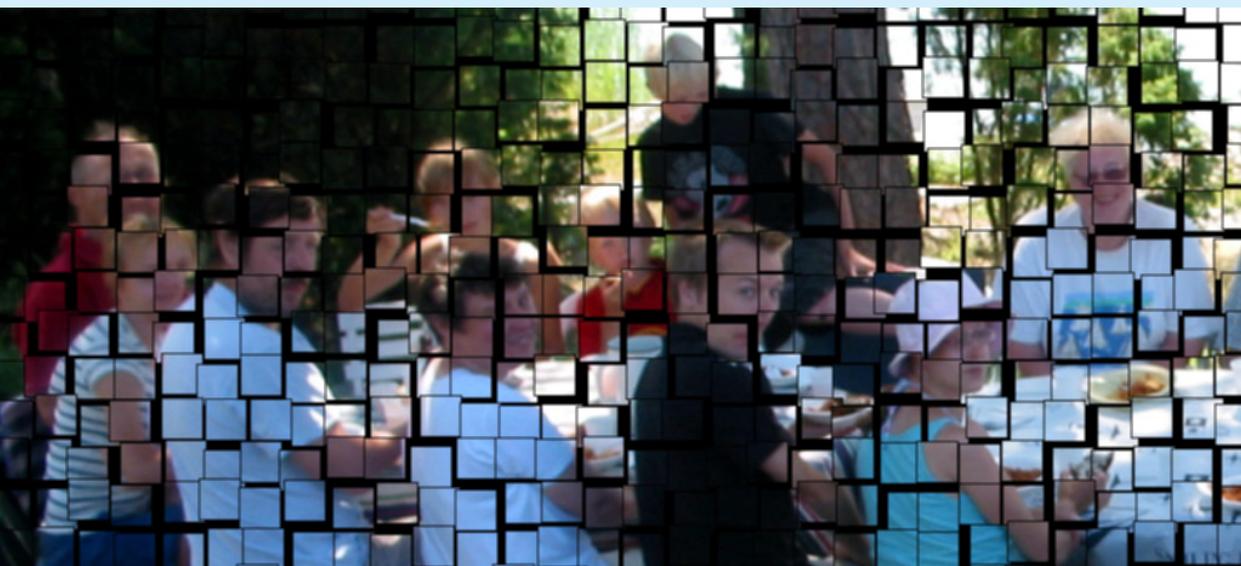


The goal of social integration is part of the ideological motivation behind the transition from institutionalised to decentralised psychiatric care. Modern community mental health care considers social integration vital for improving mental health. However, efforts to reach this goal have not been as successful as anticipated.

The study aimed to achieve a deeper understanding of the phenomenon of social integration of people with mental health problems in the community, and to develop the healthcare professionals' insight into this phenomenon by means of co-operative inquiry.



The findings showed that the neighbours reported frightening behaviours as well as complications in their contact with people who had long-term mental health problems, and the reaction was exclusion and segregation. The user perspective revealed that, when meeting people, the participants experienced shame and fear of exclusion due to lack of acceptance and loss of autonomy. Lack of work or a meaningful occupation and a low income contributed to a sense of worthlessness and loneliness. In order to achieve social integration, a person with long-term mental health problems needs to develop adequate social competence.

The co-operative research project enabled co-researchers to gain increased professional knowledge and awareness, as well as providing potential for improvements in clinical practice.

# SOCIAL INTEGRATION FOR PEOPLE WITH MENTAL HEALTH PROBLEMS

## Experiences, perspectives and practical changes



Arild Granerud

Doctoral thesis at the Nordic School of Public Health,  
Göteborg, Sweden, 2008

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**Hedmark University College**  
Faculty of Health  
and Sports

Social integration for people with mental health problems:  
Experiences, perspectives and practical changes

Doctoral thesis in public health

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## ABSTRACT

**Background:** The goal of social integration is part of the ideological motivation behind the transition from institutionalised to decentralised psychiatric care. Modern community mental health care considers social integration vital for improving mental health. However, reports suggest that efforts to socially integrate people who suffer from mental health problems have not been as successful as anticipated.

**Aim:** The overall aim of the study was to achieve a deeper understanding of the phenomenon of social integration of people with mental health problems in the community. An additional aim was to develop the healthcare professionals' insight into this phenomenon by means of co-operative inquiry. The specific research questions were: How have people with mental health problems affected their neighbourhood after re-establishing in the community? How do people with mental health problems experience social integration in the community? How does knowledge of social integration promote practical changes in mental health professionals' practice?

**Methods:** This study, which comprises four papers, has a hermeneutic design. The data collection methods took the form of interviews with 19 neighbours of group homes for people with mental health problems (Paper I) and focus groups in two separate studies of people with mental health problems, one of which comprised 12 participants in three groups (Paper II) and the other 17 participants in three different multistage focus groups (Paper III), i.e. a total of 14 focus groups. Paper IV utilises findings from Papers I-III by means of a co-operative approach. There were two areas of knowledge development in the research process: dialogue-based teaching and focus groups. The main emphasis of the dialogue-based teaching was to facilitate the articulation of practical and tacit knowledge. Twenty-two healthcare professionals and social workers participated in two different multistage focus groups, a total of 6 focus groups (Paper IV). Data-analysis methods included both the constant comparative process and qualitative content analysis.

**Findings:** The first paper begins with the experiences of neighbours of people who suffer from mental health problems. The neighbours reported frightening behaviours as well as complications in their contact with people who had long-term mental health problems, which led to increased insecurity and fear. The reaction of the neighbourhood was exclusion and segregation in the form of distancing or watching. The next two papers employed a user perspective and revealed that, when meeting people, the participants experienced shame and fear of exclusion due to lack of acceptance and loss of autonomy. Integrity proved a necessary quality for the possibility to be treated as an equal. Lack of work or a meaningful occupation and a low income contributed to a sense of worthlessness and loneliness. Those who had a job or took part in club activities seemed to achieve social companionship, which gave them a sense of being more socially integrated. The co-operative research project enabled co-researchers to gain increased professional knowledge and awareness, as well as providing potential for improvements in clinical practice. Systematic reflection on practice leads to an increased awareness of one's own attitudes and intervention methods, societal conditions and the community's attitude to the increased social integration of people with mental health problems. The experiential knowledge gained may contribute to health-promotion strategies such as social integration.

**Conclusions:** Integration difficulties are experienced by both individuals with mental health problems and their neighbouring community. In order to achieve social integration, a person with long-term mental health problems needs to develop adequate social competence. Those working in community mental health care must ensure that people suffering from mental health problems experience a sense of belonging in the community, which can enable them to develop a network and achieve social integration in the planning and development of day-time activities and work, thus promoting social integration. The neighbourhood requires, at the very least, general information when a group home is established. Co-operative inquiry can be beneficial in the public sector, although in order to achieve the best possible result, the whole team must be involved and play an active role in all areas of the research project. If the groups are too large, the participants' level of engagement may suffer. Multistage focus groups proved to be a powerful method for knowledge acquisition and should be further developed as a means of expanding new knowledge.

**Keywords:** Community mental health work, social integration, social network, qualitative methods, co-operative inquiry.

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## SAMMENDRAG

**Bakgrunn:** En viktig ideologisk motivasjon for overgang fra institusjonalisert til desentralisert psykisk helsearbeid er målet om sosial integrering. Moderne lokalbasert psykisk helsearbeid anser sosial integrering som avgjørende for å bedre menneskers psykisk helse. Men rapporter viser at mennesker med psykiske problemer ikke har oppnådd tilfredsstillende sosial integrering.

**Mål:** Det overordnede målet for studien var å oppnå en dypere forståelse av fenomenet sosial integrering for mennesker med psykiske problemer i lokalsamfunnet. Et tilleggsmål var å utvikle helse- og sosialarbeideres innsikt i fenomenet med bruk av handlingsorientert forskningssamarbeid. De spesifikke forskningsspørsmålene var: Hvordan har mennesker med psykiske problemer påvirket deres nabolag etter reetablering i lokalsamfunnet? Hvordan erfarte mennesker med psykiske problemer sosial integrering i lokalsamfunnet? Hvordan kan kunnskap om sosial integrering fremme praksisforandringer for psykisk helsearbeidere?

**Metode:** Denne studien, som omfatter fire artikler, har et hermeneutisk design. Metodene for datainnsamling var kvalitative intervjuer med 19 naboer til fellesboliger for mennesker med psykiske problemer (Art. I), og fokusgruppeintervjuer, i to separate studier, med mennesker med psykiske problemer. En studie med 12 informanter i 3 fokusgrupper (Art. II) og en studie med 17 informanter i 3 flersteg-fokusgrupper (Art. III), totalt 14 fokusgruppeintervjuer. Art. IV brukte funnene fra Art. I-III i et handlingsorientert forskningssamarbeid. Det var to former for kunnskapsutvikling i forskningsprosessen: Dialogbasert undervisning, som skulle fremme praktisk og taus kunnskap, samt fokusgruppeintervjuer. 22 helse- og sosialarbeidere deltok i 2 flersteg-fokusgrupper, totalt 6 fokusgruppeintervjuer (Art. IV). Datamateriale ble analysert med Grounded Theory og kvalitativ innholdsanalyse.

**Funn:** Naboer til fellesbolig for mennesker med psykiske problemer beskriver i den første studien opplevelser som gav usikkerhet, skremmende adferd og problemer med å få kontakt med menneskene som hadde alvorlige psykiske problemer. Dette ledet til økt usikkerhet og frykt. Nabolaget reagerte med eksklusjon og segregering. De to neste studiene hadde et brukerperspektiv, og viste at informantene opplevde skam og frykt for eksklusjon som en følge av manglende akseptasjon og tap av autonomi i møte med mennesker. Integritet var en nødvendig forutsetning for å bli møtt som likverdig. Mangel på arbeid eller annen meningsfull dagaktivitet, samt lav inntekt, bidro til en følelse av verdiløshet og ensomhet. De som hadde et arbeid eller var aktiv deltager i klubbvirksomhet fikk et sosialt felleskap som gjorde at de kjente seg sosialt integrerte. I siste studie gav handlingsorientert forskningssamarbeid medforskerne økt profesjonell kunnskap og bevissthet, samt potensiale for å forbedre praksis. Systematisk refleksjon på praksis leder til en økt bevissthet for egne holdninger og interveneringsmetoder, sosiale betingelser og lokalsamfunnets holdninger til økt sosial integrasjon for mennesker med psykiske problemer. Økt kunnskapsdannelse i praksis kan bidra til forebyggende helsearbeid som sosial integrering.

