number the person then has a choice of receiving support by phone, going to the crisis centre or hospital, or requesting a visit from the outreach team" (CAPS 1995:21).

This kind of multi-faceted crisis intervention has similarly been suggested by Robertson (1996:146):

"A catchment area could provide a crisis intervention team, an acute home treatment service or the 24-hour availability of a professional social worker ideally supported by medical staff. It should be backed up by facilities for urgent assessment and intervention on a walk-in or rapid referral basis"

A number of respondents from the Edinburgh sample (n=18) consequently identified crisis centres as one of the services currently missing in the City, in contrast to respondents from Germany, where nobody referred to crisis centres, most likely because crisis centres are a completely unfamiliar option in German mental health care.

The official mental health care debate in Germany does not include alternatives to hospital care. The issue is not on the policy and practice agenda and national, regional or local documents do not refer to any alternatives such as specific crisis services. Instead - as has been shown in the previous chapter - the local (mental) hospital is promoted as a crisis intervention service by professional stakeholders. However, the absence of this topic in the German mental health care debate may be the reason that German respondents have paid no attention to it. This may be influenced by the general lack of user involvement and the absence of user groups and campaigning activities in German mental health care. It is likely that the lack of involvement and participation sustains a relatively low level of information concerning general policy issues and future planning among German service users, and furthermore prevents the development of skills and methods for a critical reflection of the current situation.

Interestingly, the mental health terminology in Germany provides a most significant example underpinning the important role of hospital provision and confirms a point that has been made in previous chapters concerning

the strong medical orientation in German mental health care: the fact that community services as opposed to hospital care are often termed 'complementary services'. This aspect has been critically reviewed by Beins (1996:67) who observed that the perspective of psychiatric progress is often dominated by the medical profession and hospital-based experts rather than by social workers or other professional groups; Beins pointed out that experts favour the further development of community based alternatives on the one hand, and yet maintain the clinic as the central facility surrounded by other 'complementary' services. Beins identified a fundamental need to change the perspective, not just the other way around, but towards continuing integration of all services into one community-based network, where all services should complement each other (ibid. :68).

It is questionable whether hospital-based care and especially crisis intervention in the sense provided in the case-study localities contributes to the improvement of the quality of life of mental health service users in the community. Principally, psychiatric (hospital) care has changed dramatically within the last decades, and there is no doubt that this has had a downright positive effect on the quality of life of mental health patients as many studies have shown (Leff 1993, McCreadie 1983,1985, Gibbons and Butler 1987, Barry and Crosby 1995, 1996, Albrecht 1994). At the same time the present data suggest that typical institutional structures are still prevalent in the mental hospitals in both case-study localities (see also Chapter 6). In general comparison, service users from Offenbach did not raise any particular criticism concerning hospital care as such, and attached comparatively high priority to the availability of hospital provision (see table 6.1). This clearly indicates that hospital provision is an important service to users largely seen as a crisis intervention service – not only by professional stakeholders as pointed out earlier – but also by users themselves. This became also evident in the group discussion in Germany, where participants indicated that they approach the local psychiatric clinic when they feel in need for acute help and treatment (fieldnotes 1996). Interestingly, this was also pointed out in relation to

respite care. While respite care is not covered by policy guidelines and not available in practice in the German case study locality, users in Offenbach – especially those who lived with their families - indicated that they usually approach the psychiatric clinic in case the individual client or the family needed a break (fieldnotes 1996).

It is likely that the limited criticism concerning hospital care - compared to Scottish users - and at the same time the high importance attached to it, results more from a general lack of information concerning alternatives to hospital care rather than generally better hospital services in Germany. Furthermore, the general lack of opportunity concerning involvement and participation in mental health care and the absence of campaigning organisations such as user groups in Germany may also influence users perceptions and perhaps prevent a more critical attitude towards the psychiatric system.

In contrast, critical comments of service users from Edinburgh clearly indicate dissatisfaction with hospital care concerning issues such as dependence and coercion. These issues can affect the individual quality of life negatively and also maintain a dependence from institutional structures. The actual dependence is perhaps reflected by the importance attached to hospital care by many respondents in both countries. On the one hand the hospital seems to provide the security in the sense of a last resort to many individuals in need of emergency psychiatric care and may therefore be seen as a valuable resource. On the other hand, this may be largely related to the fact that better choices are not available. More research into this topic is necessary.

7.3 HOUSING AND ACCOMMODATION

It has been shown in previous chapters that housing or supported accommodation are core elements to community care both in

Britain/Scotland and in Germany/Hesse reflected in policy and practice development. The housing dimension is most significant to peoples' life in general and there is no doubt that housing and especially good quality accommodation is central to the quality of life of individuals, which has also been confirmed by other studies (Lehman 1982, 1983 Barry and Crosby 1993, Gunkel 1996). It has been found that the availability of good quality housing on the one hand and various options of support according to different levels of need on the other has a major effect on the living conditions of people with mental health problems and can notably influence their quality of life.

Service users in both case-study localities were asked about their living arrangements, generally, in which type of (supported) housing they were living at the time of the survey. The table below (table 7.2) shows the most frequent alternatives.

	Edinburgh	Offenbach
Hostel	8,3 %	18,6 %
Flat/House	90,3%	76,4 %
Psychiatric Clinic	1,4 %	3,7 %
Hotel	-	0,6 %
No Place to live	-	0,6 %

Table 7-2: Housing situation of survey respondents in Edinburgh and Offenbach

Survey results sustain the trend that an increasing number of people with mental health problems are living in individual flats and houses, alone or with others. The case study data confirm the differences highlighted in the previous chapter concerning the types of (supported) housing predominantly available: the options range from hostels (only in the German case study locality) to various forms of supported accommodation in flats and own homes. The German trend to focus upon hostel provision in addition to supported accommodation has been examined in previous chapters, and criticism was raised concerning a policy that maintains hostel accommodation despite the recognition that these institutions produce structures deemed inappropriate in contemporary mental health care (see also Zechert, Suhre 1997:4ff). This focus is evident on regional (Hesse State) as well as on national level reflected by policy and practice development (see also Chapter 5). Consequently, the German case study

material shows a similar picture, which highlights a general contrast between Scottish and German housing priorities in the field of mental health care.

The great majority of the respondents in Edinburgh (90%) live in individual flats or houses compared to three quarters of the Offenbach respondents (75%). In consequence of the German trend identified before, in Offenbach almost 20% of the respondents live in hostels.

However, the real test of community care with regard to housing must be that those using the service are generally satisfied and feel good about the quality of their lives in relation to their housing arrangements. Clearly, where people live and with whom people live may have an impact on their satisfaction and on their quality of life, and provide an indication whether this is related to more individual settings or group settings of varying size.

The figure below (figure 7.1) shows the satisfaction ratings of respondents in the case study localities.

Question 11

Satisfaction with 'Where living ?'.
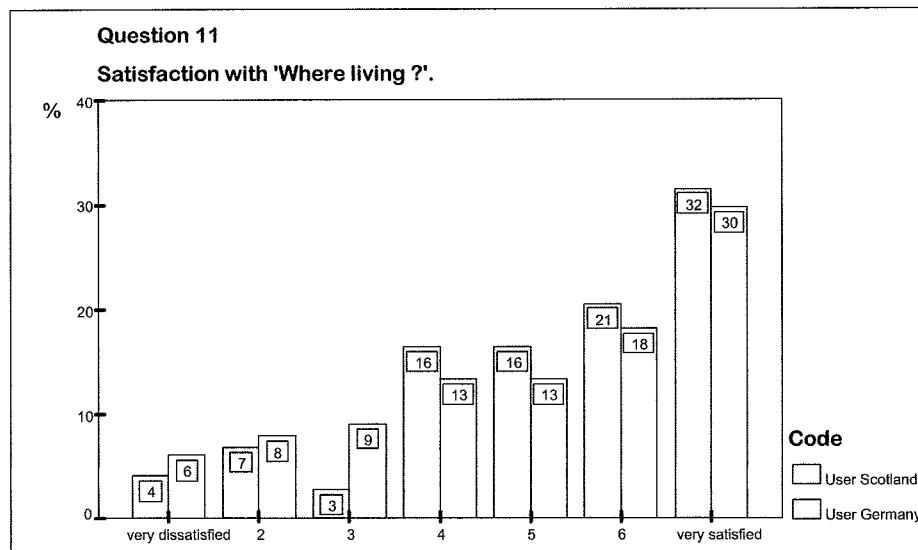
Figure 7-1: Satisfaction of survey respondents with their housing situation

In both countries more than half of the respondents ranked the two most positive options (very satisfied = 31.9% in Scotland and 30.4% in Germany or satisfied = 20.8% in Scotland and 18.6% in Germany). This relatively high level of satisfaction may be related to fairly independent living

circumstances in individual flats and houses compared to more traditional settings like mental hospitals or, to some extent also hostels. Research (Barry et al. 1993, O'Driscoll and Leff 1993, Leff et al. 1994, Stein and Test 1978) which has compared life in hospital with community based living over the last years has time and again highlighted, that most mental health clients clearly preferred living outside hospital. Studies which have compared hospital with community life have shown that moving out of hospital into the community was overwhelmingly seen in a positive light by those involved.

The case-study data reflect a generally high level of satisfaction among respondents in both countries, but it is also obvious that respondents in Germany express greater dissatisfaction than respondents in Scotland. One of the reasons at hand is related to hostel accommodation causing a possibly negative impact on service users. The interpretation of the case-study data in this sense is based on earlier findings and the subsequent notion that the generally large hostels in Germany can be seen as rather institutionalised settings, which has also been confirmed by more recent research (Zechert, Suhre 1997). The data below support this argument.

In relation to specific housing options German respondents generally expressed higher levels of dissatisfaction than their Scottish counterparts as shown in the table below (table 7.3)

	levels of dissatisfaction (1-3)	neither/nor (4)	levels of satisfaction (5-7)
hostel*			
user Scotland	16,7%		83,4%
user Germany	26,6%	13,3 %	60,0%
flat/house**			
user Scotland	13,8%	18,5%	67,6%
user Germany	20,6%	14,0%	65,3%

Table 7-3: Satisfaction with specific forms of housing

*8,3% of the total Scottish sample and 18,9% of the total German sample live in hostel accommodation; hostel accommodation in Edinburgh usually refers to small group arrangements (2-5 persons), while hostel accommodation in Offenbach refers to larger hostels (up to 36 places)

**90,3% of the total Scottish sample and 76,1 % of the total German sample live in individual flats/houses

Higher dissatisfaction levels in Germany may be related to the comparatively large number of German respondents living in hostels. Of those living in hostels in Germany (n=30) 10% expressed great dissatisfaction with this situation, although at the same time 20% expressed great satisfaction with living in a hostel. These extremes are difficult to explain as more detailed information regarding the sources of extreme satisfaction or dissatisfaction have not been obtained. However, a look at more individual living circumstances in flats and houses shows that satisfaction generally scores much higher than dissatisfaction. Strong dissatisfaction among German respondents living in individual flats and houses was relatively small with 5.8%, while satisfaction levels were high with almost 34% who said they felt very satisfied. The broad comparison between those who live in a hostel and those who live in individual flats or houses seems to indicate that the latter is generally favoured. Those living in a hostel are obviously less satisfied, which may be related to the lack of privacy and independence often related to this type of accommodation and the common German situation to provide accommodation in hostels with more than 12 and sometimes up to 50 places. This has also been confirmed by qualitative data as a number of critical remarks indicate:

"I always miss space and tranquillity, too many folks around. Also staff." (036)

" My own bedroom. I don't mind sharing one room when I'm in hospital. But I would feel more at ease if I had my own private room at the hostel." (125)

"I hate the endless discussions concerning household, shopping, laundry etc.; they treat us like children and tell us what we have to do in the house (*Wohnheim*)..."(094)

"I quite like my life here. Always someone around to help me cope with my anxieties. But I wish I had a room for myself and more privacy for me and my partner." (087)

At the same time, positive satisfaction ratings among German respondents concerning hostel accommodation are also obvious and can be related to a sense of security provided by a rather structured living environment as the last quotation above also indicates. Furthermore, some German clients may still not have had the opportunity to live more independently and develop a sense of self-reliance since hostel provision has been one of the cornerstones of the housing policy ever since care in the community has been endorsed in Germany and is therefore a common housing option.

Scottish respondents - except for one individual - did not express any dissatisfaction with group living arrangements and the few respondents (n=6) who said that they were living in a hostel type of accommodation basically felt satisfied with their living arrangement. It must be noted, however, that hostel type of accommodation in Edinburgh usually refers to group living arrangements in small groups of two to five individuals rather than bigger residential care settings like hostels in Germany . Of the Scottish respondents who live in individual flats and houses a proportion of 4.6% expressed strong dissatisfaction with this living arrangement while 33.8% said they were very satisfied.

7.3.1 HOUSING SUPPORT AND QUALITY OF LIFE

Survey data suggest that accommodation in individual flats and houses is generally preferred. Hostels, especially bigger ones, are not a favoured option, which has also been pointed out in group discussions in Offenbach. Objections were made in relation to the lack of privacy and independence and a constant feeling of control and check up (fieldnotes 1996). A study in England (Rogers 1993:114) into residential accommodation for people with mental health problems similarly showed high satisfaction ratings, while more in-depth measures indicated that satisfaction and dissatisfaction tended to centre around two major aspects: these were the physical features of the living space and the type of regime

adopted in running the homes. It was reported that 'adequate space, privacy, pleasant decor and convenient location' were the main aspects which appeared of importance to people (ibid.:115).

Based on the results of other research and the interpretation of the Scottish and the German data it seems legitimate to conclude that hostel accommodation often combines a number of negative aspects that may affect the quality of life of clients more or less seriously, dependent, for example, on the individual care regime. More specific criticism also included a dislike of rules and enforced communality for those living in more institutional settings like hostels, aspects which have also been pointed out by an earlier study into housing from people with mental health problems from (Kay and Legg 1986:20ff) and also by a user survey from England:

"The worst thing were the discussion groups which I was forced to attend" (Rogers et al. 1993:70)

More recent material again suggested that life in a hostel still produced similar negative effects to those of a mental hospital (permissive structures, hospitalisation) and clients often lacked privacy and a 'homely' setting (Ramon 1996a:142ff) aspects which have been similarly raised in group discussion (fieldnotes 1996) and that were also evident in the user quotations above.

The quality of life can be severely affected by such negative effects, but while critical aspects were highlighted by other research and have been referred to by respondents, there are a number of positive aspects that were also pointed out by some respondents: access to 24-hour support and staff available at any time which gave them a feeling of safety and security. While this may be necessary for a small minority of people with mental health problems, others would perhaps feel secure enough with a crisis service that was always available. The major question that remains is indeed whether hostel provision needs to take place in institutions with more than 10 clients as it is often the case in German mental health care.

Generally, as has been shown, clients prefer more individual living environments, sufficient privacy and personal freedom.