**Konklusjon:** Både mennesker med psykiske problemer og deres nabolag erfarte vanskeligheter med integrering. For at mennesker med alvorlige psykiske problemer skal erfare sosial integrering må de ha tilstrekkelig sosial kompetanse. Det må arbeides for at mennesker med psykiske problemer opplever tilhørighet i lokalsamfunnet, noe som kan sette dem i stand til å utvikle nettverk, og få til sosial integrering i planlegging og utvikling av dagaktiviteter og arbeid, og på den måten fremme sosial integrering. Nabolag bør i hvert fall ha generell informasjon når det etableres fellesboliger. Handlingsorientert forskningssamarbeid kan være gunstig i kommunehelsetjenesten. En forutsetning for et best mulig resultat er at hele team blir involvert og deltar i kunnskapsskapningen i praksis. Blir enhetene som deltar for store, blir det ikke noe eierforhold til forskningssamarbeidet. Flersteg-fokusgruppeintervju viste seg å være en god metode for kunnskapsutvikling, og metoden burde utvikles videre.

**Nøkkelord:** Psykisk helsearbeid i kommunehelsetjenesten, sosial integrering, sosialt nettverk, handlingsorientert forskningssamarbeid, kvalitativ metode.

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## ORIGINAL PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:

**I** Granerud A. & Severinsson E. (2003). The new neighbour: Experiences of living next door to people suffering from long-term mental illness. *International Journal of Mental Health Nursing*; 12 (1) 3-10.

**II** Granerud A. & Severinsson E. (2003). Preserving integrity: Experiences of people with mental health problems living in their own home in a new neighbourhood. *Nursing Ethics*, 10, (6), 603-614.

**III** Granerud A. & Severinsson E. (2006). The struggle for social integration in the community – the experiences of people with mental health problems. *Journal of Psychiatric and Mental Health Nursing*, 13, 288-293.

**IV** Granerud A. & Severinsson E. (2007). Knowledge about social networks and integration: A co-operative research project. *Journal of Advanced Nursing*, 58, (4), 348-357.

Permission for using the articles in this thesis has been granted by the publishing companies.



## **PREFACE**

Mental health work is an important and interesting field. My pre-understanding has developed as a result of many encounters with people with mental health problems and conversations with professionals in the field. An education in mental health nursing and experience of psychiatric nursing and community mental health work, followed by a career as a teacher of mental health studies – totalling over 25 years experience of mental health – have given me insight into the importance of social integration.

During my years as an academic, I have had the pleasure of conducting research. It was important for me to focus on research questions related to individuals' experiences. I also found it important to research the phenomenon of social interaction to find solutions for people with mental problems. There is a clear need for more knowledge. Mental health problems can be approached from a health perspective or an illness perspective. I lean towards examining mental health from the former viewpoint and, more specifically, as a public health issue. Public health and nursing science have several scientific aspects in common: the problem area (the phenomenon focused upon), the theoretical framework (how one describes and understands the problem area) and the scientific methods employed. Medical tradition differs in its theories, models and scientific methods. I was educated in the psychiatric nursing tradition. Over the years, Public Health research, specifically in the area of mental health and social integration, has become more important to me, especially public health science and patients' reactions to illness. As a consequence, I have adopted the public health and nursing science approach as opposed to the psychiatric (medical) tradition. This has provided me with an opportunity to investigate more deeply and develop thoughts on people with mental health problems. I wanted to learn about their daily life and experiences of social integration in the community. Nursing science, in its essence, is the study of the relationship between patients and health care personnel. As this thesis focuses on public health, nursing science will be only briefly outlined.

Social networks and a feeling of belonging in one's environment or with one's friends and family are important for good mental health and quality of life. People with mental health problems have difficulties in attaining a better life,

often experience problems with self-esteem and relationships with other people and are more likely to suffer a relapse if their social network is lacking in size or support. They may experience difficulties making friends because of problems reaching the arenas in which interaction generally takes place due to the fact that people are uncertain how to act towards persons with mental health problems. Mental health workers are aware of many different intervention strategies and techniques for improving people's social networks, but seldom use them. Emphasising the social networks of people with mental health problems and our strategies for helping them to develop social contacts will facilitate professionals in using these intervention methods in a more effective way. Developing specific local strategies can be particularly effective in communities.

Arild Granerud  
Hamar, Norway, February 2008

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# 1 INTRODUCTION

Modern community mental health care considers social integration and a satisfactory social network vital for improving mental health (Bengtsson-Tops, 2001, Magnusson, 2003). The reorganisation of mental health care has changed the everyday lives of people suffering from mental health problems in several ways; they now live in their own homes with professional support and opportunities to participate in ordinary life or arranged activities in the community.

Mental health problems accounted for 12-15 % of the total illness in the world in 2000. They are the most widespread form of illness, twice as common as cancer and more frequent than cardiovascular diseases (Thorncroft & Tansella, 2003; WHO, 2005). A meta-analysis estimated that about 27 % of the adult population of the European Union are, or have been, affected by a mental disorder in the past 12 months, yet only 26 % had consulted the professional health care service (Wittchen & Jacobi, 2005). The World Health Organisation (2001b) estimated that mental health problems and neurological disorders are the cause of 31 % of all disability in the world. In the EU, mental health problems account for, on average, 3-4 % of the GNP, mainly through loss of productivity. Only 24 % of adults with long-term mental health problems are in the work force, and too many spend their time inactive and alone (Office of the Deputy Prime Minister, 2004; Commission of European Communities, 2005; Jané-Llopis & Anderson, 2005). In Norway, 20 % of health service expenditure is allocated to mental health problems (Ministry of Health and Care Services, 2003).

The care of individuals with mental health problems has undergone significant changes in terms of organisation and government policy throughout the Western world with the result that most treatment for such users is provided by community health care (Commission of European Communities, 2005).

The reorganization of mental health care has been especially evident for patients with long-term mental problems (Forsberg, 1994; Erdner et al., 2002) and has changed the everyday lives of people suffering from mental health problems in several ways. The main objectives of deinstitutionalisation are empowerment, reduction of discrimination and stigma, enhancement of individual social ability and the creation of a system of social support (WHO, 2001b). The following

components have been revealed by previous research as important for achieving this goal: independent housing, meaningful daily activity, social reintegration in the community and opportunities for cultural and spiritual stimulation (Hansson et al., 2002; Evans, Wells, & Moch, 2003). The promotion of mental health and the social inclusion of mentally ill individuals are important for quality of life.

Of central importance to the expansion of mental health care in communities in Norway is the “*National Program for Mental Health 1999–2006*” (The Norwegian Social and Health Department, 1998), the aim of which is to strengthen the psychiatric healthcare system. The goals of the Program can best be realised by addressing basic needs such as housing, work related activities as well as social, cultural and spiritual stimulation (The Norwegian Social and Health Department, 1998). However, resources are limited and the past two decades have witnessed a debate between those who favour hospital treatment and those who advocate mental health services in community settings. Nevertheless, despite the evidence that a middle alternative, based on a balanced care model combining community and hospital services, may be beneficial in practice (Thorncroft & Tansella, 2003), new models of social integration in the community have not been successful (Bengtsson-Tops & Hansson, 2001).

The link between social isolation and reduced well-being is well established (Kawachi & Bekman, 2001). It has been argued (Forsberg, 1994; Aubry, Tefft, & Currie, 1995; Barham & Hayward, 1995; Brandt, 1996; Breakey, 1996; Johnstone, 2001) that this reorganization that brings people with mental health problems and the community closer together creates new systems of stigmatisation, branding and exclusion. Stigma can be defined as a mark of shame, disgrace or disapproval, which results in exclusion from parts of society. It is important to reduce stigma in order to prevent segregation and discrimination in the allocation of housing (WHO, 2001b). People with mental health problems wish to live in housing similar to that of the general population; however, a very low income hinders their ability to achieve this (Lambert et al., 2000).

In this thesis, the concept “mental health problems” includes both severe and long-term conditions. Mental health problems can be both a cause and a consequence of social exclusion (Office of the Deputy Prime Minister, 2004). Such problems are present in all cultures, but take their outward expression and causal explanations from the cultures and societies in which they occur (Hummelvoll & Barbosa da Silva, 1994). Mental health problems manifest themselves in the form of deviating behaviour as well as through thought patterns, emotional expression or ways of speaking which are difficult to understand, or which in some other way place the individual outside the social context in which he or she naturally belongs. The condition can appear suddenly and end completely after a short time, or develop gradually over time and remain a long-term problem (Office of the Deputy Prime

Minister, 2004). The central definition of the term ‘mental health problems’ is the individual’s experience of his/her condition as a difficulty in or obstacle to everyday life. It is the individual’s understanding of him/herself and his/her relationships with other people as well as feelings and thoughts that usually impair functionality and create the symptoms. The most common understanding of the development of mental health problems involves: (1) vulnerability factors; (2) stressors (life events); (3) coping strategies and (4) protecting factors (e.g. social networks) (Haugsgjerd, Jensen, & Karlsson, 1998). People with mental health problems are believed to have difficulties in carrying out everyday activities and establishing satisfactory interpersonal relationships and consequently, to suffer from social isolation (Cullberg, 1999; Erdner et al., 2002; Nilsson, 2004).

Counteracting loneliness and achieving social integration present a great challenge for people with mental health problems (Fisk & Frey, 2002). In the western world, a range of structured services is common as a means of preventing isolation and promoting integration (Kilian et al., 2001). Inadequate social networks have an adverse effect on the outcome of these challenges (Bengtsson-Tops, 2001). Without an intervention in the form of individual support and daily activity, those suffering from mental health problems may deteriorate, due to their vulnerability and difficulty integrating into the community (Seikkula, Alakare, & Aaltonen, 2001a).

Although a great deal of research has been carried out on social networks related to people with mental health problems, it is lack of a deeper understanding of the mechanisms involved. It is important to attempt to understand how people with mental health problems experience their daily life – particularly in terms of social integration and social networks – as a result of the recent reforms within mental healthcare in Norway. It is also essential to try to gain an understanding of how neighbourhoods view these new residents. Increased knowledge of how the integration process affects the neighbourhood can help us improve the chance of successful social integration for people in the process of moving into their own homes after institutionalisation or a rehabilitation program. Increased knowledge in this area will lead to greater public awareness and openness. In this study ‘neighbourhood’ is an umbrella term for the various physical and social aspects of a local environment and includes, among other things, community and commercial services and access to outdoor activities. Community mental health work focuses on persons suffering from mental health problems, as well as on the consequences of these problems for the person involved and his/her family or network. There is a need for a stronger emphasis on the connection between social networks and functioning in the case of people with mental health problems.

## **1.1 Description of the main concepts:**

### **Social integration and social network**

Social integration can be viewed as one of the ideological foundations behind the development of decentralised mental health care (Bengtsson-Tops, 2001). Generally, the treatment of people with mental health problems takes place in the community, and social integration is vital for enhancing mental health (Ramon, 2001). Social integration can be defined as “*a process which leads to the association of various social entities (individuals, groups, cultures, nations)*” (Korsnes, Andersen, & Brante, 1997, p. 288) or from an individual perspective, as participation in a broad range of social relationships (Cohen, Gottlieb, & Underwood, 2001). Integration implies co-ordination into a single unit and is derived from the Latin word integer, which means “whole” or “undiminished”. Social integration indicates that the individual is part of a united society (Barstad, 2000). In this study, social integration is defined as: *Participation in the community and local environment while maintaining one’s own culture and integrity. It is a subjective feeling of belonging to and being part of society.*

Integration in the socio-cultural sense denotes maintaining one’s own cultural identity while becoming part of a larger unit of society (Dalgard, Døhlie, & Ystgaard, 1995). In concrete terms, social integration is associated with, for example, feelings of belonging and being able to influence one’s surroundings and the degree of contact with others in the local environment (Hummelvoll, 2004).

Social network participation can indicate social integration. Relationships assessed in a typical social integration measure included spouse, close family members, friends, and members of the local community. The more types of relationships people reported, the greater their level of social integration (Cohen et al., 2001).

Other concepts closely related to social integration are the more descriptive concepts of social exclusion and inclusion (Bertram & Stickey, 2005). Sayce (2001) highlights the interactive relationship between impairment and social role and its association with social exclusion:

*“...the interlocking and mutually compounding problems of impairment, discrimination, diminished social role, lack of economic and social participation and disability. Among the factors at play are lack of status, joblessness, lack of opportunities to establish family, small or non-existing social networks, compounding race and other discriminators, repeated rejection and consequent restrictions of hope and expectation” (Sayce, 2001, p. 122).*

This definition is similar to descriptions of stigmatisation (McKeown & Clancy,

1995; Lambert et al., 2000; Johnstone, 2001). The relationship between social exclusion and mental health problems is complex. Having a mental health problem is closely related to social exclusion, while the factors leading to the latter can be causal as well as the consequences of such a problem (Sayce, 2001; Bertram & Stickey, 2005). The description of outsiders and insiders is similar to that of border-residences (Drevdahl, 2002) and liminality (Warner & Gabe, 2004).

Two social network research perspectives are predominant in the field: 1) the ego-centred network where the focus is at the micro-level and on the life of an individual, known as personal network analysis; 2) the socio-centred network, otherwise known as a partial or total network analysis where the focus is on social processes and a group of individuals (Fyrand, 2003). In this thesis, the focus is on the ego-centred network. The idea that social networks are of great significance for the individual is supported, in part, by two notions: the stress-buffering and the direct hypothesis. Reviews indicate that social support protects people from the negative psychological consequences of life stress (Cohen et al., 2001). Integration in a social network may also give rise to a psychologically positive state, including a sense of purpose and belonging, as well as security and recognition of self-worth (Kawachi & Bekman, 2001). In general, social networks are considered to affect mental and physical health due to their influence on emotions, cognition and behaviours. They are also presumed to provide a generalized positive effect in the form of stability and predictability, a sense of belonging, a recognition of self-worth, and true ability to meet normative role expectations (Cohen et al., 2001; Commission of European Communities, 2004). In this study, the following definition of social network has been developed based on the sub-studies and the literature review on social network: *The people who fulfil the individual's essential need for feelings of companionship and social integration along with emotional contact and support, as well as practical help and advice.*

The study of Alameda County in the USA (Berkman & Syme, 1979) was one of the first to demonstrate the relationship between mortality and social networks. People with good social networks lived longer than those with weak social networks. Social support has been consistently shown to act as a protective factor in a variety of health outcomes (Whitley & McKenzie, 2005). Previous research has revealed a strong relationship between social network and functioning in the case of people with mental health problems. Thus, new research should focus on interventions that can enhance social life satisfaction among this group (Bengtsson-Tops & Hansson, 2001; Evert et al., 2003).

The size of the network is significant for increased activity and functionality among people with psychotic disorders, as a better social network raises the functional level (Howard, Leese, & Thornicroft, 2000). Efforts to widen one's

network and make it more socially active are important for managing mental health problems and having an ordinary working life or protected employment (Eide & Røysamb, 2002; Evert et al., 2003). Studies show that groups that both work together and have regular contact outside of working hours positively affect the development of independent activities and create bonds with other people (Howard et al., 2000). Poor health and inadequate income are barriers that hinder participation in activities and increase social isolation and exclusion, as well as social and personal devaluation (Barstad, 2000; Ramon, 2001). People with mental health problems may encounter negative reactions from acquaintances and society in general, thus making social integration more difficult to achieve. Several studies have shown that increased closeness between people with mental health problems and other population groups give rise to new forms of segregation (Forsberg, 1994; Aubry et al., 1995; Barham & Hayward, 1995; Aubry & Myner, 1996).

A social network can either be supportive or non-supportive. One of its positive functions is social support (Dunbar, Ford, & Hunt, 1998), which refers to the provision of psychological and material resources intended to empower an individual to cope with stress (Cohen et al., 2001). Social support can be described as the interactive process by which emotional, instrumental or financial aid is obtained from one's social network (Olstad, Sexton, & Sjøgaard, 1999). Previous studies have provided evidence of the important role of support in cases of psychological distress (Hardiman & Segal, 2003). Key dimensions of social support are the size and membership of a social network (Hansson et al., 2002). Studies suggest that smaller social networks or less social support is associated with more frequent hospitalisation (Albert et al., 1998).

Without intervention in the form of individual support and daily activity, those suffering from mental health problems may deteriorate, since they are vulnerable and have difficulty integrating into the community (Seikkula, Alakare, & Aaltonen, 2001b).

## **1.2 Structure of the thesis**

After this introduction and the presentation of the aims and design of the thesis, a theoretical background will be outlined. Here, a public health perspective and the mental health reform in Norway are briefly described, followed by a review of previous research on mental health problems in the community and one of social network interventions used in relation to community mental health care.

In the methodology section, descriptions of a hermeneutic perspective are provided, and some of the core concepts explained. Since co-operative research

is based on building knowledge in the local “community”, where dialogue-based teaching is central, one way of understanding knowledge is described. Ethnography and co-operative inquiry, as developed in this thesis, are outlined in greater detail. Methods of data collection (individual interviews, focus group interviews and multi-stage focus group interviews) and data analysis (Grounded Theory and qualitative content analysis) are also presented in this chapter. The main results of each paper are presented in the summary of findings.

The interpretation and general discussion are structured in line with the three research questions. A model that summarises the analysis of the experiences contained in the two Papers (Papers II and III) and that describes people with mental health problems is also discussed. This is followed by the conclusions.

### **1.3 Aims and research questions**

The overall aim of the study was to achieve a deeper understanding of the phenomenon of the social integration of people with mental health problems in the community. An additional aim was to develop healthcare professionals’ insight into this phenomenon by means of co-operative inquiry.

The specific aims of the empirical sub-studies were:

To illuminate:

- how people with mental health problems affect their neighbourhood after re-establishing themselves in apartments of their own (Paper I).
- how people with mental health problems experience living in their own home, with focus on their psychosocial contacts with their neighbours (Paper II).

To investigate:

- how people with mental health problems experience their ability to integrate socially into a community (Paper III).
- how knowledge of social networking and integration gained by means of co-operative inquiry influences mental health professionals’ understanding and practice (Paper IV).

The specific research questions were:

- How have people with mental health problems affected their neighbourhood after re-establishing in the community? (Paper I).
- How do people with mental health problems experience social integration in the community? (Papers II and III).
- How does knowledge of social integration promote practical changes in mental health professionals’ practice? (Paper IV).

## 1.4 Design

The specific focus was on people with mental health problems in their home environment after the mental health reforms in Norway. Understanding of their social integration was used in dialogue-based teaching programs and to provide guidance for mental health work in the community.

The study was a two-part process. The first comprised a descriptive, exploratory and theory-generating approach using qualitative methods, while the second consisted of a co-operative approach, in which findings from the first part were employed (see Figure 1, p.13). The work on the thesis began with qualitative research interviews (Kvale, 1997) with 19 neighbours of people with mental health problems in order to illuminate if and how people with long-term mental illness affect their neighbourhood after re-establishing themselves in apartments of their own (Paper I). The next objective was to gain an understanding of how people with mental health problems experience living in an apartment of their own. The data collection method was focus-group interviews (Maunsbach & Dehlholm-Lambertsen, 1997) with 12 people with mental health problems in three groups from various municipalities in central Norway (Paper II). These two papers were followed by an investigation of how people with mental health problems experienced their ability to integrate socially into a community in central Norway (Paper III). Three multi-stage focus groups (Morgan, 1997; Hummelvoll, 2007b), consisting of 17 people with mental health problems, were set up in two different sized municipalities. In this sub-study, the intention was to obtain a broader and deeper picture of social integration for people with mental health problems after the community mental health reforms. Therefore, the municipalities differed to those in Paper II, and a multi-stage method was used.

In the final part, a qualitative sub-study with a co-operative action research approach (Reason, P, 1994; Hummelvoll & Severinsson, 2005) based on knowledge of social integration, was employed. Action research has the potential to facilitate changes in the field. The sub-study (Paper IV) investigated how knowledge of social network and integration gained by means of co-operative inquiry influenced mental health professionals' understanding and practice in two municipalities, one rural and one urban. There were two areas of knowledge development in this research process: dialogue-based teaching and focus groups. The sub-study was part of a four-year research collaboration project entitled "*Promotive and preventive mental health care in the local community*" between two municipalities and Hedmark University College.

Grounded Theory (Glaser & Strauss, 1967; Starrin & Renck, 1996; Hartman, 2001; Hallberg, 2002) was considered suitable as the method of data collection and analysis in two of the sub-studies (Papers I and II), since its aim is to understand the subjective meaning of an individual's reality. As Grounded

Theory is generated from and grounded in empirical data, it was important to be open to supplementary questions that arise during the data collection. The method contributed to clarification of the underlying subjective empirical experiences of people with mental health problems, which concern relationships with their neighbours, previous experiences and challenges encountered in their life situations. In the final two sub-studies (Papers III and IV), a qualitative content analysis (Denzin & Lincoln, 1998; Graneheim & Lundman, 2004) was used. These two sub-studies build on the knowledge from sub-studies I and II. Qualitative content analysis has been found to be a suitable method for co-operative inquiry (Hummelvoll 2006). The data analysis involved interpretation of the meaning and function of social integration in a local community (Paper III) as well as participation as a co-researcher in the co-operative inquiry program in the two municipalities (Paper IV).

The sub-studies in Papers I-III provided an inductive updated understanding of social integration in local communities for people with mental health problems, on which the co-operative research in Paper IV was built. Inductive reasoning, which involves moving from specific observations to broader generalizations and theories, can be described as a "bottom up" approach. This inductive reasoning began by interviewing neighbours. The resulting local knowledge acquired in both parts of the study has the potential to become central through the interpretation and use of the results in the development of a theoretical pattern (Alvesson & Sköldbberg, 1994).