7.3.2 LIVING ARRANGEMENTS AND QUALITY OF LIFE

People were also asked about their living arrangements and whether they were living on their own or with others (Figure 7.2)

Question 12

Living with :
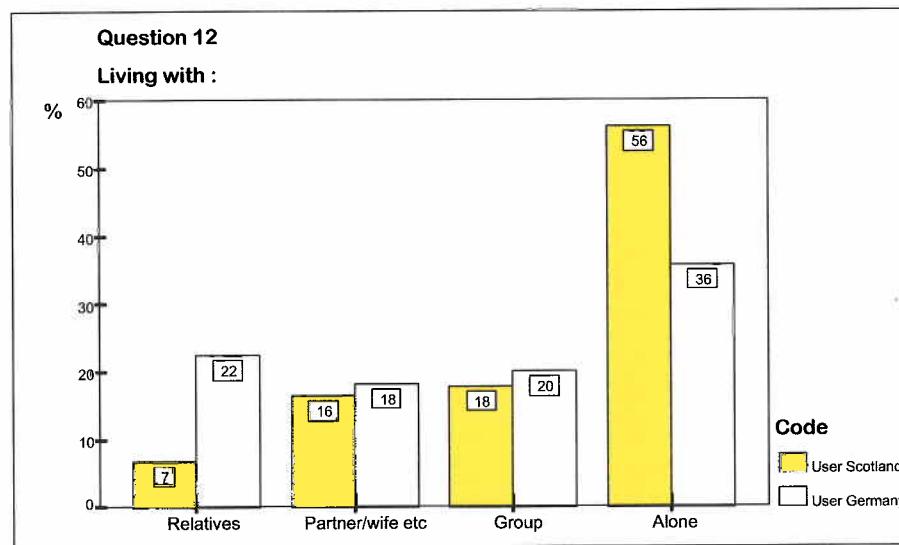
Figure 7-2: Frequency distribution of living arrangements

A variety of options was given, covering several common alternatives. The most striking differences between Scottish and German respondents appeared in the number of people living with their relatives and in the number of people living alone. Only a small number of Scottish respondents (7%) said they were living with relatives (which was specified in the questionnaire as including parents) in contrast to almost one quarter of the German respondents (23.3%). It has been pointed out before (Chapter 4) that the principle of subsidiarity and a strong emphasis on family responsibilities including the reliance on informal care generally plays a significant role in the German social system. This may have an impact on the living pattern of people with mental health problems. While the percentage of respondents living with their spouses or children (16.9%

in Scotland and 18.9% in Germany) and the percentage of people living in some sort of group setting (18.3% in Scotland and 20.8% in Germany) was quite similar in both countries, another striking difference appeared in the number of people living on their own (57.7% in Scotland and 37.1% in Germany). Obviously, instead of living alone, a larger number of German users tend to live with their kin compared to Scottish users.

Survey respondents were also asked how satisfied they were with the people they were living with. The three most positive options were ranked by a total of 71.6% in Scotland and 60.2% in Germany, which clearly indicates a generally high level of satisfaction in both countries. However, with regard to the lowest possible ranking strong dissatisfaction is more prevalent among German than Scottish respondents. 9.2% of the German respondents said they were 'very dissatisfied' compared to only 2.8% of the Scottish respondents. More specific comments and criticism concerning the sources of dissatisfaction were not given, and yet, based on the findings presented above it is likely that dissatisfaction in Germany is at least partly related to hostel accommodation, where issues such as enforced communality and limited privacy have been identified as particularly negative effects.

But dissatisfaction was also expressed by people living alone. Obviously, despite all freedom, individualism and independence that may be possible in a self-reliant and separate environment, there are also negative aspects which need to be recognised. For example, qualitative data from both countries reveal that aspects like *loneliness* and *isolation* are considered as most difficult by respondents (n=23) and similarly, *loneliness* and *boredom* were mentioned as a problem (n=15). This may not only refer to the housing situation, but can also indicate a general lack of community contacts or the absence of a meaningful daily occupation or employment. However, if other activities and contacts are lacking for some reason the housing situation can become an additional burden.

There may be other reasons that influence dissatisfaction with regard to housing, aspects, however, perhaps more related to the physical than the

social environment. Although such details have not been obtained in the survey it is worthwhile to mention one important aspect which is particularly relevant in relation to people with mental health problems. Often, people with severe and chronic mental health problems are without employment and/or on low income (see survey results further below). Generally, people on low income have only limited choice in relation to housing alternatives and are compelled to live in rather shabby flats or in run down areas. In an earlier study into community based housing alternatives in England, Kay and Legg (1986:22) reported that the major concerns expressed by people demonstrated the importance of social as well as physical aspects of housing. They concluded that "much more attention needs to be paid to ensuring that specialist and supported housing both maximise the social benefits of the support" and also, that there needs to be more awareness that the effects of poorly maintained environments and non-responsive repair services can be acutely distressing for many people with mental health problems (ibid.). Succeeding problems are therefore often related to the general housing condition and low standards, which may significantly affect individual satisfaction and, furthermore, the quality of life.

7.4   EMPLOYMENT AND DAY CARE (DAILY OCCUPATION)

It has been pointed out before that the term 'daily occupation' incorporates employment as well as day care as the two major components of daily occupation in the sense of activity-based pursuits in community mental health care. Daily occupation may be work related or more concerned with recreational activities, but also includes other possible activities such as going to school/college or just staying at home. I use the term work-related to refer to any purposeful activity, whether it does or does not attract financial remuneration. 'Daily occupation' also takes into account that the situation concerning day care and (sheltered) employment differs in many

ways in the two case-study localities as has been shown in the previous chapter.

7.4.1   TIME WELL SPENT: THE USER PERSPECTIVE

In the survey respondents were asked where they spend most of their daytime during the week. The figure below (figure 7.3) illustrates the national differences.
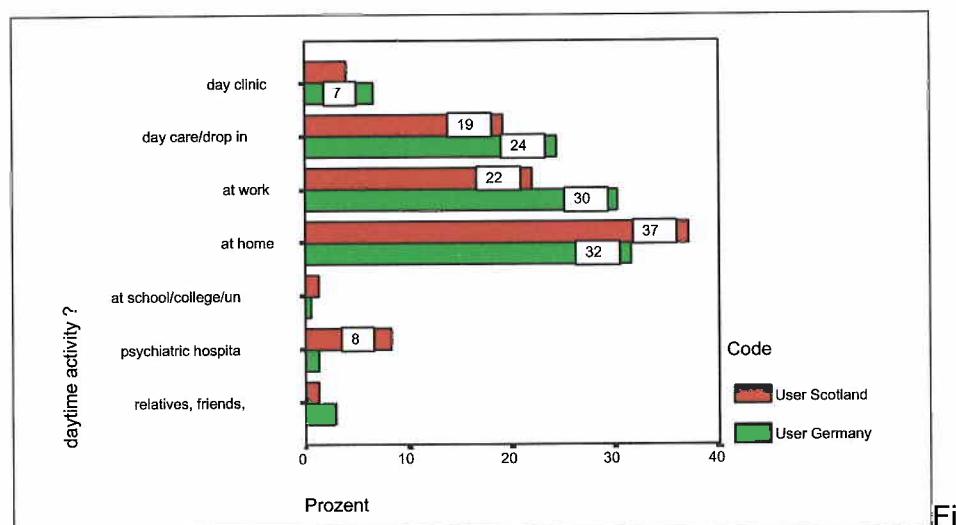
Figure 7-3:Frequency distribution of daytime activities

Of the people responding to the survey in Germany (n=165) three major groups can be identified. There are those who use day facilities such as day care or drop-in centres (24.8%), those who work (31.1%) and those who stay at home (32.3%) most of the time. In Scotland we have a similar picture which mainly differs in relation to work. The proportion of respondents who claimed to go to work is smaller in Scotland (23.5%) than in Germany while the use of day care centres was referred to by 20.6% of the Scottish respondents.

Satisfaction in relation to the daily routine was generally rated relatively high in both countries.

More than half the respondents located themselves on the positive end (three upper ranks) of the 7-item scale, altogether 56.5% in Scotland and

69.2% in Germany. This is a very general result but looking at the data in more detail and with regard to specific aspects may provides more elaborate conclusions. Most striking between respondents in Scotland and respondents in Germany is the difference concerning the highest possible ranking. Only 7.2% in Scotland said that they are 'very satisfied' with their daily routine compared to 29.6% in Germany.

However, satisfaction levels are more expressive when associated with the specific places where respondents usually spent their daytime. With regard to day-care centres the majority of those using a day care centre in Germany (62.3%) is satisfied (26.1%) or even very satisfied (36.2%) with this daily routine, while none of the Scottish respondents was very satisfied and only 12.5% were satisfied with their daily routine in a day-care centre. A more detailed account as to why respondents were generally satisfied or not satisfied with their daily routine may be related to the type of work offered as illustrated by a number of qualitative remarks:

"Being creative all day is more than boring" (GDS)

"It is hard to find things to do during the day and the centre doesn't help" (023)

It may be possible that contrasts are related to the different structure of the service in both countries. For example, in Germany *Tagesstaetten* (day care centres) provide leisure activities and meeting opportunities for service users on a daily basis, but furthermore they focus on a labour oriented approach and offer a variety of options, while Scottish day care centres usually do not provide opportunity for work oriented occupation. Furthermore, some of the day care centres in Edinburgh are not available throughout the day, but offer activities on an hourly basis which may not be considered enough for some regular visitors. Since the lack of work and employment was mentioned by many respondents as one of the things they find most difficult to cope with (n=38 in Scotland and n=45 in Germany) and a meaningful daily occupation was mentioned among other things as necessary to lead a 'normal' life (n=32 respondents in Scotland

n=51 in Germany), it is likely that the scope of activities offered in Scottish day care centres is not sufficient from the perspective of service users. In addition, the options offered are perhaps narrowly restricted to therapeutic and creative activities, which may provide only limited benefit to service users as the first quotation above also indicates.

Another problem concerning day care that became obvious was more related to the general problem of opening hours rather than the range of activities offered. For example, service users have pointed out that evening hours and especially week-ends are sometimes difficult to cope with as most of the centres are only open during week-days. This is also shown by the following quotations indicating service users preferences but also problems concerning day care services:

"A place to go to at week-ends" (194)

"Evenings are really dull, because the Tagesstaette is not open." (GDG)[55]

"It is very hard to adjust to certain 'office' hours. Day care centres should provide at least a few hours week-end service." (GDS)

The problem concerning evenings and week-ends seems to be evident in both case study localities as day care services that are regularly available at these times have not been identified by the survey. Rather, as was pointed out by users and staff in Germany, week-end activities are occasional arrangements by existent services; they usually have no further resources (staff, finances) to extend the weekly opening hours beyond the regular schedules (fieldnotes 1996).

It has also become evident that the opportunity for social contacts was clearly related to the availability of day care services as two respondent have pointed out in relation to things most enjoyable

"Meeting people at the Stafford Centre" (041)

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[55] GDG-Group Discussion Germany

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"Going to the movies with folks from the centre" (012)

The data generally suggest that day care services are important to service users for two major reasons: first, as a place to go to, meet people and engage in communicative and leisure activities, and second, as a place where meaningful daily occupation may be provided. Meaningful daily occupation seems to embody assumptions of work and may be provided in specific day care centres such as *Tagesstaetten* in Germany or – even more specified – in sheltered work places.

7.4.2 EMPLOYMENT AND SHELTERED WORK

There is a methodological difficulty concerning the accuracy of the findings in relation to the employment situation of the German respondents, which needs to be explained. While almost all Scottish survey participants (69 of n=73) answered the question concerning employment (Question 20), only three quarters of the German participants (123 out of n=165) answered the question. Out of all questions this one has generally attracted the largest number of non-respondents in Germany, while the response rate is otherwise fairly consistent throughout the questionnaire. There is no immediate misunderstanding which could be directly related to the question itself; the question was reasonably straightforward in that it was asked whether people had a full time, a part-time or no job. While all but four Scottish respondents could refer to one of the three options this was obviously different for German respondents. There is no immediate explanation as to why a quarter of the German participants did not answer this question at all. It may be possible, however, that people who attend a day centre in Offenbach and work, for example, 2-3 hours per day or a couple of mornings per week would not consider themselves as working part-time. It is fairly common in Germany to refer to a part-time job only if the weekly working hours cover at least 20 hours. Therefore it may be possible that the missing proportion of German respondents could not

refer themselves to either one of the three categories although they perhaps engage in some sort of part time work with unspecific working hours as generally offered in the *Tagesstaette*. On the whole, the tendency indicated would probably not be any different had the missing proportion of German respondents been included, in fact, the tendency indicating more employment and work-related opportunity for German users may have been even more accentuated.

The situation with regard to employment differs notably between both countries (Figure 7.4) with more German respondents who claim to have a job (26.8% full time, 28.2% part time) than Scottish respondents (10.1% in full time, 17.4% part time). Correspondingly, 72.5% of the Scottish respondents said they had no job compared to 47.2% in Germany. Despite the notable difference, the proportion of people without a job is still relatively high in both countries, which is not surprising given the generally high rate of unemployment, the widespread exclusion of people with disabilities from labour market opportunities and the limited availability of adequate alternatives.

The distribution of employment and sheltered work in the case study localities is shown in the figure below (figure 7.4).
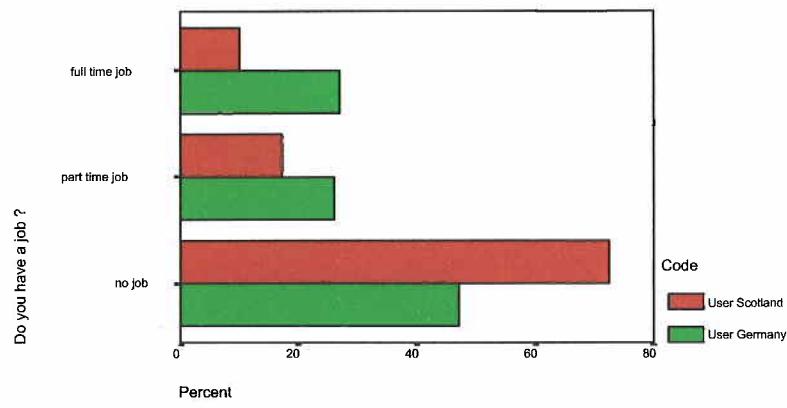
Figure 7-4: Frequency distribution of employment and sheltered work

Of those who have considered themselves as employed the majority said that employment was related to a sheltered work place (66.7% in Scotland and 79.7% in Germany). It is therefore only a small minority of people in

both countries who are actually part of the regular national work force. This is neither new nor surprising, the data support corroborated findings from other research that people with mental health problems are generally not part of the active work force and to a great extent excluded from labour market opportunities (Rogers et al. 1993:93).

People were also asked how they felt about *not* working and there was a great extent of dissatisfaction among Scottish and German respondents alike (Table 7.4). A large proportion of Scottish respondents expressed great dissatisfaction and appeared to feel even less satisfied without work than German respondents. Of those (n=48) who claimed to have no job in Edinburgh the great majority (68.7%) indicated some degree of dissatisfaction, of which about half (33.3%) claimed to be 'very dissatisfied'. The majority of German respondents also felt negative about the issue, but only 13.8% said they were very dissatisfied, while altogether 34.5% expressed varying levels of dissatisfaction. While a positive feeling towards the situation of having no job ranked very low in Scotland and only one person claimed to be very satisfied without work, a small proportion of 10,3% (n=6) in Germany indeed felt very satisfied in this way.

	user Scotland	user Germany
1=very dissatisfied	33,3%	13,8%
2	20,8%	19,0%
3	14,6%	15,5%
4	14,6%	24,1%
5	12,5%	12,1%
6	2,1%	5,2%
7=very satisfied	2,1%	10.3%

Table 7-4: Satisfaction of respondents without work

These results generally indicate that work and employment rank high in people's estimation. Consequently, being without work or employment causes dissatisfaction, which can affect the quality of life in major ways. It may have an impact on general living circumstances and the individual financial basis, it may affect the housing situation and the acquisition of commodities and it may also have an impact on more intangible aspects like self-esteem and mental stability.