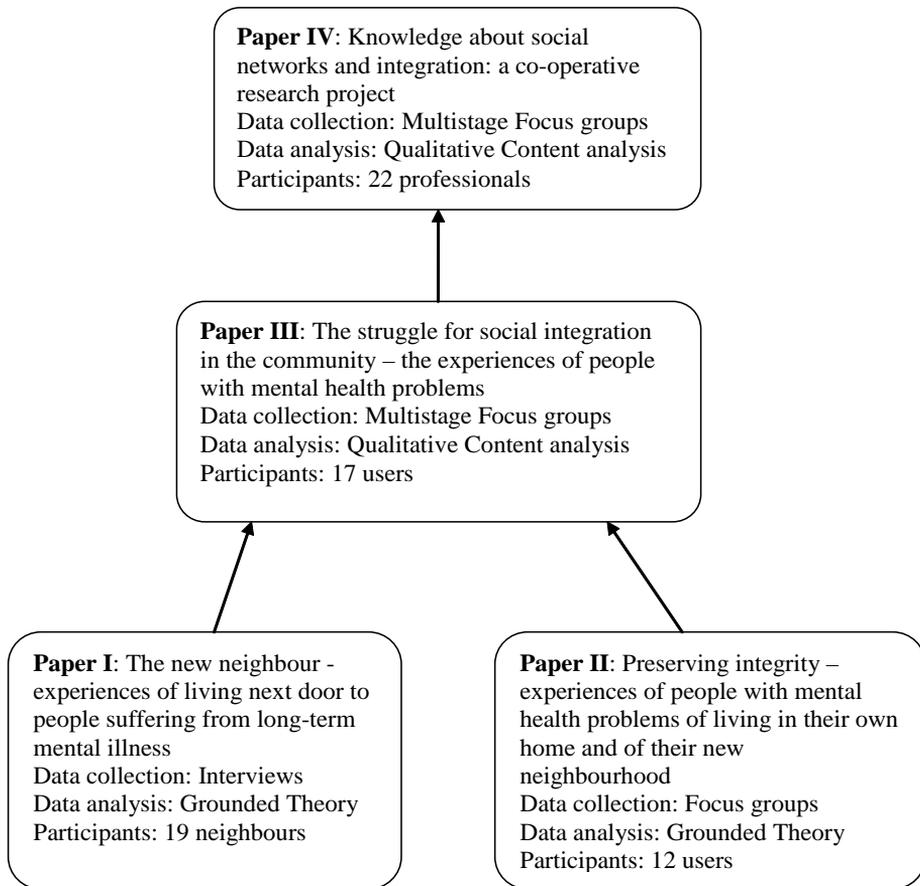


Figure 1: Development of the research process

## **2 THEORETICAL BACKGROUND – THE PUBLIC HEALTH PERSPECTIVE**

### **2.1 The public health perspective**

Public health is complex and can be divided into two areas of interest: social and economic causes of health and illnesses and the medically-focused perspective. Traditionally, public health has been associated with the investigation of various causes of health and disease (Karlberg, Hallberg, & Sarvimäki, 2002). A broader perspective, known as ‘new public health’ has recently been introduced (Beaglehole & Bonita, 2004). New public health is based on the WHO’s constitution and focuses on resources and health protection. It emphasises a positive and resource-oriented approach and places greater emphasis on living conditions and inequalities, as well as on the links between public health, policy and programmes. It emerged as a result of the recognition that major health problems cannot be solved by medical care alone. *“Public health is the collective action taken by society to protect and promote the health of entire populations.”* (Beaglehole & Bonita, 2004, p. xi). It also includes socio-structural theories as well as a variety of research methods.

The public health perspective involves reducing risk factors and strengthening those which tend to improve or maintain health. Positive factors are, among other things, the supportive aspects in our environment, our relationships with those closest to us and the social networks to which we belong. Another strong positive factor is our perception of life as meaningful, predictable and manageable (Antonovsky, 1996). These protective or empowerment factors endow people with the strength to withstand stress (Ministry of Health and Care Services, 2003).

Promoting mental health and the social inclusion of mentally ill individuals are important issues for quality of life (Commission of European Communities, 2005). A multi-faceted strategy to ensure accessible care and treatment, interventions to promote mental health and reduce stigmatisation as well as support for the human rights of people with mental health problems are all necessary (WHO, 2005). Without intervention in the form of environmental and individual support,

there is a risk of social isolation for people with mental health problems when they move into their own home (Nilsson, 2004).

Health can be regarded as an ‘investment-factor’ for quality of life. Public health work is directed towards promoting good physical health, in part by influencing living conditions and habits. However, it should also provide more support for mental health by encouraging empowerment, self-respect, human dignity and security, in addition to a sense of being respected and acknowledged. This perspective is broad and even includes the foundations of health. Health promotion simply means placing emphasis on the equitable distribution of that which forms the foundations of health (Beaglehole & Bonita, 2004). The aim of Norwegian health policy is to contribute to more years of life and contribute to good health among the population as a whole as well as to reduce differences in health between social groups and genders (Ministry of Health and Care Services, 2003).

Traditionally, public health policy, public health work and public health research have been closely linked (Diderichsen & Westrin, 2005). Public health research was defined as follows by an international research group (Kamper-Jørgensen et al., 2005, p. 46):

*“Public health research generates and systematizes knowledge about the health of the population, as well as the factors which influence public health and its distribution. It studies and evaluates measures aimed at the preservation and improvement of the health of the population. Studies of the significance of societal structure, working life, environ, health behaviours and healthcare systems for population health are in focus.”*

The link to epidemiology has always been strong, but as can be seen in the definition, public health research has opened up, not only to health prevention and promotion, but also to research on health work. A public health framework offers a promising opportunity to build new paradigms that incorporate and expand on social and behavioural science acculturation theories and cross disciplinary boundaries. The above definition is based on a broad concept of health, as in new public health, and includes the monitoring and surveillance of the health of the population as well as health service research (Kamper-Jørgensen et al., 2005).

Mental health can be described as a state of well-being in which the individual makes use of his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to contribute to his or her community (WHO, 2001a, p. 1). Mental health is an essential factor in the realisation of individual intellectual and emotional potential as well as for the fulfilment of an individual’s role in social and working life (Commission of European Communities, 2005). Mental health promotion means taking action to increase

well being and mental health among individuals and populations and involves promoting the value of mental health and improving the coping capacities of individuals (WHO, 2002).

Mental health problems are a major public health concern, as they affect a large proportion of the population and have a strong effect on the individual, the family and the local environment. Mental health problems lead to difficulties at work and in everyday social life. The burden borne by family members of people with mental health problems ranges from financial difficulties to emotional reactions, stress, and limited social activities (Ministry of Health and Care Services, 2003).

Mental health was the special topic of the World Health Report in 2002. Entitled *New Understanding, New Hope* (WHO, 2001b), it highlights the stigmatisation of, and discrimination against, people with mental health problems and demonstrates the importance of working actively with social integration and social networks. In order to create equal opportunities for all members of society, the principle of social integration must be incorporated into all major public interventions related to disability issues. Paragraph 9 of the United Nations' Declaration on the Rights of Disabled Persons states that disabled persons have a right to live with their families and to participate in all social activities (United Nations, 2003). Strategies for preventing mental health problems and promoting health emphasise the importance of strengthening the individual's sense of self-direction, social support and belonging, as well as his/her feeling of being useful, of being capable of taking responsibility for him/herself and making use of his/her own resources. A well-functioning social network and sense of social belonging are essential for quality of life and the prevention of mental health problems (Kawachi & Berkman, 2001). Becoming an active participant in the social environment, such as in a club or the workplace, provides a feeling of belonging. This belonging –i.e. membership of a group, a shared culture, the possibility to take part in new groups and to experience common support – is extremely important for creating a positive outlook on the future and recovery (Bengtsson-Tops, 2001; Hardiman & Segal, 2003).

Mental health nursing, can be based on an existential concept, where the focus is on understanding people with mental health problems in relation to their life context and trying to grasp what effects mental health problems have on their ability to function. A holistic existential model of mental health nursing is based on the assumption that nursing should be grounded in respect for the person's integrity and autonomy. This is a non-reductionistic view of man as indeterministic, multidimensional and humanistic (Lindström 1992, Hummelvoll 1994). This view is grounded in hermeneutics and can be considered from a public health perspective.

## **2.2 Mental health reform: The situation in Norway**

In Norway, as in other western countries, people with mental health problems are mostly cared for in their own homes (Forsberg, 1994; Hobbs et al., 2000). However, the movement towards home care in Norway began somewhat later than in comparable countries (The Norwegian Social and Health Department, 1998). The National Programme for Mental Health called for major investments as well as the expansion and reorganisation of services. The programme aimed at strengthening the service users' position, increasing public awareness of mental health issues through information programmes, strengthening community based services provided by the local councils and municipalities (including prevention and early intervention), expanding and restructuring specialised services for adults, expanding specialised services for children and adolescents, improving labour market services, assisting with accommodation and housing, and stimulating education and research (The Norwegian Social and Health Department, 1998, 1999). The Department of Health and Social Affairs defines the goals for the care of people with mental health problems in community health services as follows: "*The goal of mental health work in the communities is to help foster self-sufficiency and social integration for people with mental health problems and to increase their capacity to control their own lives*" (The Directorate for Health and Social Affairs, 2005, p. 7).

The same agencies are to provide services for both the general public and people with mental health problems. The municipalities are responsible for preventive efforts and the provision of primary health care services as well as care and social services, and therefore play a key role in the provision and co-ordination of services for people with mental health problems (The Directorate for Health and Social Affairs, 2005). The specialised mental health services for adults are based on three pillars: a) hospital wards, which are to provide highly specialised treatment; b) District Psychiatric Centres (DPC), which are to provide less specialised treatment on a more decentralised level and comprise rehabilitation wards, short-term beds, day wards and consultations; c) psychiatrists and psychologists in private practice, who are to provide services in cooperation with other municipal mental health services (The Directorate for Health and Social Affairs, 2005). According to the reforms, there should be a considerable increase in the number of DPC beds with only a slight increase in the corresponding figure for hospitals. The total number of beds should remain fairly stable (The Norwegian Social and Health Department, 1999).

A review after the first years of the National Programme for Mental Health revealed that it had highlighted mental health and healthcare and led to an increase in the treatment capacity of many services for people with mental health problems (Myrvold, 2006). There has been a marked increase in staff, while the number of beds continues to decline. The number of large psychiatric hospitals has been

significantly reduced. During the past 25 years, there has been a 50 % reduction in the number of psychiatric hospitals in Western Europe (WHO, 2001b). In Norway, the number of institutional beds was reduced by approximately 60 % between 1975 and 1995 (Almvik & Borge, 2000). Since 1998, the number of beds has dropped by 900 (16 %). At present, there are a total of 5039 adult beds, either in psychiatric hospitals or DPCs (Pedersen, 2006).

In other areas – in relation to co-operation and co-ordination – the review failed to reveal the anticipated development (Myrvold, 2006). The total operation expenditure on mental healthcare in 2005 was 12.3 billion NOK, a 23 % increase since the start of the programme (Pedersen, 2006).

### **2.3 A brief overview of community mental health research**

Community is a complex concept and different kinds of communities exist. A community can be defined by geographic location, service use, shared interests or occupation or by characteristics such as culture and religion. In recent years, virtual communities have arisen (James & Baker, 2002). The multicultural constitution of communities and the number of people with special needs present new challenges. Community can be described as a geographic base with a history of collaboration which facilitates access to resources (cf. James & Baker, 2002). Local communities can be characterised by individuals relating to one another as a whole person, usually simultaneously within several different contexts (Hedelin, Severinsson, & Hummelvoll, 2003). In general, it can be said that the significance of the local environment varies among its residents and is most significant for those who have limited access to other areas in terms of work, development and social interaction – such as people with mental health problems. Being a member of a community is complex for a person with mental health problems – when they seek to participate, they may encounter the boundaries connecting ‘us and them’. Admittance to communities is influenced by numerous factors, e.g. physical characteristics, relationships with other members, income and place of residence. To focus on community is also to raise the question of power. People try to find their place in the community by means of participation. They are educated, trained and socialized into particular ways of being. Community is both a home and a border, a place where one feels part of the collective, where identities are formed and revolve around mutual beliefs and values (Drevdahl, 2002).

There is evidence that mental health problems are more common among women than among men. Depression and anxiety are twice as common among women, while men suffer to a much greater extent from alcohol and drug-related problems (Kringlen, Torgersen, & Cramer, 2001). Poor mental health occurs in all age groups, in both genders and in different cultures and population groups.

Nevertheless, people with a lower socio-economic status are far more likely to experience mental health problems than those with higher socio-economic status (Jané-Llopis & Anderson, 2005). Mental health problems are 60 % more prevalent among people who live alone than among those who are married or cohabiting (Kringlen et al., 2001). For families, mental health problems are a significant burden. It is estimated that one in four families in the world has one or more members with mental health problems (WHO, 2001b).

Barham & Hayward (1995) described how people with mental health problems try to distance themselves from stereotypes associated with being a psychiatric patient in order to create meaning in their lives. Trying to re-establish oneself in society is described as a process of being 'on trial' as opposed to still having patient status. Exclusion, burden and reorientation are problem areas that long-term psychiatric patients have to contend with. In Canada, Aubry, Tefft and Curri (1995) concluded that people with mental health problems must be helped to integrate socially and taught social skills in order to ensure a successful transition from an institution to a home of their own. The less deviant the behaviour, the more successful the integration. This is supported by studies (Rapchuk, 1998; Pinfold, 2000) which show that, when a group home was opened in a neighbourhood, most of the neighbours (with the exception of one segment) had a positive attitude to both the home and its residents.

A Norwegian study concluded that patients with mental health problems have few social relationships and are not well integrated socially, with men being particularly isolated (Elstad, 1999). A study on loneliness among people with mental health problems by Nilsson (2004) showed that such problems created a sense of loss, defeat and a feeling of detachment from one's own social network and life. This includes loss of work relationships, stable romantic relationships and friends, as well as economic loss (Nilsson, 2004). A Swedish researcher (Erdner et al., 2002) concluded that lack of friends and meaningful activity, in addition to lack of participation in their own care, can leave an existential vacuum for people suffering from mental health problems. The problems of feeling lonely and experiencing difficulties integrating in society have also been confirmed in another Swedish study by Bengtsson-Tops (2001). Poor health and low income act as a barrier to participation in social activities and increase isolation and exclusion, as well as leading to social and personal devaluation (Ramon, 2001). People with mental health problems wish to live in housing similar to the general population, however a very low income hinders them from achieving this (Lambert et al., 2000). Often, the discrimination they experience can compound the distress that results from the illness and a lower-than-average standard of living (Johnstone, 2001), which is supported by other studies (Brandt, 1996; Breakey, 1996). Without active interventions in the form of community participation and individual support, people with mental health problems who

move into private housing can find themselves excluded from the social network (Hardiman & Segal, 2003). A Canadian study showed that persons with mental health problems report lower levels of both social contacts with neighbours and general life satisfaction compared to other community residents (Aubry & Myner, 1996). People with mental health problems are vulnerable, feel different and are dependent on help from professionals (Johnstone, 2001).

McKeown and Clancy (1995) identified three main factors that contribute to the stigmatisation of the mentally ill: the media, a lack of education about mental problems and fear. The impact of stigma on people with mental health problems can lead to avoidance of social contacts.

A review of mental health nursing and community mental health work (Hedelin et al., 2003) showed that mental health care in local communities is characterised by working with people with mental health problems in their homes, as well as caring for and helping them in their daily lives. The tasks involved in community mental health work changed both structurally and in terms of content with the implementation of the new reforms. The work is now characterised by stress and a heavy workload, which creates the need for support and guidance as well as high competence (Hedelin et al., 2003). Caring for people with mental health problems in their homes can make the professionals feel that they are intruding and cause ethical problems that render clinical supervision necessary (Magnusson, 2003).

## **2.4 Literature review: Social network and social support interventions in community mental health care**

A literature review was undertaken to describe previous research in relation to social networks and social support in community mental health care. Electronic database searches were made for available articles in which social network interventions were used in community mental health care. A systematic literature review involves the identification, selection, critical analysis and written description of existing information (Polit & Beck, 2006). In this search, a careful examination of all aspects of the articles was conducted in order to judge their merits, limitations, meaning and significance (Burns & Grove, 2005). The following online databases were searched for publications: Academic Search Elite (ASE), which has a multidisciplinary research approach; CINAHL (Cumulative Index of Nursing and Allied Health Literature); and EMBASE (the Excerpta Medica database) with a broad health profile including public health and psychiatry. The initial search terms were *social network*, *social support* and *psychosocial models*. These were combined with the terms *community mental health*, *rehabilitation*, *psychiatry*, *schizophrenia* and *occupational*. Studies were included if they met the following criteria: 1) written in English; 2) containing

data on social network and social support interventions in community mental health care; and 3) peer reviewed. A large number of articles were identified by means of a combination of the search words. A significant percentage was excluded following examination, hence a total of 229 articles were included for further analysis. Of these, 20 articles from the period 1998 - spring 2005 met the inclusion criteria. The reason for using 1998 as a starting point was to obtain the most up-to-date research, as this period is sufficiently long to allow reliable conclusions to be drawn.

The analyses revealed that a spectrum of interventions and strategies were used to help people with mental health problems improve their social networks. Four categories were identified:

*1) Peer support and volunteer partnership:* There were two main groups in this category. The first involved persons with psychiatric disabilities who worked in community mental health teams or support programmes, mainly as health care assistants. Such programmes help individuals with mental health problems, facilitate empowerment and improve motivation and social integration. An 'after hours' pre-crisis telephone service run by peers also provides mutual social support and the opportunity to become involved. Self-help can lead to strengthened social networks (Page, Lafreniere, & Out, 1999; Pudlinski, 2001; Fisk & Frey, 2002; Hardiman & Segal, 2003; Yuen & Fossey, 2003; Craig et al., 2004).

The other group comprised volunteers who took part in different programmes aimed at promoting social integration among people with mental health problems in which healthy people worked together with people with long-term mental health disorders. The articles reported increased social activities and that having someone to talk to was extremely important (Bradshaw, Haddock, & Bradshaw, 1998; Davidson et al., 2001; Davidson et al., 2004).

*2) Day-time activities and work:* This category presents models such as the 'Fountain-house' and other clubs and groups, cooperative work places, and different kinds of work placement. The conclusions were that occupation is important for meaning in life, social integration, training and work experience and as a means to obtain an ordinary paid position (Irurita & Williams, 2001; Kilian et al., 2001; Pilisuk, 2001; Fieldhouse, 2003; Hvalsøe & Josephsson, 2003).

*3) Social network approaches in community based mental health care:* This category describes different types of interventions such as: Case Management, Assertive Community Treatment, the Intensive Service Team in the community mental health service, and Open Dialogue, where social network and social

support were important tools and targets of the interventions. The different types of intervention led to greater social opportunities and improved the patient's social network (Becker et al., 1998; Stein et al., 1999; Seikkula et al., 2001a).

*4) Independent living and learning programmes focusing on social skills:* This category contains articles on the subject of living skills programmes, social skills training programmes as well as programmes aimed at increasing the service user's social network. The articles recommended learning programmes and group activities for promoting social integration among people with mental health problems. However, the majority of contacts tended to be with other service users. One's own home was essential for self-esteem (Preston, 2000; Hansson et al., 2002; Angell, 2003).

In terms of methodology, nine of the articles used a quantitative approach. The number of participants in the studies differed greatly. There were eight qualitative studies, while three articles combined a qualitative and a quantitative approach. The number of participants was sufficient to provide satisfactory results. The research design, which can be defined as the overall strategy for addressing a research question, including methods for enhancing a study's integrity (Polit & Beck, 2004), was described and explained in different ways. The qualitative studies have a wide range of both data collection and analysis procedures. Articles which used a clearly defined qualitative analysis instrument provided a description of the philosophy and methodological approach employed, as well as citing sources. However, the arguments for employing the given analytical processes were in most cases weak, something that detracts from the methodological rigour (Burns & Grove, 2005). The studies combining qualitative and quantitative data collection and analysis methods lacked a description of the methods employed.

The outcome measures in the studies with a quantitative approach were surprisingly similar. Most of the studies employed some of the most common instruments that have proved reliable in mental health research projects and other studies on the life experience of individuals, thus facilitating comparison. The strengths and weaknesses of the studies were stated in the articles. Evaluation took place from three months to three years after the start of the intervention. Eight of the studies compared groups or had a control group. The most common variables were network size, symptom reduction, social skills development and quality of life.

Overall, the qualitative studies had few tables or figures to provide an overview of the theme and categories. Nevertheless, the heuristic relevance was clear, and in most cases the reader was able to follow the intervention phases. Nevertheless, the integration of the findings into ordinary mental health work will require several studies of the methods employed.

In summary, the review showed that there has been much research in the area of the deinstitutionalisation of people with mental health problems and the value of social integration. However, there is a gap in the literature which this study is intended to fill.

This literature review did not provide a general picture of the interventional and working methods used for helping people with mental health problems achieve social integration. It seems that the published scientific articles in the English language present quite a narrow picture of the above-mentioned aspects. There are many community programmes, ranging from clubs and day centres for people suffering from functional disorders, to user associations, many of which have never been described in peer reviewed articles, nor referred to in text books. There are probably several interrelated reasons for this, e.g. lack of experience and knowledge of publishing scientific articles, the fact that professionals (social workers, nurses and psychologists) working in this area prefer more practice-oriented papers, and that the academic and clinical reality are divergent. There may also be difficulties in gaining acceptance in academic circles due to unfamiliarity with the language employed. In a broad sense, we believe that this is due to differing paradigms. The review reveals that none of the studies employed indirect methods, such as a social network map or other strategies to enable professionals and clients to better understand the latter's social network.