In comparison, survey data suggest that Scottish respondents seem more dissatisfied with their situation. A possible explanation is related to the relatively limited scope of opportunity in Scotland. Particularly users of day-care centres from the Offenbach region show a fairly high level of satisfaction with their daily routine and moreover seem to refer to their daily occupation as work in the sense of full or part-time employment, but in a protective environment. This is also evident when looking at satisfaction ratings of those respondents who claim to have a job where the majority in both countries also expressed a relatively high degree of satisfaction.

Those respondents who claimed to have a job, either sheltered or not, were also asked how they feel about their payment. On the grounds that most respondents in both countries work in some kind of sheltered employment and therefore receive very little money (see section on 'therapeutic earnings' further below), the level of dissatisfaction was surprisingly low. This is especially interesting in view of the data presented further below on the financial situation of respondents in both case study localities. Respondents on low income generally expressed dissatisfaction with their financial situation, but apparently the association of work in relation to payment for work seems less disturbing from the perspective of service users. The reasons why, for example, respondents on low income expressed more dissatisfaction regarding their general financial situation rather than in direct association with payment for their work are not entirely clear. It is possible that mental health service users as members of a devalued group of people with limited opportunities (Ramon1991:9ff) have adapted to a traditionally inequitable situation that is, above all, characterised by limited aspirations of those concerned with regard to the payment they receive for (sheltered) work.

However, there is a tendency towards greater satisfaction among German users of employment and work-oriented services, while Scottish users are obviously more dissatisfied with their situation. The results presented here highlight the importance of work and employment and indicate that

satisfaction is dependent on the principal availability of work as well as on the type of tasks. This was also pointed out by research in England (Rogers 1993:101) where criticism concentrated on the tedious, repetitive and boring nature of some tasks but also on the negative effects of unemployment.

7.4.3 EMPLOYMENT, DAY CARE AND QUALITY OF LIFE

In this section the discussion focuses on work and work related activities and their potential contribution to the quality of life rather than on day care in the sense of structured leisure activities and opportunity for communicative and social activities. These subjects are also seen as important elements to community care as has been shown before, but not explicitly addressed here.

It is not new that the availability (or absence) of work can have a major impact on mental health clients' successful rehabilitation (Bennett 1983:15ff, Bennett 1970:225), on the acquisition of commodities and material goods, on mental stability and self-confidence – aspects that can have a major effect upon the quality of life of people with mental health problems (Barry and Crosby 1993, Rogers 1993:91ff, Ramon 1991). These aspects can affect the quality of life in a sense of personal fulfilment and social acceptance, but if opportunities for meaningful daily occupation with adequate financial remuneration (see section on therapeutic earning below) are missing, life may be seen to be more monotonous and boring. The case-study data from both countries suggest that loneliness and boredom are most problematic issues for many respondents and most difficult to cope with (n=15), while in addition financial problems are a source of extreme dissatisfaction and financial security is considered highly important (see section on finances further below).

Generally, the comparison of the data shows that respondents in both countries attach high importance to both, a meaningful daily activity but also financial security, a combination which is usually granted by stable employment. But while work should be recognised as an important component of any comprehensive mental health service (Pilling 1988:196) in Britain, there is criticism that the professional literature and planning discussions tend to focus on such themes as: the problems of providing mental health care; interdisciplinary working in the community; and administrative barriers to the implementation of hospital run-down programmes. Rogers et al. (1993:91) have criticised that little mention is made of employment opportunities, or rather the lack of them. Looking at the positive effects of employment (for example, a structure to one's time, social relationships outside home, personal fulfilment, better social status) or the devastating impact of unemployment (material threat, fading self-confidence, stigmatisation) which has also been confirmed by a number of studies (Jahoda 1981, Warr and Jackson 1985) it seems obvious that the availability - or the lack - of employment affects people's quality of life significantly. While it should not be denied that work itself can also produce pressure and strain, which may be less problematic if support is available according to different levels of need, there is little doubt that the extensive absence of employment opportunities must have adverse affects on people's mental stability and mental health.

The comparison of case-study data has generally shown that diversity and availability concerning opportunities for daily occupation differs widely in both case study localities, which affects service users satisfaction and the quality of life. However, one important issue remains that appears highly problematic in both countries: the common practice of providing therapeutic earnings, which may also have a major impact on the quality of life of mental health service users as will be discussed below.

7.4.4 THERAPEUTIC EARNINGS

The topic of therapeutic earnings is part of this section on work and daily occupation; it is nevertheless an issue which is also relevant to the following section on finances. However, according to causality the issue appears here as work is usually the basis for payment.

In recognition of the fact that work can be of therapeutic value for people with mental health problems, the Governments in Britain and in Germany, through earnings allowances for people in receipt of state benefits and experiencing mental health problems, allow for 'therapeutic earnings'. This is where a person in receipt of higher rate benefits such as Severe Disablement Allowance (SDA), Disability Living Allowance (DLA) or Incapacity Benefit is permitted to earn a specified maximum amount for carrying out work which is deemed to be therapeutic. At present the limitations upon therapeutic earnings are that it should not involve more than sixteen hours a week and remuneration should be less than a figure which was in 1995 £43.60 per week in the Edinburgh case study locality (ECT 1995:90).

The regulations in Germany are quite similar and apart from structural differences, the final outcome for service users is the same: if people receive state benefits[56] they are not allowed to earn more than the permitted amount (therapeutic earning) or otherwise they will lose their benefits. Consequently, payment structures conform to these requirements and are arranged in a way that they do not affect the benefit system. In other words, payment in sheltered work-places is so poor that even if someone was working full-time, the person could never earn enough to make a living. For example, the maximum possible wage in a sheltered

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[56] State benefits are commonly known as *Sozialhilfe* in Germany and mainly include financial support for daily subsistence (*Hilfe zum Lebensunterhalt*) according to national legislation (Bundessozialhilfegesetz-BSHG)

work-place in Germany is similar to Scotland and ranges round about DM 100 (£45) per week.

Clearly, it could be argued that sheltered work-places do not usually operate on an economically efficient basis, i.e. they are more or less state-subsidised and therefore could never pay 'real' wages. But this is not the relevant point. The point of my concern is the diversion of payment through different channels, where those who work in sheltered employment are only allowed so-called 'therapeutic earnings' and receive bits and pieces of their monthly 'income' from different sources.

Current benefit structures in Scotland and Germany ensure that people receive state money for different purposes (i.e. housing, furniture, clothes etc) and sometimes even from different state sources, structures which make a mockery of a policy aimed to enable people to live an ordinary and independent life. For those working full-time in sheltered work the main sources of financial assistance are still state controlled and not 'earned' by work. This reduces the level of control over a 'real' income in direct relation to one's work and keeps people - one must assume deliberately - dependent on the state benefit system.

In view of policy aims like 'independence' and 'ordinary living' it seems contradictory that the state benefit system sanctions work in a sheltered work place by poor payment. These payment structures maintain dependency and furthermore stigmatise the work accomplished in sheltered workplaces, as if it was not as valuable as 'real' work.

At the same time these structures interrupt the move into open employment. Current benefit structures penalise those who attempt to work on a part-time basis instead of encouraging them, by reducing their benefits considerably after reaching a very low level of earned income. This has also been criticised by Ramon (1991:183).

Consequently, every advantage should be taken of schemes which allow a person to earn a full wage instead of government subsidies covering various areas of everyday living separately. This structural disincentive

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needs to be addressed by politicians and policy makers in Germany and in Scotland to facilitate the likelihood of users becoming more independent members of society. Therefore, current legislation and policy guidelines in the countries of comparison require rebalancing or resourcing. Current payment structures focus on therapeutic earnings on the one hand and state benefits on the other and thus increase social exclusion and stigmatisation rather than working against them. Furthermore, since sheltered work is not paid as other work, it is often not seen to be as valuable as other work. While consideration must be given to strategies appropriate to approach the labour market on the one hand, payment regulations for people in sheltered work must change on the other.

Employment, and namely paid work, is a crucial aspect of ordinary living in a society where people are judged by what they do for a living and especially how much money they earn. It is thus also an aspect affecting the quality of life to a great extent. It may affect individual autonomy and self-respect and also the opportunity to access good quality housing and the possession of other commodities and material goods. It may also affect the ability to participate more fully in society, for example concerning social and leisure activities, which has also been indicated by survey results as shown further below.

In overall conclusion of this section on day care and employment the data suggest that the quality of life is positively affected by the availability of a meaningful daily occupation. In this context it appears not important whether this is available in a day-care centre or a sheltered work place. What seems more important is the fact that daily occupation makes sense, provides a level of fulfilment and is properly paid. These aspects seem to be more related to work-oriented activities rather than leisure pursuits and indicate that work is apparently highly valued and generally preferred to other day care activities.

7.5 FINANCES

Given the generally high rate of unemployment among people with mental health problems and the inadequate payment structures related to sheltered work discussed above, it is hardly surprising that the case-study data reflect the experience of living on state benefits and on relatively low income levels. The dependence on income support and the associated stigma on the one hand, but also the pressure of poverty on the other were major concerns raised by service users in Scotland and Germany.

Issues like "a well paid job" or "more money" or "my own bank account" or "regular income" were mentioned frequently (n=26 in Scotland and 39 in Germany) as important aspects by service users in both countries.

In relation to their financial situation respondents in Edinburgh and Offenbach stated their major income source as shown below. In both countries a high proportion of dependency on state support is evident, but also considerable contrast concerning some national particulars as shown in the table below (table 7.5).

Major income source	Welfare benefits (Social Assistance)	Employme nt	Private sources	Old-Age Pension	Employme nt Disability Pension	Sick-Leave Allowance
User Scotland	97,2%	2,8%	_____	_____	_____	_____
User Germany	30,8%	21,8%	12,2%	26,3%	7,1%	1,9%

Table 7-5: Frequency distribution of income sources

The overwhelming majority of respondents in Scotland (97.2%) live on welfare benefits, while the income sources of German respondents are more differentiated. In Germany only one third of the respondents (30.8%) live on state benefits, while almost 35 per cent receive funds from governmental pension schemes. For 21.8% the main source of income was employment while 12% covered their subsistence through private sources.

Looking at the various sources in more detail a major contrast for mental health service users in Scotland and in Germany and their respective financial basis must be seen in the way the social security system is structured. The German insurance and pension system provides alternatives dependent on age or other preconditions, and maintenance may be available through channels associated to differentiated pension schemes. Relevant in the current context is - next to old age pension - a disability pension for people with chronic impairments. The so-called 'employment disability pension' (*Erwerbsunfähgkeitsrente*) is provided on the grounds that firstly, applicants have been in full-time employment (and thus contributed to the state pension scheme on a compulsory basis) for a minimum of 5 years, secondly, this was not more than three years ago and thirdly, future employment is unlikely because of the chronic state of physical or mental impairment.

The survey data show that a comparatively high proportion of German respondents (33.4%) receive a pension, of which 7% is related to employment disability and the remaining proportion to old age pensions.

Generally, the financial situation among survey respondents appears more positive in Germany with almost 22% of the respondents apparently able to live on their income. The survey data show that only 2.8% of the Scottish respondents state employment as their major source of income compared to 21.8% German respondents. This was confirmed by the data on employment presented further below, where - despite a generally difficult situation in both countries - the proportion of German respondents in employment was higher than in Scotland.

Another difference is evident concerning private sources of income or income support. Private sources were further specified in the questionnaire as general savings, but also support by relatives which is not unusual in Germany. None of the Scottish respondents named private sources as an income source, compared to 12.2% of the respondents in Germany. The relatively high level of private financial support in Germany may be linked to the principle of subsidiarity, where families are bound to

support their children before the state security system provides for financial subsistence in case of need (see also Chapter 4).

Respondents in both countries were also asked about the amount of money that is left after they have paid for all living expenses, in other words, money which may be left for leisure purposes. Here, again, a contrast between users living in Scotland and users living in Germany became evident as shown in the table below (table 7.6).

	£< 10/week	£10-49/week	£50-99/week	£>100/week
User Scotland	36,6%	57,7%	5,6%	_____
User Germany	18,3%	42,5%	26,8%	12,4%

Table 7-6: Frequency distribution concerning 'pocket money'

The comparison of Scottish and German income figures can be affected by differences in the general national GDP affecting in turn the expenses for living. However, since the accurate conversion of figures is difficult and complex, the gross comparison of basic monthly living costs (for example, rent and food) suggests that these are broadly similar in both countries; while rents may be somewhat cheaper in Scotland (though not in Edinburgh), food may be cheaper in Germany, however, differences are minor (see also the section on costs for leisure activities below).

The table above shows that the overwhelming majority (94.3%) of Scottish respondents have less than £50 compared to 60.8% of the German respondents, of which a relatively high proportion in Scotland (36.6%) claimed that they have even less than £10 compared to 18.3% in Germany. Only 5.6% of the Scottish respondents claimed to dispose of a weekly amount somewhere between £50 and £99, while none of the Scottish respondents had more than £100 per week. In Germany, however, a quarter of the respondents said they had something between £50 and £99 and 12.4% had even more than a £100 per week to spent on leisure.

A comparison of income sources shows that the amount of money people have is largely related to the main source of their income. For example,

the majority of respondents on welfare benefits in both countries has either less than £10 per week or something between £11 and £50 per week which is left for leisure purposes. Since the latter group was not more differentiated it is not clear whether the majority of this group tends more to the lower or upper half of the scale. However, while the Scottish respondents did not provide significant data on other income sources except welfare benefits, German respondents who receive pensions or others who earn money through employment seem to be generally better off. Respondents in Germany who claimed to have more than £50 or even more than £100 have mainly other income sources than welfare benefits such as pensions, employment or private sources.

7.5.1 FINANCES AND QUALITY OF LIFE

Clearly, there is hardly an objective way to judge what may be the appropriate amount of money one should have left for purposes other than daily subsistence (e.g. leisure, material commodities) but there may be ways of approaching the issue by looking at what the costs for common activities are in both countries. For example, a service user in Edinburgh and a service user in Offenbach would spend about the same amount of money for a cinema outing or a football game or perhaps a drink in a pub or a meal in a basic restaurant. If someone is a heavy smoker the costs for cigarettes often outrun the activities mentioned above in general, but the situation would be even worse for Scottish smokers since costs are much higher in Scotland than in Germany. However, it is not difficult to imagine that enjoying some comforts and leisure activities on £10 per week is not easy, either in Scotland or in Germany. In Edinburgh more than one third of the respondents (36.6%) has to cope with a very low amount of money, while the majority of respondents from Offenbach is somewhat better off and only a smaller proportion - yet still substantial - of 18.3% of the respondents has less than £10 per week to spend.

It needs to be acknowledged that the comparison of gross income data must be seen and interpreted within the wider national context, the national GDP and the average living costs. However, a look at the satisfaction levels in both countries verifies the objective value of aggregate income data against subjective measures. It also allows one to reflect on issues concerning the quality of life of mental health service users in relation to their financial setting.

Obviously, subjective data reflect a situation which is largely determined by objective circumstances, i.e. the amount of money a person has per week, and according to survey results German respondents appear generally more satisfied with their financial situation as indicated by the table below (7.6).

Satisfaction with financial situation	user Scotland	user Germany
1=very dissatisfied	26,4%	19,3%
2	9,7%	6,8%
3	12,5%	11,8%
4	16,7%	17,4%
5	19,4%	14,9%
6	8,3%	14,9%
7=very satisfied	6,9%	14,9%

Table 7-7: Satisfaction of respondents with financial situation

While almost one third of the German respondents indicated a relatively high level of satisfaction and said that they were either very satisfied (14.9%) or satisfied (14.9%) only half of this proportion (15%) fall into this category in Scotland. 6.9% of the Scottish respondents said that they are very satisfied and 8.3% said that they were satisfied with their financial situation. At the same time users in Edinburgh and users in Offenbach also indicate a fairly high level of great dissatisfaction in relation to the very lowest satisfaction ranking. 26.4% of the respondents in Scotland said that they are very dissatisfied with their financial situation, but also 19.3% of the German respondents stressed being very dissatisfied.

A look at satisfaction levels in relation to the income source shows that it is likely that people living entirely on welfare benefits are among those most dissatisfied in both countries. In Scotland 47.1% of the respondents who

receive welfare benefits indicated dissatisfaction on the three lowest levels of which great dissatisfaction was expressed by the majority of respondents (27.1%), while in Germany a slightly bigger proportion of respondents (54.2%) also pointed to the three lowest satisfaction levels. It is nevertheless surprising that a relatively high proportion of respondents in both countries appeared in the medium ranks expressing neither satisfaction nor dissatisfaction (17.1% in Scotland and 22.9% in Germany) while the remaining proportion appeared to be fairly satisfied with their financial situation.

While employment did not play a significant role with regard to the financial situation of respondents in Scotland (only 2 respondents claimed employment as their major source of income), this was different in Germany, where a total of 34 respondents indicated a link (see table 7.4). In Germany the income through employment is not necessarily related to greater satisfaction (26.5% of the respondents with employment said they were very dissatisfied with their financial situation) most likely because day-care centres or sheltered employment does not provide an income level to cover daily subsistence.

It is also interesting to look at the amount of money people have left after they have paid for all living expenses and relate this to satisfaction levels. Naturally, satisfaction with the financial situation is more limited for those who have little money left for leisure purposes, and great dissatisfaction was expressed by the majority of respondents in both countries. 46.2% of respondents who claimed to have less than £10 pounds per week said they were very dissatisfied in Scotland compared to 51.9% of the German respondents in this group who said the same.

The generally higher level of satisfaction among German respondents may be related to two major reasons. First, the objective amount of weekly spending money (for leisure and social activities) is overall higher in Germany compared to Scotland, while the costs of participating in social activities are fairly similar in both countries. Higher income levels in Germany may be related to the different income sources, for example,

insurance benefits such as old age or employment disability pensions, which are usually higher than the average state social assistance. While state social assistance in both countries is just above the national subsistence level and therefore cannot differ widely, the availability of other income sources in Germany offers a more substantial financial background evident in generally higher income rates. Since 33.4% of the German respondents fall into the category of pension recipients, they have usually more money than state social assistance (*Sozialhilfe*) would provide, which may have had an impact on their satisfaction. Another interpretation may be related to the higher proportion of respondents in open labour market employment which may also have influenced satisfaction levels.

Obviously, financial independence and money - or rather the lack of it - must have an impact on the client's quality of life, for example, concerning opportunities to engage in (leisure) activities and participate in social life. In view of the data just presented it is not surprising that the proportion of respondents who said that they feel excluded from social life due to lack of money is higher in Scotland than in Germany. 26.4% of Scottish respondents said they feel very much excluded compared to 12.5% in Germany. On the other end of the 7-item scale the difference is even more obvious. 35% of German respondents said that they do not feel excluded from social activities for lack of financial resources compared to a minority of only 7% of the Scottish respondents who said the same.

Amongst the participants in the group discussions but also with regard to the answers given in the open question section there was a clear understanding that welfare benefit levels were too low and a consequent sense of anger and abandonment pervaded some of the comments. A number of people found that their financial situation was difficult to handle and the context in which this was expressed was often related to a general exclusion from social life and activities and a lack of employment opportunities.

"I often have no money left for the week-end to take my girl friend to the movies" (GDG 4)[57] or "sometimes I just live on cigarettes and coke" (GDG2)

"You can't really make a living if you are dependent on the state" (044)

"No work - no money, but tell me how to find a job these days ?" (GDS2)

"I go to my mum when I need money" (GDS 4)

It can be seen from the data, that the quality of community living with regard to the particular context of participation in social life and activities is dependent on financial resources. Poverty prevents people from access to many ordinary activities and good-quality material possessions, especially those which are desired but not indispensable. A number of points that determine the extent to which people are trapped by poverty have been made by Oliver et al. (1996:90). Two of them are particularly relevant if applied to the situation in the case-study localities. They include the amount of state benefits and restrictive rules concerned with the acquisition of further income from employment of some kind. People who do not have the means to participate in (social) life, and furthermore little chance to acquire such means are disadvantaged in more than one sense: first in a very objective material sense and second in a social and emotional sense; both factors principally affect mental and emotional stability. Material disadvantages tend to accumulate over time and can include poverty, poor housing, homelessness, unemployment or few opportunities for meaningful work and little chance of recreational activities. These issues affect the quality of life in major ways: they prevent independence, i.e. service users are kept dependent on the state benefit system and they do not, therefore, allow a sense of personal freedom and autonomy which usually results from participation in social activities and access to common commodities.

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[57] GDG refers to group discussion Germany while GDS refers to group discussion Scotland

The pressure of poverty has also been highlighted by the study carried out by Rogers et al. (1993:118) and especially welfare benefit levels were a principal source of criticism:

"Terrible – feel like a pauper and degraded, when having to visit the DSS (Department of Social Security). This does nothing for your self-respect. Feel like a scrounger. "(Rogers 1993: 118)

7.6 SUPPORT SERVICES, SOCIAL CONTACTS AND QUALITY OF LIFE

The provision of care and support through specific services are core elements to community care policy and practice development in both countries of comparison, and important service facilities have been developed in significant areas of life such as housing and employment. But support is more wide-ranging than the assessment of facilities: support can be formal and informal, and can include tangible objects (i.e. a service or facility) but also intangible aspects such as emotional security. The following quotations highlight the principal importance of support to people with mental health problems:

"I've lived in hostels and supported accommodation and it took 6 years to get my own flat; if I didn't have the support I don't know where I'd be" (059)

"I believe that my recovery is due to the acknowledgement of my illness and being able with terrific support to cope well. Other people may sometimes lack the means of emotional support " (066)

"Since I got out of hospital it has taken me 5-6 months to manage with everyday life with the help of emphatic support workers" (039)

"I find going to the day centre gives me tremendous boost" (024)

"Most helpful for me is the understanding and kindness of the staff and other patients at the day unit I attend" (028) and "Support with planning how to pay bills etc and to plan social life and work successfully" (068)

"I find my CPN visiting helpful and going to the drop-in centre" (019)

Some negative comments also highlight the importance of support, but refer to problems concerning availability:

"Lack of Stafford Centre not having longer opening hours – Lack of community care and support for all mental health sufferers" (064)

"Not enough places in the community" (005)

" It is all very well to put people in the community but there are only skeleton services available and these tend to be limited" (019)

"When I first came out of hospital I felt neglected and left to fend for myself" (021)

A user quotation cited in a publication by the Scottish Affairs Committee refers to the importance of support on the one hand and the Scottish situation on the other: "Support has to be unobtrusive, but sympathetic to our needs, not their convenience. These care plans are a good idea but a sick joke because the funding for the resources just isn't there." (Scottish Affairs Committee 1995:103)

It has been shown repeatedly in previous sections – especially concerning significant areas of life - that the provision of support is generally important to service users. It is therefore not surprising that the quality of community living is dependent on the availability of support. This section presents the user perspective beyond the support areas introduced before and includes both formal and informal support arrangements, but also social contacts, which are often a major source of support.

In the survey people were asked about their individual support arrangements and the services they were using at the time. The question

With regard to all areas there was overall agreement in both countries that support is generally important to mental health service users as shown in the table below (table 7.8). The three upper levels of the 7-item rating scales have been taken together to illustrate the tendency.

Individual support options	user Scotland	user Germany
supported accommodation	59,1%	57,9%
employment/sheltered w.	63,7%	50,5%
day-care/drop-in centres	78,4%	61,6%
leisure activities	63,9%	55,6%
psychiatric crisis services	62,1%	66,3%
in-patient hospital care	53,8%	69,1%
counselling services	67,3%	67,9%
self help/user groups	65,0%	52,9%

Table 7-8: Importance of individual support service options

While respondents in both countries consider support provision as generally important, Scottish users scored even higher than German users in all areas except one (in-patient hospital care). This difference is difficult to explain since a more detailed account was not obtained in the survey. But a look at the interpretation of the findings presented above in the section on hospital provision and housing (especially hostels) may be useful: data comparison concerning the importance of hospital provision and satisfaction with in-patient care or data concerning housing options suggest that Scottish service users are more critical concerning institutional forms of care than German service users for reasons mentioned above.

Respondents were also asked about their general satisfaction with the support they receive from a) professionals[58] and b) from others[59] as shown in the table below (table 7.9). In both cases respondents in Scotland and in Germany scored more positive than negative yet there are some small national differences, which may be related to the different role attached to family support in both countries (see also Chapter 4).

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[58] This was further specified as including for example social support workers, psychiatrists, nurses, GP's etc.

[59] This was further specified as including for example relatives, friends, neighbours etc

	professional support		support from others	
	user Scotland	user Germany	user Scotland	user Germany
1=very dissatisfied	2,9%	4,5%	10,0%	7,4%
2	5,7%	2,6%	7,1%	6,8%
3	7,1%	7,8%	12,9%	10,1%
4	21,4%	16,2%	21,4%	14,2%
5	18,6%	15,6%	18,6%	12,2%
6	21,4%	27,3%	18,6%	27,0%
7=very satisfied	22,9%	26,0%	11,0%	22,3%

Table 7-9: Importance of formal and informal support

While more than half of the German respondents scored the two upper satisfaction levels on the 7-item scale (53.3%) with regard to professional support and similarly with regard to other support (49.3%) this was different in Scotland. Although Scottish respondents also scored fairly high with regard to professional support (44.3%) they were less satisfied concerning 'other' support and only 29.6% scored the two upper satisfaction levels. As a result Scottish users scored higher on the other end of the scale. Profound dissatisfaction with professional support was low in both countries, while more dissatisfaction was expressed with regard to informal support. It may be possible that the principle of subsidiarity and the traditionally different role of family care in Germany has an impact on this perception. This interpretation may be supported by users' own perception concerning the availability of family contacts. For example, the majority of respondents in both countries said they wish they had more contact with their relatives, but the proportion was considerably higher in Scotland (70.6%) than in Germany (49.7%), while the perception concerning more contacts with others (i.e. friends, neighbours etc) was similar in both countries (50.8% Scottish users and 49.4% German users wanted more contact).

Overall, there was clear evidence that for most respondents in both countries not only support services as facilities but often a specific support worker is most important as some comments illustrate:

"Without the help of the Home Care Team I don't know where I'd be today" (028)

"Having support workers call regularly and help with house chores and bills and appointments" (039)

"Continued consultancy with my GP and psychiatrist" (066)

The quotations indicate that one of the main resources of a mental health service is the people who provide it (i.e. the professional support workers) and furthermore, obviously the quality of the interactions between users and staff. This indication was confirmed by results from another question (Question 28), where users were asked whether they have a person they can trust and confide in and many users reported that a professional support worker is the person to trust and confide in rather than, perhaps, a friend or a relative as will be seen in the section below.

7.6.1 SOCIAL CONTACTS

In many ways social contacts cannot be seen as isolated from support, in fact, social contacts can often provide support and emotional stability. However, social contacts or social networks have generally been recognised as a crucial aspect in the process of de-institutionalisation and community integration especially for people with mental health problems (Holloway and Carson 1996:87).

While social contacts are important to the integration and general well-being of clients in the community, the type and frequency of a person's contacts with other people may provide an indication of the degree of isolation they may be experiencing. This, however, may directly affect the individual quality of life in community settings.

In this survey social contacts were anticipated to include both relatives and other people (e.g. friends, neighbours etc.), but survey results indicated that professionals also play a significant role, at least in the social network of service users, which will be seen further below. The majority of

respondents in both countries confirmed that they had relatives[60], just a small minority (app. 6%) had none.

However, satisfaction with these relationships did not show major differences. In both countries respondents scored rather equally on both sides of the scale with a tendency towards the positive end as shown in the table below (table 7.9).

relationship with	a=neighbours, friends		b=relatives	
	user Scotland	user Germany	user Scotland	user Germany
1=very dissatisfied	7,0%	10,3%	18,2%	11,0%
2	8,5%	10,3%	10,6%	6,9%
3	12,7%	8,3%	9,1%	6,9%
4	19,7%	18,6%	7,6%	19,3%
5	21,1%	11,5%	21,2%	13,8%
6	14,1%	17,9%	10,6%	20,7%
7=very satisfied	16,9%	23,1%	22,7%	21,4%

Table 7-10: Satisfaction with relationships

The table above indicates that only in the case of strong dissatisfaction do Scottish users seem to be less satisfied with their family contacts than German users, which may be related to more limited family links in Scotland previously identified in the section on living circumstances above. The greater dissatisfaction among Scottish service users is also reflected in their wish for more contact as shown in the table below (table 7.11).

	a.) more contact with neighbours, friends		b.) more contact with relatives	
	user Scotland	user Germany	user Scotland	b)user Germany
yes	50,8%	49,4%	70,6%	49,7%
no	49,2%	50,6%	29,4%	50,3%

Table 7-11: Required frequency of contact

While the frequency of contacts concerning other relationships (i.e. neighbours, friends etc.) showed similar results in both countries, differences occur in relation to relatives, where the majority of Scottish users (70.6%) wished to have more contact.

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[60] The term relatives was not further specified and may have included next of kin as well as more distant relatives

The data indeed suggest that family contacts are generally seen as important by the majority of respondents, in spite of sometimes problematic family structures and inherent conflicts as identified in families with members suffering from mental health problems (Laing and Esterton 1964, Dörner 1982)

Overall, respondents appear reasonably satisfied with their social network which is also evident in relation to the following aspect. A high number of respondents in both countries (80% in Scotland and 88% in Germany) reported to have a person to trust and confide in. This person was further specified as being a relative by almost 59% of the German sample, as a friend by 28% and a professional by 21%. In Scotland family contacts again appear to be less intense compared to Germany and a relative as the person to trust and confide in was mentioned by only 31% of the Scottish respondents, while a friend was mentioned by 25%, but a professional by 38%. What is most important and also remarkable is the relatively high proportion of people who indicate that formal carers (e.g. professionals) are particularly important to them. This shows again that support service provision is very important to people with mental health problems, an aspect which has also been pointed out by other studies (Baker et al. 1985, Mercier 1994).