A well-functioning social network and a feeling of social fellowship are vital for well-being as well as necessary for preventing the return of mental health problems (Kawachi & Bekman, 2001). Active participation in a social situation, for example, in a club or working environment, leads to a sense of belonging and promotes group solidarity, cultural harmony, and opportunities for participating in new groups and experiencing mutual support, where everyone helps each other. This, in turn, often leads to a positive outlook and a faster recovery from mental health problems (Bengtsson-Tops, 2001; Hardiman & Segal, 2003).

However, reports suggest that the social integration of people who suffer from mental health problems has not been as successful as anticipated (Pirisi, 2000). People who have a supportive social network recover faster from serious illness than those who have less social support (Sanderson, 2004). The size of the network is significant: a larger network of people can provide a higher level of activity and, hence, better opportunities for people with psychosis to improve their ability to function (Evert et al., 2003). Employment is also considered important. Groups that work together and meet after work have a positive influence on self-activity and help to create a mutual bond (Howard et al., 2000). Different ways of increasing social activity and expanding the social network are an important means of mastering mental health problems and thus increasing one's ability to work (Eide & Røysamb, 2002).

### 3 METHODOLOGY

The study had an explorative design (Polit & Beck, 2006) in order to achieve a deeper understanding of the phenomenon of social integration of people with mental health problems and to develop the mental health professional's insight into this phenomenon by means of co-operative inquiry.

A hermeneutic synthesis approach (Hummelvoll & Barbosa da Silva, 1994) is used as a method of understanding the entirety. Therefore, this chapter begins with a short description of the hermeneutic approach. Co-operative inquiry is described in the second part of the thesis and the approach used is also elucidated in this chapter.

The lives of people with mental health problems in the community as well as the co-operative intervention were examined from an ethnographic perspective. This took the form of ethnographic research without fixed characteristics. In this thesis, ethnography is understood as an adaptable practical activity and an ongoing reflective process at all stages of the research process, which means it is not possible to plan it wholly in advance (Hammersley & Atkinson, 1996). The research process was reflective, and choices had to be made to limit the scope. It is therefore described in detail in order to enable the reader to judge the validity of the results.

This study emphasizes the understanding of a person's life experiences through qualitative data and methods of analysis. The general characteristics of qualitative research design are evident in this study: the methods used were flexible and could be adjusted throughout the research process; the researcher was intensely involved for a long period of time, there was a strive to understand the whole; and different types of data collection strategies were employed (Polit & Beck, 2006). Qualitative research studies phenomena in their natural environment and seeks to understand them through the meanings assigned to them by individuals from their own perspectives and personal histories. It is methodically diverse in its focus and has an interpretive and naturalistic closeness to the object of study (Hummelvoll, 1995; Silverman, 2006).

### **3.1 A hermeneutic perspective**

Hermeneutics uses the life experiences of people as a tool for better understanding their social, cultural, political and historical context. The focus is on the meaning and interpretation of their world within their given context (Polit & Beck, 2006). A hermeneutic approach seeks to understand the individual as a cultural human being and as an entity interacting with its surroundings (Hummelvoll & Barbosa da Silva, 1994). Social interaction has often been discussed in the field of philosophy (Svenaesus, 1999). Both Gadamer (1997) and Ricoeur (Kemp, 1999) were engaged in the understanding of others. There is a struggle in all human relationships to be recognised by the other party. The intensity of this struggle varies with the individual's life situation. It can be a Master – Journeyman relationship, where one party holds power over the other, including the power to define the appropriate worldview. On the other hand, it can be a dialectical relationship in which two people meet on equal terms with the goal of understanding each other (Gadamer, 1997). Meaningful aspects of Gadamer's (1997) perspective on human reflection, consciousness and understanding are wholeness, openness, process and integration. Central to his hermeneutic philosophy is the idea that understanding is always self-understanding, i.e. understanding of one's own understanding.

There are several core concepts in the hermeneutic frame of reference that affect the interpretation and understanding of the content. In this thesis, the following concepts are especially central: pre-understanding, the hermeneutic circle, dialogue, meaning, interpretation and fusion of horizons.

Pre-understanding is especially valuable in hermeneutical understanding, because a person cannot understand without already having some understanding. Thus, pre-understanding gives direction to the search for understanding. Without understanding, no problem can exist and there would be nothing to suggest where the answer should be sought (Kvale, 1997; Ödman, 2001). This leads to sensitivity towards texts that require an awareness of one's own bias and allows the written word to be understood in all its uniqueness and to assert its own truth (Gadamer, 1997; Bégat, 2006).

A central aspect in hermeneutics is the hermeneutic circle or spiral (Ödman, 2001). There is a dialectical movement between the whole and the parts, and between explanation, understanding and pre-understanding (Gadamer, 1997; Berggren & Severinsson, 2006). In this thesis, the hermeneutic spiral is a more appropriate concept, because the process of understanding and interpretation creates a steadily increasing totality and precision in relation to the developing knowledge (Ödman, 2001). Furthermore, reflection arises in the interaction between experience and pre-understanding.

Dialogue with a text develops together with the culture, traditions and environment which the text represents, but also with the researcher's reflective capacities (Ödman, 2001). Understanding and meaning are mediated through the dialogue (Gadamer, 1997), an understanding that occurs not only between people, but between texts, works of art and other meaningful elements (Molander, 2000).

Meaning in hermeneutic philosophy is always contextually dependent. It can never be static, but changes and extends during the process and over time. Meaning depends upon the history of its context and pre-understanding, as well as the history of the person studying a phenomenon (Bégat, 2006).

Interpretation is always guided by a pre-understanding of "being-in-the-world" and the readers must articulate their understanding from their own situation and horizon. One cannot begin such an understanding from scratch (Svenaesus, 1999). Hermeneutic interpretation involves a systematic description of the text within its own scope and context, and one of its strengths is that it permits the scholar to respect and retain the perspective of the research participants (Berggren & Severinsson, 2006).

Humans are historical beings and cannot free themselves from traditions and pre-understandings. Our horizons affect our meetings with other horizons. In this context, horizon is something we look out from, the perspective we have, thus the horizon changes with our perspective. The goal is a fusion of horizons, which allows the creation of new understanding (Gadamer, 1997; Hallberg, 1999; Eilertsen, 2000). However, fusion of horizons is not synonymous with the same understanding as that of the person who wrote the words one reads (Svenaesus, 1999). A distance which separates – and at the same time unites – horizons can be dynamic, which provides an understanding from our point of view and which encompasses our prejudgement (Gadamer, 1997). A wide perspective is necessary for understanding. In order to broaden one's horizons, one must learn to see beyond the immediate while still keeping it in mind.

The above-mentioned core concepts form a whole, each dependent upon the others. In the same way, the different sub-studies in this thesis make up a whole which, when taken together, can contribute to deeper knowledge and improved practice.

### **3.2 An understanding of knowledge**

Schön (1987) states that people know more than they can articulate, which he describes as 'knowing-in action'. The more or less unarticulated practice arises spontaneously and automatically in the course of daily work. Within health

research, knowledge is sought in order to understand something which stands in opposition to the concept of co-operative inquiry, where one seeks knowledge-in-action (Reason, 1988). Knowledge-in-action is dynamic, and the knowing is in the action (Schön, 1987). Here, abductive reasoning enables the use of empirical knowledge for formulating theory, which in turn provides a way back to understanding a hidden, empirical pattern. This implies a hermeneutic process that leads to theory development (Alvesson & Sköldberg, 1994).

Molander (2000) describes a knowledge-optimistic stance that is in accordance with co-operative inquiry: “There is nothing so good that it cannot be improved – a good thing may not be good enough, but it may be considered so as long as there is no better alternative with which to replace it” (Molander, 2000, p. 74 author’s translation).

The skilled practitioner’s knowing-in-action is characterised by reflection-in-action: being open to reflection and making one’s own actions the source of knowing-in-action (Schön, 1987). If one has too narrow a view, one can fail to see the broader picture, but reflection-in-action can prevent this. Professional learning develops through several steps, which Schön (1987) describes as: i) knowing in action; ii) surprise; iii) reflection in action; iv) experimentation; v) reflection on action; vi) new knowing in action. This means that through knowledge and experience, the professional gains an understanding of how practice should be carried out and what its contexts are. Consider the case where a professional has new experiences which do not completely agree with his/her experience-based knowledge, something which stimulates reflection over his/her practice. The next step after reflection is experimentation, which leads to reflection on practice and further new knowledge. In these steps, the knowledge developed must connect with the professional’s own understanding and values. This reflexive process can be promoted by good coaching and development of reflexive skills. According to Schön (1987), this is a universal process and the steps emerge regardless of profession. The ability to act through these steps differentiates a reflexive and developing professional from one whose development has stalled.

Reflected knowledge is the knowledge inherent in people’s actions. Through reflection-in-action the professional develops a feeling for how he/she should act in different situations and becomes more skilful both through reflection and action. Thus, knowledge both originates and develops in action (Schön, 1987). Molander (2000) criticises this view and states that in order to reflect, one needs distance and the opportunity to think over the situation. This form of knowledge is too uncritical and fails to sufficiently problematise. Systematic criticism presupposes something which can be questioned. Dialogue is central to the establishment and maintenance of a common understanding and co-operation. It is a foundation of human existence and can be seen as a basic model for knowledge development,

due to the fact that the dynamic of knowledge and the dynamic of dialogue are similar (Schön, 1987; Molander, 2000).

### **3.3 Ethnography**

An underlying assumption of ethnographers is that every human group eventually evolves a culture that guides the members' view of the world and the way they structure their experiences (Polit & Beck, 2006). Ethnography is essentially a form of social research that includes some or all of the following characteristics: an exploration of a social phenomenon, "unstructured" data, a small number of cases, and analysis that involves an interpretation of the meaning of human action (Hammersley & Atkinson, 1996; Hodgson, 2000; Silverman, 2006). There is no single unambiguous definition of ethnography. Rather, different descriptions are used to refer to a group of closely-related methods for obtaining empirical data (Hammersley & Atkinson, 1996; Silverman, 2006). One of the bases of ethnography is in hermeneutics. Ethnography seeks to study the social world as it naturally occurs. It is, therefore, important to make the researcher's own position in that social world clear. Hammersley & Atkinson (1996) explain this as reflexivity: we are a part of the social world we study, which means that the researcher's orientation is affected by his/her socio-historical standpoint and the values and interests that standpoint confers (Hammersley & Atkinson, 1996). Research is an active process, through which one describes the world by means of one's own observations and theoretical interpretations of the objects studied. The naturalistic perspective, which is an ethnographic perspective on social science, emphasises that the researcher should adopt an attitude of respect for and belief in the distinctive character of the phenomenon in the social world in focus (Hammersley & Atkinson, 1996). Different interpretations and actions in the social world reflect various cultures or understandings of it, and in this way people create different social worlds through their actions (Blumer, 1969).

Today, ethnography is used in a broad range of work and focuses on seeing things in their context and understanding different ways of life from the perspectives of other people (Hodgson, 2000; Silverman, 2006). Ethnography means learning from people, and the knowledge gained through empirical data is intended to help the researcher to understand the participants by means of a mutual sharing of experience (Hodgson, 2000). Ethnography tends to take facts and values into consideration and implies influencing society, as in order to be of value, its results must be of use to society (Hammersley & Atkinson, 1996). In this thesis, the knowledge gained from the participants in the first three sub-studies (Papers I-III) was used in dialogue-oriented teaching with the aim of developing the community practice of mental health professionals as well as shared with others in the form of published papers. An ethnographic approach can provide an

opportunity to understand the perspectives of people with mental health problems and their neighbours and to discuss this knowledge in dialogue-oriented teaching. The sub-studies attempt to increase understanding of the perspective of the group under study in order to deepen understanding of what is happening in a particular as well as a wider social and historical context, in which social life is considered to involve an interlocking series of events (Silverman, 2006). In this study, an ethnomethodologist perspective “*which seeks to describe methods persons use in doing social life*” (Silverman, 2006, p. 100) is evident in the findings.

### **3.4 Co-operative inquiry**

In the final sub-study (Paper IV), a co-operative action research approach was implemented, based on the knowledge of social networks and integration. Action research has the potential to facilitate understanding of, and lead to, changes in the field by means of a dialogue-oriented, co-operative approach (Hummelvoll & Severinsson, 2005). Co-operative inquiry can play an important role in assisting health care professionals to integrate theory and research in community settings, as it includes not only practical aspects, but also the development and integration of the knowledge or theory on which the actions are based (Reason, 1994, Hummelvoll & Severinsson, 2005). Empirical knowledge can be further developed by means of knowledge-in-action.

Lewin (1951) introduced social action research shortly after the Second World War. A major theme in Lewin’s thinking was that theory and practice can co-exist in a fruitful symbiotic relationship. This generated a new paradigm within research and practice (Holter & Schwartz-Barcott, 1993). Kemmis and McTaggart (2000) describe social action research as a learning process which can lead to changes in what people do and how they interact with others and society, in their opinions and values, and in discussions of how they understand and act in the world.

All ethnographic research exerts an influence on what it studies by the mere act of asking questions, and the response one receives reflects that influence. As a result, most scientific research projects have an element of action. Research, or at least its consequences, cannot be value-neutral. Action research is, on the whole, a powerful research tool, as it provides direct access to the area of investigation (Coghlan & Casey, 2000).

The loyalty in social action research relates to the action and the person(s) involved in it. Social action presupposes that something will be improved. It is a feedback process, in which practical action and knowledge acquisition follow from and contribute to each other, leading to an alternating pattern of theory and action:

the movement from theory to action provides insight and freedom of action that can result in opportunities for further action. The well-known Norwegian social action researcher, Mathiesen (1973), describes social action research as a moral field in which choices must constantly be made. However, social action research is not simply and inherently moral or right, even if the researcher is faced with moral choices.

There are three distinct traditions within co-operative inquiry (Starrin & Lundberg, 2001): i) the pragmatic tradition, which focuses on people who can affect the changes which develop, ii) the ideological and political tradition, which is more radical and seeks change in societal structures, especially in the third world where poverty is rife, and iii) the feminist tradition, which has a separate scientific perspective and emphasises the hierarchy and structures in society that contribute to controlling research and the development of knowledge.

In this sub-study (Paper IV), the focus is on the pragmatic tradition. According to the English social scientist Reason (1988), co-operative inquiry is based upon three inter-related aspects: i) Participation and holistic knowledge, where the former is by implication complex and comprehensive. Comprehension must be understood as the meaning of the whole for the individual parts, while participation involves empathy, which in turn brings responsibility. When focusing on the whole, theoretical knowledge is not separated from practical action and experience, and the understanding is both descriptive and systematic. ii) Critical subjectivity implies uniting objectivity and subjectivity in our consciousness. Personal experience is put to conscious use in the research process, and it is clearly understood that the individual sees the world as his/her own world as opposed to the world in general; emphasis is therefore placed on individual experiences and perspectives. iii) Knowledge in action implies that knowledge is created for and through action, rather than for and through reflection. In other words, it focuses on the fact that practical knowledge is meaningful and can lead to the development of new practice (Hummelvoll, 2006).

An important characteristic of social action research is that it is carried out in co-operation with those who experience the phenomenon (termed co-researchers). An attempt is made to find solutions to practical problems in order to create new general knowledge (Coghlan & Casey, 2000). Traditional research seeks knowledge for understanding, while in co-operative inquiry the goal is knowledge for action. This results in an entirely different “bottom up” approach, where local relationships and priorities are fundamental (Hummelvoll, 2006). It is the researcher’s attitude that characterises the way in which the research process develops, i.e., how power is distributed in the project. Possibly the most significant difference between co-operative inquiry and traditional research is who defines the research problem(s) and how they deal with them. The methods

employed are often similar to those used in traditional research. This type of research is characterised by reflexivity, flexibility and procedural, as opposed to the traditional linear process (Coghlan & Casey, 2000; Hummelvoll, 2003). However, this also presents special challenges for the researcher, as the co-researchers play an active part in planning the project, in the data collection and often in the data analysis, as well as in the presentation of the results. Thus, the researcher does not have absolute control over the development of the new knowledge (Starrin & Lundberg, 2001).

In co-operative inquiry, working in four phases is essential for acquiring good results. These phases should ideally proceed in a spiral, which produces continual improvement in practice. The methods can continue to be used in the workplace after completion of the research process and projects. As previously described, this intervention study was a part of a larger co-operative inquiry project carried out in collaboration with two municipalities and Hedmark University College, Norway. The first two phases were characterised by co-operative inquiry involving all the participants. In this thesis, the main focus is on phases 3 and 4. The following is a brief overview of the phases, with reference to Hummelvoll (2003, 2006) and Reason (1994):

*Phase 1: Reaching agreement about goals and methods.* The researcher and co-researchers agree on an area of inquiry, and identify some initial research propositions by exploring several aspects of their experience, or agreeing to test the practical application of certain methods, skills or approaches. They reach agreement about the goals and what sub-projects should take place in order to achieve them.

*Phase 2: Putting ideas and procedures into practice.* The researcher and co-researchers implement the agreed actions and observe and record the outcomes of their own and each other's activities. The consequences of using this procedure in everyday practice are discussed. It is important to retain the aspects which function well. In this phase, it is also decided how to carry out the co-operative inquiry. It is essential to clarify the overall principles and aims of the workplace in a written report.

*Phase 3: A deepening of practice.* This full immersion stage is decisive for the entire research process, as such daily practice can develop openness to what is going on the part of both the researchers and the co-researchers and their environment. This openness can contribute to a bracketing of prior beliefs and preconceptions and to seeing the experience in a new light. The dialogue-based teaching proved to be a valuable tool, as it is a reflexive process that allows the participants to study their work, gain new experiences and develop new ideas. In this way a feeling of mutual support develops between the co-researchers, whose

feedback in the form of reports and summaries of the focus group interviews contributes to the process, as do reports from the other participants.

*Phase 4: Review, revision, and possible consolidation.* After an appropriate period of work on phases two and three, the researcher and co-researchers returned to reflect upon their original research propositions and assumptions in light of their experience, in order to reformulate or reject them and adopt new hypotheses. They also improve and develop their research procedure as a means of more fully recording their experiences. At this time it is decided how the intervention will be continued in the future. Evaluation of the tested ideas and methods can be made using various methods, such as narratives, focus group interviews, round-table discussions and seminars. These methods can be used to critically scrutinise the practice, and the researcher and co-researchers are obliged to summarise the interventions and co-operation. The documentation of the co-operative inquiry is published in the form of reports and scientific articles.

There were two areas of knowledge development in the research process: dialogue-based teaching and focus groups (Paper IV). The main goal of the dialogue-based teaching was to facilitate the articulation of practical and tacit knowledge. Articulation of different experiences in the group facilitates and stimulates in-depth-reflection (Reason, 1994). When employing a co-operative research approach, the strength of the focus group method is the opportunities it provides for deepening the discussion and reflection on the themes focused upon (Hummelvoll & Severinsson, 2005). (The focus groups are described in more detail in section 3.6.2.)

A basic feature of this form of dialogue based co-operative inquiry is learning through reflection with other co-researchers in order to further develop knowledge. The pedagogical intention is that dialogue-based teaching should enhance opportunities for knowledge development and, by systematic use of reflection, release, transform and verbalize it so that it can be shared (Hummelvoll & Severinsson, 2005). The relationship between the co-researchers should be characterised by reciprocity, negotiation and willingness to share the knowledge (Lax & Galvin, 2002). In community mental health work, the process of participation, collaboration and development cannot be achieved without good communication and inter-professional collaboration. One way of creating relationships and promoting collaboration between different professional groups is through dialogue-based teaching.

In this part of the research, 27 health care professionals and social workers (15 from the urban and 12 from the rural community) took part in an hour long dialogue-based teaching intervention once a month over the course of 18 months (2004-2005), which totalled 21 sessions (Paper IV). The content of the sessions

included several methods that are usually implemented when developing a social network, such as social integration and support programmes, social network mapping, social networking with family and friends, network meetings, development of meeting places, use of day-centres, work placement, clubs and community recreation programmes. In order to concentrate the development of knowledge, ten of the professionals were invited to take part in a 'core group', where they had the opportunity to receive closer follow-up over the course of one year. In this way, there was a greater opportunity for the participants to deepen their knowledge.

### **3.5 Participants**

The participants in each sub-study (Papers I-IV) were recruited independently, and each sub-study was conducted separately.

#### *3.5.1 Paper I*

Neighbourhoods in five different areas in eastern Norway, in which group homes for people with mental health problems are located, participated in this sub-study. In each neighbourhood, four to five randomly selected neighbours were asked by letter if they were willing to be interviewed. The 19 neighbours (10 women and 9 men) who agreed to participate were aged between 30 and 57. With the exception of one participant, all were either married or co-habiting, and 14 had children between the ages of 4 and 12 years.

The participants lived in detached houses or houses divided into a few flats, and all but one were owner occupiers. Five of the informants worked in industry or sales, five in banking or public administration, and five in health or social work. Three were retired. The group was, for the most part, homogeneous in terms of age and number of children. This may be due to the fact that two of the municipalities were newly developed areas. The municipalities have usually opted to build housing for people with mental health problems in ordinary residential areas. The interviews were conducted six to eight years after the establishment of the group homes. The researcher was not acquainted with any of the informants prior to the interviews.