Another aspect in relation to social contacts indicating a certain level of community integration is the involvement in activities[61] outside the home. The table below (7.12) shows that while about one quarter of the respondents in both countries indicated that they rarely or never take part in outside activities another quarter in both countries said that they often did so. The remaining proportion ranged between the two sides of the scale.

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[61] Activities was further specified to include attending social clubs, church, pubs, cinema, dancing, sports etc

Activities outside home	User Scotland	User Germany
1=never	13,9%	13,1%
2	12,5%	11,3%
3	16,7%	15,6%
4	16,7%	18,8%
5	13,9%	13,1%
6	8,3%	11,3%
7=very often	18,1%	16,9%

Table 7-12: Frequency of activities outside home

The level of activity by itself does not provide any indication that may allow one to draw conclusions concerning individual well-being and the quality of life in community settings. And yet what is indeed accentuated is the high proportion of respondents in both countries who wish they had more opportunity to take part in outside activities. A majority of 70% in Scotland and 69% in Germany have clearly expressed this inclination.

Similarly, a great number of people have referred to the subject area of social contacts when asked about the things they find most difficult in their lives. For example, loneliness and isolation have been among the obstacles mentioned most frequently.

There may be various reasons for limited activities ranging from scarce financial resources to limited opportunity of arranged activities. For example, group discussions highlighted the problem that especially in the evenings and at week-ends many service users are left to themselves, but that there was a need for more opportunity to engage and participate in leisure activities. There was a clear understanding that many clients are in need of a supportive framework of organised activities to help them to cope with everyday life and the problems of isolation.

Qualitative data gave evidence that formal and informal support is generally important, but needs to be offered according to different and varying levels of need and individual preferences. Many individual answers provided in the survey referred to issues related to support in one way or another: to the importance of service provision and facilities in significant areas of life, of individual support workers as key persons, of general community care policy and practice and individual expectations or

perceptions in relation to this. Overall, it can be seen that while individual support services are mainly seen to be positive, the entire system is viewed rather critically:

"Care in the community is a headache, more training should have been given before it started to relative departments!" (005)

"Sometimes waiting to see a GP can be a problem as a crisis phase can have come and gone" (014)

"Yes, there should be more awareness of mental health illnesses" (033)

"Things have progressed far too slowly in the area of psychiatry. I only hope that other people's lives in the future will not be totally ruined by bad and wrongful psychiatric treatment" (036)

"I think job centres should give more information to people who need emotional support or sympathetic employers. As yet I find Disability Employment Advisors are not given enough credibility or even that people do not know what help they can give" (065)

"There is a lot to do that people with disabilities can participate in everyday life" (237)

"There should be more public acceptance of people with disabilities" (230)

"In my opinion there should be more campaigning to raise awareness for people with mental health problems"(224)

"Most difficult are the prejudices of so called 'normal' people because lack of information. That is almost unbearable" (213)

7.7 SUMMARY AND CONCLUSION

This chapter has presented the user perspective on community mental health care, especially users' satisfaction with community-based living arrangements and support in the case-study localities. It can be seen from the data presented that the quality of community living for psychiatric patients in both countries is dependent on a number of factors. Important factors are, for example, access to care and support in times of crisis, a sense of choice and control over accommodation, gaining and maintaining employment as a meaningful daily occupation, financial security without dependency. Other empirical studies in Britain and the US (Rogers et al. 1993; Mercier 1994) indicate similar results. The life domains with which people with severe mental disorders express dissatisfaction correspond to the traditional spheres of intervention: housing, employment, principal occupation and leisure, social relations and finances.

Policy analysis in earlier chapters has shown that hospital care is still at the heart of planning and funding in the countries of comparison and analysis of the welfare mix in the case-study localities consequently reflected that acute mental health care is generally provided in mental hospitals or specific wards. The user perspective concerning acute care as presented in this chapter has shown that service users in Edinburgh principally showed a more critical attitude concerning traditional forms of psychiatric care in hospitals and also related issues such as medical treatment, while service users in Germany expressed little criticism, but attached high priority to the availability of hospital based care. This variance may be related to limited information concerning other forms of acute care in non-hospital settings (e.g. crisis centres) among German service users. The rather strong reliance on traditional forms of care among German service users may be sustained by little to no opportunity for participation in mental health care policy planning and practice development as reflected by a generally low level of campaigning activity and user involvement.

The user perspective concerning housing and accommodation indicates that most people with mental health problems in the case-study localities prefer individual forms of living such as supported accommodation in flats and houses. More institutional living environments like hostels appear to be less favoured. The relatively high level of satisfaction with current housing in this study corresponds with other studies (Barry et al. 1993, McCourt Perring 1994; Leff et al. 1994) that have shown that community life is preferred to hospital life (see Chapter 2). Although this study has not gone into more detail concerning specific reasons for satisfaction it is very likely that satisfaction is influenced by aspects highlighted in other studies such as a higher degree of privacy, choice and freedom in everyday life (Rogers 1993:113ff). This has also been indicated by the analysis of the qualitative data, i.e. answers to open questions. Data analysis in the area of housing suggests that the quality of life is dependent on a degree of privacy, autonomy and independence. Furthermore, enforced communality and dependence on strict rules and rigid care regimes are also aspects that influence users' satisfaction and can have a negative impact on their quality of life. Comparative analysis has shown that satisfaction ratings may be influenced by specific national features, for example, the German trend of hostel accommodation.

Comparative analysis of the user perspective in the area of housing has shown that German service users expressed similar criticism with their living situation in hostels than Scottish service users expressed in relation to hospital provision. This is not surprising as similar structures appear prominent in both cases, but paradoxically German service users raised criticism in the area of housing but not in the area of hospital provision. The interpretation of the data suggests that the comparatively strong reliance on medical care and hospital treatment among German service users may be influenced by aspects pointed out before: little general and no official criticism concerning hospital care as the currently most common form of acute treatment in Germany, and therefore a low level of information concerning other alternatives. In contrast, housing alternatives such as supported accommodation are also common in Germany and the

level of information as to what may be more appropriate from the perspective of service users is likely to be higher thus leading to a more differentiated view including the availability for critical assessment.

Employment and work-related activities score high in people's estimation and the data presented in this chapter suggest that in both countries work and meaningful daily activities are seen as important components of community care. While the previous chapter has shown that the options concerning work and day care differ widely in both countries, the data presented in this chapter indicate that satisfaction with the daily routine is higher in Germany than in Scotland. This is likely to be influenced by the wider scope of opportunity for work or work-related activities available to people with mental health problems in the German case-study locality compared to rather limited diversity and also limited availability in Scotland.

Employment and a regular income can be seen as interdependent issues. Therefore it is hardly surprising that the data presented on employment and especially the apparent exclusion of people with mental health problems from the open labour market also reflect that the majority of respondents is dependent on welfare benefits. The findings in respect of the individual financial situation have shown, that the overwhelming majority of service users in the Scottish case-study locality live on state provided social assistance, while the situation in Germany is more diversified also including other income sources like pensions. This may provide a better financial basis to some German service users, since pensions are sometimes higher than social assistance, which may have influenced the higher satisfaction levels among German service users. However, the general tendency in both countries highlights that many service users live on small budgets and perceive their situation as unsatisfactory, and even indicate that they feel excluded from social life through the lack of money. This has a negative impact on the quality of life of service users especially in relation to two major aspects: it generally

affects the acquisition of common commodities and material goods but it also affects personal autonomy, self-respect and independence.

It has been shown in this chapter that the financial situation of many mental health service users is often severely affected by current payment structures (i.e. therapeutic earnings), a problem prevailing in both countries. It has been highlighted that these structures keep people dependent on state benefits and are not affirmative to 'normal' living structures and ordinary living circumstances. These arrangements also affect individual independence and autonomy, and furthermore imply that work in sheltered employment may not be seen as valued as open labour market activities.

Formal support was principally regarded as important by respondents in both countries and a generally high level of satisfaction with professional support services was reported. Service users in both countries clearly indicate that social support is very important and therefore regular contacts with family, relatives and friends is highly valued by a majority of respondents. At the same time contacts with professionals also seem to fall into the category of significant social contacts; the study has shown that professionals in the mental health field are often seen as people to trust and confide in and significantly contribute to service user's social network.

The evidence from this survey indicates that generally in both countries people show a fairly high level of satisfaction even if circumstances are objectively inadequate as, for example, in relation to the financial situation of most people in the study (especially in Scotland) and the poor amount of payment most people receive in sheltered workplaces (in both countries). However, a relatively high degree of satisfaction is commonplace in studies of patient satisfaction with health care and related issues (Kilian 1995). It is possible that the frequent endorsement of positive satisfaction ratings may reflect the effects of institutionalisation and the limited aspirations resulting from this. As Knapp et al. (1992) have reported, people who have spent a considerable time in rule-bound

institutional settings may be reluctant to voice negative opinions about their environment or their care and their responses may not always reflect their personal views accurately. The inclusion of open-ended questions required clients to give more than pre-set responses, thereby counteracting the tendency towards providing a positive answer to many questions. It is also possible that some of the respondents may not have been entirely sure whether the questionnaire was really treated confidentially, since the sample in the present study was approached via service agencies, i.e. usually via staff.

However, it is evident that mental health service users in both case study localities generally regard support as very important, both to improve their general living circumstances and their quality of life. The chapter has shown that in significant areas of life specific aspects are important to enhance the quality of life of mental health service users. They include mainly personal freedom, privacy, a meaningful daily occupation and financial security. Other aspects may affect the quality of life negatively such as a high degree of financial and institutional dependence. Comparative analysis has highlighted both: specific areas and aspects, where national characteristics may have a positive or a negative impact on the quality of life of mental health service users. On the positive side, for example, more diverse employment opportunities exist in Germany, while on the other hand a stronger reliance on institutional structures may be seen as having a negative influence.

In the final chapter the most significant similarities and differences will be taken up again, summarised and reviewed in the light of the quality of life debate and other issues that have been found to be of relevance to further improve the quality of life of mental health service users such as policy objectives and practice development.

CHAPTER 8

SUMMARY AND CONCLUSIONS

This comparative study into community mental health care has attempted a collation of empirical evidence about the living circumstances and especially the quality of life of people with mental health problems in community-based settings in two countries, Scotland and Germany. Based on comparative evaluation, the purpose of the study was to analyse outcomes in community mental health care and identify positive and negative effects of community care policy and practice from a user perspective.

This chapter provides a summary of the main themes and major results of the study that have been examined and discussed throughout the previous chapters. Major effects of community mental health care on the quality of life of mental health service users arise from respective national policy characteristics and – related to this - the developments concerning significant life domains or components of community mental health care (Chapter 5). Before the chapter summarises relevant policy and practice implications, the main findings and conclusions concerning the application of the concept quality of life to this study are summarised below.

8.1 QUALITY OF LIFE: POTENTIAL AND LIMITATIONS FOR THIS STUDY

Theoretical implications concerning quality of life as a concept and tool for measurement have been examined in Chapter 2 and positive as well as negative aspects have been identified.

The concept quality of life has not yet been applied to a study in a comparative context, but to studies in the US (Baker and Intagliata 1982, Lehman et al. 1982) and the UK (Barry and Crosby 1995) as has been examined before. Principally, this study into community mental health care has shown that the concept quality of life can provide a useful theoretical basis to examine the effects of a policy such as community care from a user perspective. It has been seen that the concept is not only useful to assess community living as such, but also the support dimension in relation to it. For example, based on the concept quality of life the evaluation of community based support in significant life areas has allowed the identification of aspects and elements that appear most important to service users' quality of life such as employment opportunities or financial independence.

In the context of this study the concept quality of life has also provided a useful framework for comparative research. The instrument developed for this study on the basis of previous research (Barry and Crosby 1993) includes structural elements that are compatible and therefore useful in a comparative context, at least in countries with a similar economic and cultural background. For instance, the identification of significant areas of life can be seen as a structural element that may not be applicable in any case, but was useful in the present context. The concept was applied in two countries with a similar economic, cultural and historic background concerning the development of community-based mental health care. That means, the wider economic and social structures prevailing in industrial countries of the western hemisphere are similar in both countries and include, for example, the problems associated with unemployment or the dependence on state social security and financial subsistence systems. It

seems important that the application of the concept is broadly based on similar values when attitudes and perceptions should be compared. This has been the case in the present study and findings show that - in overall comparison - similar perceptions and tendencies seem to be prevailing in the countries under comparison, for example, concerning a general desire for social participation (regular income, job, access to material goods etc.). The application of the concept in countries with different economic or cultural structures and wider gaps between what is achievable or available for daily living and subsistence is of course arguable.

Based on the concept quality of life and the theoretical framework especially developed for this research (Chapter 2), the study presents results highlighting specific aspects and issues that affect the quality of life of mental health service users as summarised below. Findings, however, are on a relatively broad basis, which may be seen as a negative consequence concerning the general application of the concept. Criticism concerning the measurement of quality of life has been pointed out before (Kilian 1995) and is discussed again below. On the positive side, however, the findings are useful to highlight broad tendencies as well as general similarities and differences and identify potential and limitations concerning national mental health policy and practice from a user perspective. The findings can be used as a basis for further discussion and development and, furthermore, are a valuable source for more in-depth research.

8.1.1 QUALITY OF LIFE AND SATISFACTION MEASUREMENT

It is recognised that the concept quality of life and especially satisfaction measurement is associated with problems concerning the validity of subjective indices as has been discussed in Chapter 2.

These problems or weaknesses have also been pointed out by other researchers (Kilian 1995, Barry and Crosby 1993). Especially quantitative indices as used by Barry and Crosby (1993) and also in this study do not directly measure issues of personal freedom and autonomy which emerged from the qualitative data as important concepts for service users. In this study an attempt was made to reduce the problems concerning satisfaction ratings and include qualitative measures to validate the subjective data, but overall, the findings of this study show similar weaknesses as the British study by Barry and Crosby, but also similar strengths. Strengths include a relatively short interview schedule with simplified question and response formats for self-completion, adapted for psychiatric clients in two different countries. As has been explained before the present study required a tight instrument for self-completion, applicable to a relatively large sample in two different countries. Therefore, an instrument for quantitative evaluation appeared more appropriate. The results of this study reflect that data collection was successful concerning the measurement of objective indices, while subjective ratings were necessarily influenced by aspects such as a simplified question and response format or general brevity. The data obtained from the questionnaire survey are nevertheless useful for broad comparisons, but show that for more detailed evaluation concerning the subjective assessment of living circumstances and quality of life finer distinctions need to be made. Especially, data on satisfaction need to be more focussed on the subjective interpretation of objective circumstances.

Overall, the present data set is not detailed enough to qualify the problems concerning subjectivity and assess the subjective interpretation of objective circumstances. The questionnaire used in this study includes mainly highly-standardised questions with a fixed set of answers, which offered little opportunity to express a more differentiated view; the major reasons - and potential limits - for this approach have been explained in the methods chapter. While the answers to open questions are more differentiated, the small number of questions together with the general brevity of the issues covered is too limited to provide more detailed results.

However, answers to the open questions are useful for the interpretation of general tendencies and broad comparisons and also beneficial to illustrate tendencies and interpretations thus providing a more lively account of service users perceptions. Generally, it has been shown that highly-structured measures based on a concept such as quality of life provide a basis for gross data for comparison. Findings indicate tendencies and highlight users' preferences and aversions thus providing a useful foundation for focussed in-depth research. Based on the present findings more detailed explanations and reasons could now be obtained by a follow-up study including a smaller sample and more detailed measures.

Altogether, the application of quality of life as a concept and instrument for comparative evaluation for this study has both strengths and weaknesses. Strengths include aspects such as comprehensiveness and a great potential for user involvement, while weaknesses include the problems concerning subjectivity and measurement. Strengths and weaknesses are reflected by the instrument developed for this study and can also be seen from the findings, i.e. comprehensiveness concerning living circumstances and support options on the one hand but relative broadness and little detail concerning the subjective evaluation of objective circumstances on the other.

8.2 POLICY IMPLICATIONS IN COMMUNITY MENTAL HEALTH CARE

Policies on caring for people with mental health problems gradually became more specific during the last decades of the twentieth century in Scotland and in Germany, mainly in response to economic and humanitarian considerations. While similarities are evident concerning the principal move towards community based care and the provision of specialist services (Psychiatrie Enquete 1975, DoH 1989), the prominence

of relevant concepts and themes such as quality of life and the role of service users are dealt with differently in respective national policy. British as well as Scottish policy documents (DoH 1989 1.8, DoH 1994:para 4.5, Lothian Health 1995:25) make ample use of conceptual phrases including a lot of rhetoric and emphasise the important role of service users as participants in policy planning and practice development, whereas in German policies little is said about specific concepts and the role of service users is not considered at all. More detailed comparison of regional and local policy guidelines similarly shows that Scottish policies often include broad rhetoric statements rather than referring to actual need in terms of place numbers, while German policies mainly include details such as place numbers and planning estimates but little rhetoric concerning concepts and ideas. In general comparison, monitoring and evaluation of community care development appears more difficult in Scotland than in Germany, because Scottish policies are comparatively broad and unspecific lacking more definite criteria and realistic targets. Principally positive appears the general tendency to provide a theoretical basis for user involvement and participation in Scotland, a policy objective which has apparently influenced increasing user activity and has provided the basis for the development of user groups and user led services as evident in Edinburgh. This differs fundamentally from the present development in mental health care in Germany, where service users are still more passive recipients of service provision rather than active participants in planning and practice development. Reasons for these differences may be related to respective national policy foundations concerning the delivery of health and social care.

Current mental health care policies and practical outcome are thus influenced by major national differences such as the principle of subsidiarity and a strong medicalisation of care in Germany (Naegele 1992, Dieck 1994) or the increasingly market oriented approach in Britain and Scotland (George and Taylor-Gooby 1996). In Germany the principal of subsidiarity conveys traditional values and responsibilities on the one hand and provides the basis for a relatively uniform network of support

services with little scope for more innovative approaches such as user led services on the other. Policy planning as well as (scientific) evaluation in German mental health care are dominated by professional experts (often from the medical professions) with no user input, whereas in Britain service users are increasingly involved in policy planning and practice development (DoH 1989) not least in response to consumerist approaches (Campbell 1996:220). While this study does not provide data concerning the general success of user involvement and participation in Britain or Scotland, the policy as such seems to provide a useful conceptual basis to overcome traditional arrangements and coercive traditions. However, consumerism and the mixed economy of care can also produce negative features such as diffuse organisational structures (Alcock 1996:86, Petch 1996:5) as evident in scattered networks of care, but have presumably positively influenced the role of service users.

The legal right of service users to contribute to policy and practice development as active participants as set out in British law has probably influenced the widespread presence of active user groups and their representation on national, regional and local level. The formal process, i.e. the implementation of legal rights for mental health service users must therefore be seen as a positive step in Britain. It is a useful and essential basis for the implementation of different, perhaps more democratic structures in community care policy planning and practice development, provided that the views and perceptions of service users are treated seriously and are transferred into practice.

8.3 COMPONENTS OF COMMUNITY MENTAL HEALTH CARE

The implementation of community based mental health care started later and more slowly in Scotland and in Germany in contrast to England. The

difference across Britain is particularly obvious concerning the closure of mental hospitals (House of Commons 1995:vi), while more general policy characteristics, for example, concerning major components of community care show similar properties on national, regional and local level. British as well as German mental health policies cover concepts and themes according to respective national relevance - as summarised above – but provide a similar framework concerning the components of community care. Major components or areas of support service provision - identified in this study as *health, housing or accommodation, employment or day care* - are broadly similar in the countries of comparison, but show distinct characteristics concerning support services and their availability. Other components relevant to this study include *finances, support* and *social contacts.*

Cross-national comparison concerning major components of community mental health care highlights specific national patterns of service provision in Scotland and the regional state of Hesse (Chapter 5) but also on case study level (Chapter 6). The *health* component - defined as including acute care in mental hospitals or specific wards – generally reflects a rather traditional attitude towards mental health care in the countries of comparison indicating that mental hospitals or specific wards are still at the centre of planning and funding. National differences, however, are mainly evident concerning general availability and place numbers for acute psychiatric beds, which are much higher in Scotland than in Germany. *Housing or accommodation* have been central to community based service provision and opportunity ranges from residential care in homes or hostels to supported accommodation in individual flats and houses. While residential care – especially in larger hostels – seems to be outdated in Scotland in favour of more individual forms of housing support, German housing options generally include hostel provision as a major form of service provision. E*mployment and day care* is generally provided in sheltered work-places, training projects or day care centres. In cross-national comparison differences appear concerning the conceptual definition of day care in day care centres and especially the general

availability of sheltered work, which is obviously influenced by the specific national importance attached to work and work-related activities in mental health care. Germany provides a comprehensive network for daily occupation with a clear emphasis on work and work-related activities ranging from *Werkstaetten* to *Tagesstaetten,* whereas Scottish development in this area is less developed and places are few.

8.4 EFFECTS OF COMMUNITY CARE IN SIGNIFICANT AREAS OF LIFE

Comparative analysis of the welfare mix in the case-study localities and analysis of the user perspective concerning community living and support service provision in significant areas of life has highlighted a number of effects that seem to influence the quality of life of mental health service users in the community.

In Scotland and Germany hospital care is still a central element in community based mental health care. The important role of mental hospitals or specific wards for acute care and treatment is evident in most policy documents and consequently reflected by practice development. Comparative policy analysis and practical outcome shows that in both countries acute mental health care is mainly care in hospital settings, usually grounded in the field of orthodox medicine. The implications on the quality of life of mental health service users are similar to those known from the past and institutionalising structures such as more or less coercive living conditions in mental hospitals seem to be common in these institutions as reflected by case study data. Comparative analysis of hospital care in the case study localities emphasises a number of typical features that have a negative effect on the quality of life of mental health service users, for example, the geographical distance between the mental hospital and the general living environment in the German case study

locality or the relatively rigid care regime in the REH. The user perspective concerning acute mental health care reveals a number of aspects which affect the quality of life of mental health service users negatively: for example, limited independence, lack of privacy, a certain level of coercion and control, dependency on care regimes and lack of social contacts.

Comparative analysis indicates national differences concerning the acceptance of alternatives to hospital care. While 'the need for a place of refuge away from their domestic situation and stresses' (House of Commons 1995:viii) in a *non-hospital* setting is officially promoted in Scotland and the Scottish Association for Mental Health (SAMH) spoke of service users' wish to avoid the disruption and stigma of hospital admission (ibid.1995:75), the German mental health debate completely lack coverage of the issue. But despite all rhetoric in Scotland, alternatives to hospital care such as crisis intervention centres (Mosher and Burti 1994:63ff, Stein and Test 1980, Hoult 1986) are not available in practice. This has been criticised on national level by the Scottish Users Conference (SUN 1994:6) who stated that "the actual service provision that is almost universally lacking and universally desired is community based crisis support: Twenty-four hour crisis centres which should be sited in the community" and on local or case-study level by CAPS (1995).

In comparison, criticism of hospital care and the discussion of alternatives seems more widespread in Scotland than in Germany. This is also reflected by the user perspective. Scottish users have expressed more qualitative criticism, for example, concerning the adverse effects of medical treatment and psychometric drugs or the suppression felt by rigid care regimes in hospital settings or by being a mental patient in general; they have also attached less importance to hospital provision than German users. While service users in both countries generally emphasise the importance of acute care and treatment, service users in Scotland have also opted for other forms of acute care such as crisis services. Data generally suggest that German service users seem to rely more heavily on institutional forms of care which may be explained by a lack of critical

involvement in policy and practice development in mental health care that sustains the traditionally passive role of mental health service users in Germany. Furthermore, the level of information concerning alternatives to hospital care such as crisis services is comparatively low among German service users since the official debate does not include these issues and efforts from other quarters, i.e. campaigning user groups or interested professionals, are still marginal. A most interesting aspect for further development is indeed whether hospital provision could be further reduced or even replaced by other services that would provide emergency care and crisis intervention as part of a comprehensive community based support network. The question arises as to whether a psychiatric clinic could generally be replaced by a more homely and friendly setting, because even under the most favourable circumstances, a hospital usually remains a clinical setting with all the associated features. More research into this area would be useful.

In Britain - including Scotland - various forms of supported accommodation have largely outrun residential care in institutional settings such as hostels or homes. In contrast, current German policy recommendations as well as case study data reflect that more institutional forms of care are also common. Although it was officially admitted in Germany that some patients were obviously 'misplaced in homes' (Expertenkommission 1988:74ff), the accommodation of people in homes of considerable size is still one of the major features of current community mental health care in Germany. This situation is increasingly viewed critically by professional experts (Zechert 1996,1997) and also by service users. Especially crucial appears the fact that the German policies provide no recommended limitations concerning size (i.e. place numbers) - despite contemporary understanding that care in larger settlements is usually characterised by institutionalising and hospitalising structures. Hostels of considerable size, for example, 36 places in Offenbach, are still common in German mental health care thus contrasting to developments in Scotland where more individual housing options such as supported accommodation is prevailing.

These differences in housing options appear to have an impact on users' satisfaction and affect the quality of life of mental health service users in the countries of comparison. According to clients' perceptions in both countries individual living arrangements seem to be preferred, while more institutional care settings such as hostels were not favoured by respondents for reasons related to specific limitations: limited privacy, lack of personal freedom, dependence on (rigid) care regimes, control and repression. This has also been found by other research in this area (Ramon 1996a, Rogers et al. 1993).

Overall, data analysis from the case study localities suggests that housing in Edinburgh seems to meet the preferences of mental health service users more adequately, while the emphasis on hostel provision in Offenbach (and generally on region state level) gives reason for concern especially concerning the future development of such housing. Implications for a better quality of life are dependent on flexible services according to individual levels of need and especially services that - while providing support - do not restrict autonomy, privacy and independence. The data show that supported accommodation together with highly individual living arrangements can provide a more suitable basis for independent living than highly structured environments. This requires a housing policy that respects clients' ambition for privacy, dignity and choice according to individual need. The current German housing policy provides only an insufficient basis for this and reasons for this may be similar to what has been said before in relation to hospital care: a comparatively strong emphasis on institutional forms of care dominated by professional power and with no user input, for example, concerning housing options.

Day care and employment opportunities vary greatly in the countries of comparison concerning both concepts and general availability. The comparison of current options and place numbers indicates that German service users can choose from different options especially concerning work-related activities (*Tagesstaetten, Werkstaetten*), but in Scotland

work-related-opportunities are limited and sheltered work places are few, while a scattered network of day care services offers leisure activities and social contacts rather than work. The comparatively diverse network of sheltered employment and work related opportunities in German mental health care has been a principal feature of the initial psychiatric reforms in the Seventies (Psychiatrie Enquete 1975) and the specific emphasis on work as a central element to community care may be influenced by principal German policy foundations (i.e. insurance based health care) which embodies assumptions about the centrality of work.

Comparative analysis of the user perspective concerning general satisfaction with the daily routine and especially the importance attached to the availability of day care and employment suggests that work-oriented services seem to be more preferred to other day-care activities such as occupational therapy or creative tasks. The activities usually available in day-care centres or day clinics in Scotland include mainly creative and therapeutic measures together with opportunity for social contatcs, but seem to meet users preferences not as adequately as German *Tagessteatten* or *Werkstaetten* with their predominantly work-oriented profile.

Despite the general result that German service users are apparently more satisfied with their daily routine than service users in Scotland, a number of general problems and specific shortfalls that may seriously affect independence in community living and the quality of life of mental health clients concerning this significant area of life have been identified. For example, the relative pertinence caused by high unemployment and the lack of alternatives such as sheltered work especially in the Scottish case-study locality. Furthermore, closely connected to employment support are the negative effects of therapeutic earnings (Chapter 7), an issue that is seen with great concern in relation to both countries. Therapeutic earnings keep clients dependent on a support system that is more characterised by state control than by measures to encourage independence and autonomy.

However, transition into and support in mainstream employment is one of the aims of employment rehabilitation services but the issue must be seen in the context of whether it is realistically achievable at present. While some agencies and services aim to assist people back in to mainstream employment (*BBD* in Germany, DEA in Scotland), barriers that often prevent such a transition must be recognised. In an environment of high unemployment, people with mental health problems find it even more difficult to enter the labour market and earn a living. Especially in countries with high unemployment the prospects of employment for people with mental health problems are obviously poor. Thus, there is great need for (policy) measures which support the provision of various options and alternatives, like, for example, the general availability of sheltered work, but also measures which link into mainstream employment. The general comparison of national specifications in this area has shown that in the Scottish case-study locality less availability, less variety and less general emphasis on the vital role of employment is prevailing. On national British level it is surprising that even critical voices, like Rogers and Pilgrim (1996) in their recent introduction to mental health policy in Britain do not address the significance of employment more radically, although they have found that the issues of greatest concern for service users were money, accommodation and a need for employment or occupation, as reported in an earlier publication (Rogers et al. 1993).

Rehabilitation into mainstream society must cover the accessibility of resources available to everyone, and government policies need to provide an appropriate structural background and realistic incentives. The German legislation, for example, has a quota system with the aim to ensure that in factories, companies and businesses of a certain size employers are under obligation to employ a small number of people with disabilities. While this is often seen as an example of 'good practice' espoused by many politicians to put forward a kind of 'social economy', the scheme has obvious limitations. These limitations are evident in elaborate ways to circumvent the legal requirements. For example, some companies rather pay a penalty to the state than fulfil the quota. Similarly, the British

Disability Discrimination Act makes it unlawful for employers to treat a disabled person less favourably than anyone else and requires employers to make a reasonable adjustment to working practices to overcome substantial disadvantage caused by disability. In response to such legal requirements Ramon (1996a:154) has pointed out that "more often than not the state fails to ensure that the law is implemented in the spirit intended, as the lobbying power of people with disabilities is weaker than that of employers". She suggests that unlike housing, employment is not seen as a basic need or a basic citizen's right and concludes that employment is less about freedom from a threat , as housing is, and more about freedom to fulfil oneself, to enhance ones social position and to contribute to society (1996a:148).

Survey results clearly show users preferences and the importance many of them attach to a meaningful daily occupation. This is prevailing in both countries. While threatening issues such as starvation or homelessness may currently not affect the majority of people with mental health problems[62]in the countries under comparison, issues that also affect the quality of life such as personal fulfilment or a better social position are perhaps more subtle threats in countries with relatively high living standards. Consequently, the user perspective indicates that the quality of life is notably influenced by the availability of meaningful daily occupation and also a degree of financial independence which is especially reflected by qualitative data and users' reflections on most adverse or most important aspects to their lives.

Given the generally high rate of unemployment among people with disabilities and furthermore, the common practice to provide 'therapeutic earnings' rather than real wages for work in sheltered workplaces or related services, it is hardly surprising that the survey data reflect that the

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[62] It must be noted that homelessness is an increasing problem among people with mental health problems, see also Fisher, Kevin and Collins, John (ed.). 1993. Homelessness, Health Care and Welfare Provision, London:Routledge

majority of respondents in both countries are living on state benefits. Despite a number of specific national income sources in Germany (e. g. particular pension schemes) which apparently provide more appropriate means for subsistence, overall comparison suggests that respondents who live on state benefits find this very difficult. Data comparison shows that the dependence on welfare benefits affects the quality of life in major ways, for example, concerning the acquisition of common commodities and material goods such as good quality housing and also concerning more intangible aspects such as personal freedom and independence. The effect on self-respect and individual independence is particularly negative if people work part or full time in sheltered work but receive only small payment and continue to live on state benefits.

The comparison of other support services that are available in addition to the major areas of support shows particular national discrepancies concerning two specific services: first, respite care and second, user groups. National policy guidelines in Britain and Scotland highlight respite care as an area where service provision should be available to those in need, and although places are very limited in Edinburgh (3 places) respite care is at least recognised as an important support element, while this is not the case in German policy and practice. Similarly, this can be seen in relation to user groups, where practice development in Scotland - including Edinburgh – shows a growing body of user groups increasingly acting as participants in policy and practice development and also as political campaigners for the further inclusion of service users' views. The general role of service users in mental health care policy as well as major national differences have been summarised in the previous section. The following section provides a final summary of a theme central to this study.

8.5 THE ROLE OF THE SERVICE USER

The national differences concerning the role of mental health service users have become evident throughout this study: first, in relation to policy guidelines and central policy objectives and, second, in relation to practical outcome, e.g. user groups. While service users in Germany have no rights for participation and are thus rather passive recipients of services, users in Britain including Scotland have conceptual and legal rights to participate in mental health care policy and practice. In any case it is important that service users have not only rights for participation but also develop skills and competence to be fully accepted partners when negotiating policies and funding mechanisms.

Research by the Joseph Rowntree Foundation (see Chapter 2) has thus highlighted an issue of importance: that service users needed a range of training and support in order to be fully involved in decision making, for example, by employing experienced user consultants. Caps in Edinburgh is a Scottish example of this kind of support provision, highly valued by local service users. Consultation and advocacy services such as Caps can be seen as being directly supporting the empowerment of people with mental health problems. The development of skills and competence, for example, to participate in discussions and develop a critical attitude towards central themes in mental health care, may be seen as a central contribution of such services to empower people. In addition to policy guidelines and specific objectives it is the availability of such services that provide realistic chances for genuine participation.

Wilson suggests (Wilson 1995:3) that one of the most positive aspects of the health and social service reforms in Britain is the new emphasis on user views. Compared to Germany, where such emphasis is officially non-existent, the British policy appears indeed advanced (see Chapter 4). Hurst (1995:529) even points out that in relation to user involvement the UK may have some messages to give to the rest of Europe. She argues that in many respects, because of the strength of the UK disability

movement, there is a greater awareness of choice and empowerment for disabled people than in any other country in Europe. In relation to comparative research this aspect is particularly significant and comparative studies like the present one may thus contribute to the transmission of concepts and ideas such as user involvement and user participation in mental health care.

8.6 SUMMARY OF MAIN CONCLUSIONS

This study provides an overview on mental health care policy and practice in Scotland and Germany and highlights major effects on the quality of life of mental service users. While comparative data on mental health care policies have started to emerge on a background of increasing interest in comparative research and policy transfer, cross- national data on the quality of life of mental health service users does not exist. Data collation has been comprehensive providing broad findings of policy development and service users preferences concerning the practical outcome of community based mental health care in significant areas of life. For more detailed accounts further in-depth cross-national research is necessary. The study demonstrates the complex national policy foundations and patterns of service provision as well as the interrelationship between policy guidelines and practical outcome.

The study has shown that health care in terms of acute care is important to mental health service users, but especially the Scottish data indicate that acute care in mental hospitals and specific wards is increasingly viewed critically and other alternatives such as crisis centres are favoured. Housing alternatives must include various options according to different levels of need, but generally service users prefer highly individual living arrangements in non-institutional settings; hostels – as commonly

available in German mental health care – are not favoured for reasons related to more or less institutionalising structures such as limited privacy, control and dependence on care regimes. Employment and day care are important support options for mental health service users and especially work-oriented services rather than just day care are generally preferred. Other aspects that have been identified as essential include a degree of financial independence, opportunity for social contacts and the participation in social life in general.

The study has indicated that support services are generally seen as important by mental health service users and can help to avoid or reduce particular threats affecting the quality of life negatively such as loneliness and isolation. Overall, there was widespread agreement among service users in both countries that support service provision is principally valuable, for example, in order to cope with life in general and with mental illness in particular. The results from both countries indicate that support services and often also the individuals - i.e. staff - attached to them are direct contributors to the quality of life of mental health service users.

This study has thus confirmed findings from other studies (Barry and Crosby 1995), that resources are a major issue and that the lack of resources directly affects service users and their abilities to cope with life in general and the problems caused by severe and chronic mental illness in particular. Consequently, a lack of resources or inadequate resources are major factors which affect the quality of life of mental health service users negatively, while services that help and support in times of crisis or general daily living can increase personal independence and freedom, objectives highly valued by service users in both countries. Comparative analysis has shown that particular types of services seem to meet users' preferences more adequate than others as evident in relation to major areas of service provision such as health, housing and employment. A benchmark for adequate service provision can be seen in the contribution of users own views and their involvement in policy planning and practice development.

In practice, the availability of support service provision, i.e. professionally delivered support, is often affected by financial restraints. The current debate in the countries of comparison is characterised by the distribution of increasingly scarce resources that is affecting service provision in mental health care and therefore also the quality of life service users. And yet, funding problems are not a new phenomena and have influenced the social services more or less radically dependent on respective political dispositions. It requires co-operation and co-ordination of users, carers and professionals to forward preferences and concerns on to the public and political agenda and, above all, a strong user movement that is to participate in all areas of concern.

While users' assessment of the quality of services has not been substantial to this evaluation, it is obvious that the quality of services is to some extent related to the quality of life. On a broad basis, this has also been indicated by the data presented in this study, where the contribution of support services to service users' general quality of life was regarded as important. However, both the quality of services and related to this the quality of life is based on the extent to which service users are treated as human beings who have already devised personalised courses of action to fulfil their values and desires. Usually, when it comes to developing such strategies, people with mental health problems have very few means at their disposal and little control over their environment to do so. It is particularly in this context that people with mental health problems in Germany are more disadvantaged than their counterparts in Britain, as has been become clear in relation to the role of the service user in both countries.

The different role of mental health service users in the countries of comparison may be seen as the most remarkable result of this study and, currently, perhaps the most wide-ranging difference affecting further planning, the pattern of service provision and not least the quality of life.

Strengthening the role of the service user in both countries is perhaps the most important task for the future, since involvement and participation are

seen as preconditions for increasing autonomy and independence, and for the development of support and social care (services) harmonising with users needs based on their views and perceptions. It is hoped that findings and issues raised in the context of this study contribute to the debate of community mental health care in the countries of comparison, especially concerning the increasing integration of a user perspective for further policy and practice development.

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APPENDIX

10.1 LIST OF SERVICES

10.1.1 SCOTLAND/EDINBURGH

Atlantic Text, SAMH (Training for Work)

Ballenden House (Day Hospital)

CAPS – Consultation and Advocacy Promotion Service

Craigmillar (Day Care Centre)

Craigentinny Health Project (Day Care Centre)

EAMH - Edinburgh Association for Mental Health (Supported Accommodation)

ECT - Edinburgh Community Trust (Employment and Training Project)

Edinvar (Housing Association, Supported Accommodation)

HCP/HCT - Home Care Project/Home Care Team; Edinburgh (Supported Acommodation)

OTRU – Occupational Therapy and Rehabilitation Unit (at Ballendan House)

Penumbra (Housing Association, Supported Accommodation)

REH - Royal Edinburgh Hospital

SAMH- Scottish Association for Mental Health, Head Office, Edinburg,

The Head Office is mainly functioning as fund-raiser and campaigner, while regional offices also function as service providers (e.g. Atlantic Text is run by SAMH)

Stafford Centre (Day Care Centre)

10.1.2 STADT UND KREIS OFFENBACH

Diakonie - Diakonisches Werk, Offenbach District: Neu-Isenburg, Dreieichenhain (Supported Accommodation)

WH – Wohnheim (Hostel), Offenbach City and Offenbach District: Obertshausen

GPZ – Gemeindepsychiatrisches Zentrum (Community Psychiatric Centre), Offenbach District: Obertshausen und Langen

PSZ – Psychosoziales Zentrum, Offenbach/City

TS – Tagesstaette (Day Care Centre), Offenbach/City and Offenbach District: Obertshausen und Langen

WfB – Werkstatt für Behinderte (Sheltered Employment), Offenbach City

TK – Tagesklinik (Day Clinic), Offenbach City

Stadtkrankenhaus Offenbach, Psychiatrische Klinik (Psychiatric Clinic) Offenbach City

*Philippshospital (*Psychiatric Hospital, Riedstadt)

SPDI- Sozialpsychiatrischer Dienst (Socialpsychiatric Service, Offenbach District)

10.2 QUESTIONNAIRE

Survey on Community Care Experiences

Questionnaire for Clients and Service Users

Please tick the answer you want to give to each question or write in the space provided. All answers will be anonymous and completely confidential. Your help is very much appreciated.
Please complete only one questionnaire.

1. Are you ☐ male ?   ☐ female ?

2. What is your age ? └──┴──┘ years

3. Are you ☐ single ?   ☐ widowed ?
☐ married ?   ☐ divorced ?

Health

4. When did you first have contact with any mental health service ?   1 9 | | |

5. Have you ever been an in-patient in a mental hospital ?   ☐ Yes   ☐ No

> If you have answered yes, please answer questions 6. and 7., if you have answered no please go now to question 8.

6. How long was the longest period (in-patient) you ever spent in a mental hospital ?   _____

7. Do you think that you were/ have been well enough prepared for discharge ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
not well prepared   very well prepared

Please tick one box which most closely reflects your opinion from 1 = not well prepared to 7 = very well prepared

How would you describe

8. your physical health at present ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
poor   excellent

9. your mental health at present ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
poor   excellent

Living situation

10. Where are you living now ?

Please tick only one box

☐ I live in a hostel
☐ I live in a flat/house
☐ I have no place to live
☐ I live in a psychiatric hospital
☐ other : _____

11. Are you satisfied with where (question 10) you are living ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
very dissatisfied   very satisfied

12. Are you living

☐ with your parents/relatives ?
☐ with your wife/husband/partner/children ?
☐ with one or more others/group ?
☐ alone ?
☐ other : _____

13. Are you satisfied with this (question 12) living situation ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
very dissatisfied   very satisfied

Finances

14. At the moment, where does most of your income come from ?

Please tick only one box

☐ welfare benefits (e.g. income support, disability living allowance, housing benefit etc.)
☐ income from employment
☐ private sources (e.g. savings, support by relatives, etc.)
☐ other : _____

15. Once you have paid for all living expenses, how much is left for leisure ?

(e. g. going out, holidays...)

☐ less than £10 /week
☐ £10 - £49 /week
☐ £50 - £99 /week
☐ £100 or more /week

16. Are you satisfied with your financial situation ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
very dissatisfied   very satisfied

17. Do you feel excluded from social life/activities because lack of money ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
yes, very much   no, not at all

Daily occupation

18. Where do you usually spend most of your daytime during the week ?

Please tick only one box

- ☐ at the day clinic
- ☐ at a day care and drop-in centre
- ☐ at work (incl. vocational training)
- ☐ at home
- ☐ at school, college, university
- ☐ at the psychiatric hospital
- ☐ other : _____

19. How satisfied are you with your daily routine ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
very dissatisfied   very satisfied

20. Do you have

- ☐ a full time job/work (incl. vocational training) ?
- ☐ a part-time job/work   (incl. vocational training) ?
- ☐ no job ?

If you have a full time or part time job or please only answer questions 21. and 22a,b,c - if you have no job please only answer question 23.

---

21. If you have a job, is it in a sheltered workplace ?

☐ Yes   ☐ No

22. How do you feel about

22a. your job ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

22b. the people you work with ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

22c. the amount you get paid ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
very dissatisfied   very satisfied

23. If you are not working or studying - how do you feel about it ?
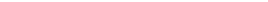
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
very dissatisfied   very satisfied

Support

24. Which of these community support services do you currently use ?

You may tick more than one box

- ☐ supported accommodation
- ☐ employment support/sheltered work
- ☐ day care and drop-in
- ☐ leisure activities
- ☐ psychiatric hospital
- ☐ counselling services
- ☐ self-help and user group(s)
- ☐ other : _____

25. How satisfied are you with the support you receive from

25a. professionals ?
(e.g. social support workers, psychiatrists, nurses, GPs...)

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
very dissatisfied   very satisfied

25b. others ?
(e.g. relatives, friends, neighbours...)

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
very dissatisfied   very satisfied

26. How important is it for you that the following (support) services are available ?

1 = not important   7= very important

26a. supported accommodation
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

26b. employment/sheltered work
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

26c. day-care and drop-in
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

26d. leisure activities
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

26e. psychiatric crisis service
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

26f. in-patient hospital treatment
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

26g. counselling services
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

26h. self help and user groups
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7

Social contacts

27. Do you have any relatives ?
☐ Yes ☐ No

28. Do you have anyone you can trust and confide in ?
☐ Yes ☐ No

29. If yes, who is it ?
(e.g. relative, social worker, nurse, friend...)

_____

30. How satisfied are you with the relationships you have

30a. where you live ?
(e.g. neighbours, friends, people living around you...)
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
very dissatisfied   very satisfied

30b. with your relatives ?
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
very dissatisfied   very satisfied

31. Would you like to have more contact with

31b. neighbours, people living around you ?
☐ Yes ☐ No

31a. relatives ?
☐ Yes ☐ No

32. Do you take part in any activities outside the home ?
(e.g. attend social clubs, church, pubs, cinema, dancing, sports...)
☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7
never   very often

33. Would you like to have more opportunity to take part in activities mentioned above ?
☐ Yes ☐ No

General

34. In general, do you think that you can cope with everyday life ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
not at all   very well

35. What are the things you most enjoy in your life ?

_____

_____

36. What are the things you find most difficult in your life ?

_____

_____

37. What kind of support is most helpful for you ?

_____

_____

38. Is there any particular kind of support you miss in Edinburgh ? If yes, what is it ?

_____

_____

39. What do you consider is necessary to lead a fairly 'normal' life ?

_____

_____

40. Any other comment you want to give ?

_____

_____

THANK YOU VERY MUCH FOR YOUR HELP

10.2.1 USER INFORMATION SHEET

Survey on Community Care Experiences

What is it all about?

This study is concerned with improvements in community care provision for people with mental health problems in two different countries, Scotland and Germany. The area of specific interest in Scotland is Edinburgh, and the research will look at the available services and their impact on service users in the area. Patients/users and professionals across the range of different services (from hospital to various facilities in the community) will be asked to give information about their experiences in their community, to find out what might be missing or what could be organized more effectively. Most of the questions asked deal with aspects of everyday life such as accommodation, day-care and employment opportunities. The research will ask questions regarding your current living situation as well as finding out about what you think could be or should be improved.

The views of service users are particularly important and that is the reason for addressing you.

What next?

If you want to participate in the study please complete the attached questionnaire.

The questions should be easy to complete and mostly you only have to tick the appropriate boxes. A small number of questions (5) are for your written comment to give you the opportunity to express your opinion in more detail. If you have particular questions while completing the questionnaire please contact a member of staff or the person who gave you the questionnaire for advice. You also receive an envelope for the completed questionnaire; please return the questionnaire in the sealed envelope to a member of staff or send it to me directly.

You might be asked at several community support services to complete **this questionnaire** but **please complete only one form.**

If you want more information about the project or have particular questions you

can contact me at the address below. You are welcome to receive a summary of the final results as soon as it is available.

You are free to decide whether you want to participate in this study.

If you decide to complete the questionnaire your answers will be anonymous and completely confidential.

Thank you very much for your help.

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10.3 FRAGEBOGEN

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Umfrage über Gemeindepsychiatrie

Fragebogen für Klienten

Bitte kreuzen Sie das jeweils entsprechende Kästchen an oder schreiben Sie
in die vorgesehenen Spalten. Alle Antworten sind anonym und werden
vertraulich behandelt.
Vielen Dank für Ihre Mitarbeit.

1. Sind Sie   ☐ männlich ?   ☐ weiblich ?

2. Wie alt sind Sie ? |_____| Jahre

3. Sind Sie   ☐ ledig ?   ☐ verwitwet ?
                               ☐ verheiratet ?   ☐ geschieden ?

Gesundheit

4. Wann hatten Sie zum ersten Mal Kontakt mit
einem psychiatrischen Dienst/einer
psychiatrischen Einrichtung ?   1   9 |_____|

5. Waren Sie schon einmal in
stationärer psychiatrischer   ☐ Ja   ☐ Nein
Behandlung ?

Wenn Sie die letzte Frage mit ja beantwortet haben, dann beantworten Sie bitte die Fragen 6 und 7, wenn
Sie mit nein geantwortet haben, dann gehen Sie bitte zu Frage 8.

6. Wie lange dauerte Ihr
längster Aufenthalt in einer
psychiatrischen Klinik ?   _____

7. Sind Sie der Meinung,   ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
daß Sie gut auf Ihre   nicht gut   sehr gut
Entlassung vorbereitet
wurden ?   Bitte kreuzen Sie das Kästchen an, das Ihrer Ansicht
                                     am nächsten kommt (1 = nicht gut, 7 = sehr gut)

Beschreiben Sie bitte Ihre
gegenwärtige

8. körperliche Gesundheit   ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
                                     schlecht   hervorragend

9. psychische Gesundheit   ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
                                     schlecht   hervorragend

Wohnen

10. Wo wohnen Sie zur Zeit ?

Bitte nur ein Kästchen ankreuzen

☐ in einem Wohnheim
☐ in meiner eigenen Wohnung/Haus
☐ Ich bin ohne festen Wohnsitz
☐ in einem psychiatrischen Krankenhaus/Station
☐ Sonstiges : _____

11. Wie zufrieden sind Sie damit, wo (Frage 10) Sie wohnen ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr unzufrieden   sehr zufrieden

12. Leben Sie

☐ mit Ihren Eltern Eltern/Verwandten ?
☐ mit Ihrem/Ihrer (Ehe) -partner/in und/oderKindern ?
☐ mit anderen zusammen ? (Wohngruppe, Wohngemeinschaft)
☐ allein ?
☐ Sonstiges : _____

13. Sind Sie mit dieser Wohnsituation (Frage 12) zufrieden ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr unzufrieden   sehr zufrieden

Finanzen

14. Was ist zur Zeit Ihre hauptsächliche Einkommensquelle ?

Bitte nur ein Kästchen ankreuzen

☐ Sozialhilfe (z. B. auch Wohngeld, Arbeitslosenhilfe usw.)
☐ Arbeitseinkommen
☐ private Quellen (Ersparnisse, Geldmittel von Eltern od. Verwandten etc.)
☐ Sonstiges : _____

15. Wenn Miete, Umlagen, Lebensmittel etc. bezahlt sind, wieviel bleibt Ihnen für Freizeitaktivitäten ?

(z. B. Kino, Ferien, Kneipe...)

☐ weniger als DM 25,- /Woche
☐ DM 25,- bis 99,- /Woche
☐ DM 100,- bis 200,- /Woche
☐ DM 200,- oder mehr /Woche

16. Wie zufrieden sind Sie mit ihrer finanziellen Situation ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr unzufrieden   sehr zufrieden

17. Haben Sie häufig den Eindruck, aufgrund von Geldmangel ausgeschlossen zu sein (z. B. von Freizeitaktivitäten) ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr häufig   nie

Alltagsgestaltung

18. Wo verbringen gewöhnlich Sie die meissten Tage während der Woche ?

Bitte kreuzen sie nur eine Aussage an !

☐ in der Tagesklinik/Beschäftigungstherapie
☐ in der Tagesstätte
☐ an meinem Arbeitsplatz
☐ zu Hause
☐ in der Schule, Universität, Weiterbildung usw.
☐ in der Psychiatrischen Klinik
☐ Sonstiges _____

19. Sind Sie zufrieden damit, wie Sie Ihren Alltag verbringen ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8
sehr unzufrieden   sehr zufrieden

20. Haben Sie

☐ einen Vollzeit-Arbeitsplatz (z.B. auch WfB) ?
☐ einen Teilzeit -Arbeitsplatz (z.B. auch WfB) ?
☐ keinen Arbeitsplatz ?

Wenn Sie einen Vollzeit- oder Teilzeitarbeitsplatz haben, beantworten Sie bitte die Fragen 21. und 22.a,b,c; wenn Sie keinen Arbeitsplatz haben, beantworten Sie bitte die Frage 23.

21. Wenn Sie einen Arbeitsplatz haben, ist es ein ' Beschützter Arbeitsplatz ' (z. B. WfB) ?

☐ Ja   ☐ Nein

22. Wie zufrieden sind sie
22a. mit ihrer Tätigkeit ?
22b. mit ihren Kollegen/innen ?
22c. mit ihrem Einkommen ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr unzufrieden   sehr zufrieden

23. Wenn Sie keinen Arbeitsplatz haben (und kein Schüler/Student sind) - wie zufrieden sind Sie damit ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr unzufrieden   sehr zufrieden

Unterstützung und gemeindepsychiatrische Dienste

24. Welche der genannten Dienste nehmen Sie zur Zeit in Anspruch ?

Sie können mehrere Antworten ankreuzen !

☐ Betreutes Wohnen
☐ Werkstatt für Behinderte
☐ Tagesstätte
☐ Psychosozialer Dienst (PSD)
☐ organisierte Freizeitaktivitäten
☐ stationäre Behandlung
☐ Psychosoziale Beratungsstelle
☐ Selbsthilfegruppen
☐ andere : _____

25. Wie zufrieden sind sie mit der Unterstützung durch

25a. professionelle Helfer ?
(z.B.Sozialarbeiter, Psychiater, Pflegepersonal, Therapeuten...)

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr unzufrieden   sehr zufrieden

25b. nicht-professionelle Helfer ?

(z. B. Freunde, Verwandte, Bekannte...)

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr unzufrieden   sehr zufrieden

26. Wie wichtig ist es für Sie, daß die folgenden gemeindepsychiatrischen Dienste zur Verfügung stehen

1 = nicht wichtig   7 = sehr wichtig

	1	2	3	4	5	6	7
26a. Betreutes Wohnen	☐	☐	☐	☐	☐	☐	☐
26b. Werkstatt f. Behinderte (WfB)	☐	☐	☐	☐	☐	☐	☐
26c. Tagesstätte	☐	☐	☐	☐	☐	☐	☐
26d. Organisierte Freizeitgestaltung	☐	☐	☐	☐	☐	☐	☐
26e. Krisendienst(e)	☐	☐	☐	☐	☐	☐	☐
26f. Psychiatrische Klinik	☐	☐	☐	☐	☐	☐	☐
26g. Beratungsstellen	☐	☐	☐	☐	☐	☐	☐
26h. Selbsthilfegruppen	☐	☐	☐	☐	☐	☐	☐

Soziale Kontakte

27. Haben Sie nähere Verwandte ?   ☐ Ja   ☐ Nein

28. Gibt es jemanden, dem Sie vertrauen können ?   ☐ Ja   ☐ Nein

29. Wenn ja, wer ist es ?
(z. B. ein Freund(in), Kollege(in), Verwandte, Krankenschwest, -pfleger, Arzt)

_____

30. Wie zufrieden sind Sie mit Ihren Kontakten

30a. dort, wo Sie leben/wohnen ?
(z. B. Nachbarn, Freunde, Menschen die um Sie herum leben...)

☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7
sehr unzufrieden   sehr zufrieden

30b. zu Verwandten ?

☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7
sehr unzufrieden   sehr zufrieden

31. Hätten Sie gerne mehr Kontakt

31a. in Ihrer Nachbarschaft und unmittelbaren Umgebung ?   ☐ Ja   ☐ Nein

31b. zu Verwandten ?   ☐ Ja   ☐ Nein

32. Unternehmen Sie viel in Ihrer Freizeit ?
(z. B. Kino, Theater, Bücherei, Disco...)

☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8
nie   sehr oft

33. Würden Sie sich wünschen, häufiger solche Möglichkeiten (Frage 32) zu haben ?   ☐ Ja   ☐ Nein

Allgemein

34. Finden Sie, dass Sie im Grossen und Ganzen gut mit den alltäglichen Anforderungen zurechtkommen ?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7
sehr schlecht   sehr gut

35. Was geniessen Sie am meissten in Ihrem Leben ?

_____

_____

36. Was finden Sie am Schwierigsten in Ihrem Leben ?

_____

_____

37. Welche Art von Unterstützung ist für Sie besonders hilfreich ?

_____

_____

38. Gibt es irgendwelche Hilfsangebote oder gemeindepsychiatrische Dienste, die Sie in Stadt und/oder Kreis Offenbach vermissen ? Wenn ja, welche ?

_____

_____

39. Was, glauben Sie, ist notwendig, um ein 'normales' Leben zu führen ?

_____

_____

40. Möchten Sie abschliessend noch etwas hinzufügen ?

_____

_____

Herzlichen Dank für Ihre Mitarbeit !

10.3.1 KLIENTENINFORMATION

Info zum Fragebogen über Gemeindepsychiatrie

Worum geht es?

Der beiliegende Fragebogen gehört zu einer Studie, welche die gemeindepsychiatrische Versorgung in der BRD und Grossbritannien (Schottland) untersucht . Die Regionen von besonderem Interesse sind die Stadt und der Kreis Offenbach in Deutschland sowie die Stadt Edinburgh in Schottland. Im Rahmen einer Fragebogenaktion werden Patienten/Klienten und Mitarbeiter in beiden Regionen um ihre Erfahrungen und ihre Sichtweise zur 'Psychiatrie in der Gemeinde' und zum 'Leben in der Gemeinde'gebeten. Ziel ist es herauszufinden, was verbessert werden sollte.

Die Sichtweise von Betroffenen ist dabei besonders wichtig und deshalb bitte ich um ihre Mitarbeit beim Ausfüllen des Fragebogens.

Wie geht es weiter?

Wenn Sie an der Umfrage teilnehmen möchten, dann füllen Sie bitte den beiliegenden Fragebogen aus.

Die meisten Fragen sind durch Ankreuzen eines entsprechenden Kästchens zu beantworten; nur die letzten fünf Fragen erfordern eine schriftliche Beantwortung und sollen Ihnen die Möglichkeit geben, Ihre Meinung etwas ausführlicher darzustellen. Wenn Sie während des Ausfüllens Fragen haben, wenden Sie sich bitte an einen Mitarbeiter der Einrichtung, in der Sie den Fragebogen bekommen haben. Mit dem Fragebogen erhalten Sie einen Umschlag; den verschlossenen Umschlag mit dem ausgefüllten Fragebogen geben Sie bitte möglichst bald an einen Mitarbeiter dieser Einrichtung zurück. Der Fragebogen wird dann an mich weitergeleitet. Leider kann ich für mögliche Fragen und zusätzliche Informationen nicht persönlich zur Verfügung stehen, weil diese Fragebogenaktion von Schottland aus durchgeführt wird. Sie können mir aber gern an die unten angegebene Adresse schreiben, wenn Sie mehr über diese Untersuchung wissen möchten oder an einer Zusammenfassung der Ergebnisse interessiert sind.

Sie werden möglicherweise in verschiedenen Einrichtungen gefragt,
ob Sie **diesen** Fragebogen ausfüllen möchten, aber bitte füllen Sie
nur einen Fragebogen aus.

Vielen Dank für Ihre Mitarbeit.

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10.4 EXPERT INTERVIEW GUIDE

A. Service related

1. Please describe this service/organisation/agency (e.g. number of visitors, users and number and qualification of staff, opening hours, source and security of funding, scope of activity, theoretical concept/policy, major potential of the service, major problems...

2. What do you think should be improved ?

3. What are the most positive features the service can offer ?

4. What are the major problems this service is suffering from or facing ?

5. Any other issues you find of relevance for consideration ?

B. General

What would you think are the major problems people with mental health problems face in the community ?

What would you think must be improved in relation to community based care in Edinburgh/Offenbach ?

What kind of service provision is not available in Edinburgh/Offenbach or where do you perceive severe shortages ?

What would you consider as very advanced or positive in terms of support for people with mental health problems in your locality ?

What do you think about community care

a.) in general and

b) in relation to your locality ? (e.g. major problems, measures for improvement...etc)

10.5 GROUP DISCUSSION GUIDE

General

What do you know about community care (*Gemeindepsychiatrie*) ?

What kind of services and/or other support do you currently use ?

What kind of support and service provision is most important for you ?

What kind of support and /or service provision is currently not available but important for you ?

Health

Where do you go when you feel that you are in need for acute care and treatment ?

What kind of service is necessary to provide care and support in times of acute psychiatric crisis ?

Housing and Accommodation

What kind of accommodation should be available for people with mental helath problems ?

What are the housing options currently avaiable for you ?

What kind of housing alternative is most favoured or considered as being most suitable for you ?

Employment and Day Care

Where do you usually spent your day ?

Would you like to go to work ?