#### *3.5.2 Paper II*

In the sub-study exploring how people with mental health problems experience living in their own apartment, the participants were recruited from three different day-care centres for people with mental health problems in the Eastern part of Norway. They were initially invited to participate by letter, after which the time and place for the focus group interviews were decided over the telephone. Twelve people (nine men and three women) participated in the study, four in each focus

group. Their ages ranged from 24 to 72 years, with a mean age of 42 years.

All of the participants lived on a disability pension as a result of mental health problems. Ten of them had spent several years in psychiatric institutions, as well as having had many years of contact with the mental health community services. Though several previously had mental health problems with psychosis, none of the participants were psychotic at the time of the focus group interviews. They had lived in individual accommodation for two to seven years. Six of the participants lived in group homes (i.e. four or five apartments in the same house with or without support staff) and six lived in ordinary apartments. A day centre was available to the participants as a place for meeting and activities.

### *3.5.3 Paper III*

This sub-study explored the ability of people with mental health problems to integrate socially into a community. Three focus groups were set up to obtain a cross-section of the participants' experiences. Two groups came from an urban community, one of which was recruited from the local division of 'Mental Helse,' Norway's largest user organization, and the other from among individuals who were registered as users of mental health services in the municipality. The third group was formed in a rural community and the participants recruited both from 'Mental Helse' and among users of the mental health services.

The inclusion criteria were as follows: the participants should i) have or previously had a mental health problem, ii) have been admitted to a psychiatric hospital, iii) be resident in one of the two counties in central Norway in which the study took place.

Seventeen people, three men and 14 women aged between 25 and 57 (with a mean age of 43 years), participated. Sixteen lived alone and 14 were in receipt of a disability pension. Eight of the informants had had a mental illness with psychosis, and nine suffered from anxiety, depression and personality disorders. Three informants had no contact with mental health services at the time of the focus group interviews.

### *3.5.4 Paper IV*

In this sub-study, a qualitative co-operative action research approach, based on knowledge of social network and integration, was implemented in two municipalities. A total of 22 persons participated in the focus group interviews, and their ages ranged from 32 to 53 years. In the urban municipality (N=12), nine of the participants were registered psychiatric nurses and assistant nurses, and three were social workers. They worked either with clients in the home or at the cultural centre. Of the participants in the rural municipality (N=10), six were registered nurses or assistant nurses, and four were occupational therapists

or social workers. They mainly worked with older people or children but also had experience of people with mental health problems. Two participants cared exclusively for people with mental health problems.

### **3.6 Data collection methods**

There were two main methods of data collection; individual open-ended interviews and focus group interviews, which will be described separately.

#### *3.6.1 Individual interviews*

In the first sub-study (Paper I), a qualitative research interview was conducted, such as that described by Kvale (1997), with neighbours of group homes for people with mental health problems. An interview is a form of self-report (Burns & Grove, 2005) as well as a flexible way of obtaining information and can allow the researcher to explore greater depths of meaning than can be achieved with other techniques. An individual interview must be understood from the perspective of the context in which it takes place. In the interview, the researcher tried to gain an understanding of the way he/she used him/herself as a tool and employed physical and emotional methods aimed at generating understanding. This can enable unique access to the participant's life world (Kvale, 1997).

In this sub-study (Paper I), the time and place for the interviews was decided by phone after receipt of written declarations of informed consent. The participants were interviewed individually in their homes, with the exception of one interview, which took place in a café. The interviews, which were recorded, lasted between 40 and 100 minutes. An interview guide (Appendix I) was used by the researcher, which, in addition to demographic details, contained eight open-ended questions related to experiences of living in the vicinity of a group home for people with mental health problems.

#### *3.6.2 Focus group and multistage focus group interviews*

Focus group interviews were the method of data collection in three of the studies (Papers II, III and IV). This form of data collection has many advantages when gathering information from a more or less homogeneous group of people. A focus group interview is a planned discussion among a group of people on a subject chosen by the researcher. The ideal group size is six to eight informants (Morgan, 1997; Tillgren & Wallin, 1999; Hummelvoll & Severinsson, 2005), as it minimises the interviewer's influence on the data and makes the reflection of social reality more accurate compared to other methods (Morgan, 1997; Madriz, 2000). Kitzinger (1994, p. 103) defines focus groups as follows: "*Focus groups are group discussions organised to explore a specific set of issues... the group is focused in the sense that it involves some kind of collective activity*".

The reason for using the focus group interview method was that the group process can help the participants to express and clarify their points of view in a way that might not be possible in a one-to-one interview. The group members were encouraged to reflect, develop their own views and discuss statements. Spontaneous and emotionally-laden comments often emerged (Kvale, 1997). In this way, the focus group interviews brought to light dimensions and understandings that would have been difficult to capture using other methods (Kizinger, 1995). One of the main challenges in a focus group interview is the creation of proper conditions for a favourable group dynamic. All the participants must feel that they are part of the discussion and that they can encourage one another in a creative way. Group interaction is important for data collection and was taken into consideration both during the focus group interview and in the analysis (Reed & Payton, 1997). When the group dynamic functioned well, the conversation took new and unexpected directions (Kizinger, 1995). The advantage of focus group interviews is that they break down the asymmetry of interaction which can dominate individual interviews (Maunsbach & Dehlholm-Lambertsen, 1997). The situation tends to correspond to the natural development of knowledge, by means of mutual influence and group interaction (Kizinger, 1995).

In sub-study II (Paper II), one interview took place in each of the day-care centres, i.e. a total of three focus-group interviews with four participants in each group. The discussion was facilitated by a “moderator” (the author of this thesis). An observer (co-moderator) was also present, who concentrated on group dynamics and supported the moderator (Maunsbach & Dehlholm-Lambertsen, 1997). During and on completion of the interview, the opinions expressed were summarised to ensure that the informants had been understood correctly. On several occasions, this led to the inclusion of new elements and to the viewpoints expressed in the discussion becoming more nuanced. Each focus group interview lasted for about 90 minutes and was recorded.

In multistage focus groups, the same group meets several times in order to stimulate a deeper process. The participants become better acquainted and develop more confidence in each other, which makes it easier for them to share stories and experiences. New viewpoints develop over time, and the group’s internal life becomes richer (Morgan, 1997; Thornton, 2002; Hummelvoll, 2007b). It is possible to investigate the common understanding of topics. This is a reflection of the process in a co-operative research inquiry (Hummelvoll & Severinsson, 2005). The *Promotive and preventive mental health work in the local community project* is a good example of this form of knowledge generation (Holte & Hummelvoll, 2004; Beston, et al., 2007).

During sub-study III (Paper III), two of the focus groups met on four occasions, while the third had three meetings, which took place at intervals of approximately four weeks. There were five to six participants in each group. The reason for the four meetings in two of the groups was that on one occasion only three participants took part in the focus group session. Eleven focus group interviews thus took place, each of which lasted for approximately two hours, with the researcher acting as moderator. A co-moderator participated as an observer and facilitator at each of the eleven sessions. The co-moderators were a mental health nurse, a professional attached to the municipal cultural department and a researcher involved in the main project. Although none of the observers had had professional contact with any of the focus group participants, they were nevertheless familiar to most of the participants. The focus-group interviews were audio-taped.

In sub-study IV (Paper IV), there were three focus-group interviews in each municipality (at the beginning, middle and end of the dialogue-based teaching). Each group contained six to nine members, thus a total of 22 persons participated in the six focus-group interviews. Continuity was achieved by the fact that half of the participants were present for at least two of the three interviews, which lasted for 90-120 minutes. After each focus-group interview, the content was transcribed and the texts condensed. Additionally, an analysis was made prior to the second and third focus-group interviews. The summary of the content was presented to the participants at the next focus group interview and they were asked to clarify their statements, which sometimes led to new discussions. The second interview focused on topics that arose in the first. In the final session, a form of round-table discussion served to conclude the intervention. The collected material from the multistage focus group interviews formed the basis for the entire analysis. This type of multistage focus group was useful for obtaining new information from the participants, in order to facilitate comprehension of the meaning they attributed to and their understanding and perception of the situations discussed. It also provided understanding in the form of an 'inside view' of what was significant.

### **3.7 Data analysis methods**

A Grounded Theory method was used in the analysis (Glaser & Strauss, 1967; Starrin, Bengt & Renck, 1996) carried out in Papers I and II. Qualitative content analysis was employed in the last two studies (Papers III and IV).

#### *3.7.1 Grounded Theory*

The use of and interest in Grounded Theory as a method of analysis have grown in different areas such as pedagogy and public health research, and especially in nursing research (Polit & Beck, 2006). Grounded Theory is linked to symbolic

interactionism, which focuses on the manner in which people make sense of social interactions (Polit & Beck, 2006) as well as on an influential approach to methodology in ethnographic work (Silverman, 2006). Grounded Theory implies the systematic collection and interpretation of, as well as reflection on, data for the purpose of a theoretical construction of social processes, such as interaction between people in neighbourhoods (Papers I and II) (Glaser & Strauss, 1967; Charmaz, 1994; Willumsen, 2006). The sampling of participants and the collection and analysis of data are recursive processes (Polit & Beck, 2006) generated from and grounded in the data, where it seeks to understand the subjective meaning of people's own realities (Hallberg, 2002; Magnusson, 2003; Polit & Beck, 2006). The concurrent work, involving question, data collection, coding and additional meetings with new informants until saturation, is reached is unique to this method and at the same time its strength. This method is described by Starrin (1991) as constant comparison. Saturation in this context means that no new information was gained from further data collection and analysis (Hartman, 2001).

In Papers I and II, the interviews were tape recorded. After the initial interview occasion, the first open coding was carried out and the interview guide amended for the next set of interviews. The focus group interviews took place after the interviews with the neighbours, in order to make use of the knowledge gained in the analysis of the data from the neighbours. The analysis process followed the steps described below. In this way, the researcher was able to gain a close perspective on the collected data and the analysis process. Such a perspective is necessary for strengthening the validity of the results.

The analysis followed three phases (Glaser & Strauss, 1967; Hallberg, 2002): *i) open coding*, in which the researcher looks for key concepts in the participant's story. These concepts (substantive codes) are labels that illuminate the content of data. After saturation, the researcher proceeds to the next phase. *ii) selective coding* concentrates on those categories that are relevant to the tentative core category, which emerges during this phase. The categories are sorted and an attempt is made, by means of further data collection, to discover which are important and to describe their characteristics. *iii) theoretical coding*, where a tentative core category is developed and a model constructed to illustrate the theoretical framework. The core category and the other findings are compared with the interviews and some adjustment may be necessary.

Theoretical sensitivity was used during the analytic process. The researcher keeps theory-building in mind and is sensitive to the data in order to focus on its theory-building potential (Glaser & Strauss, 1967; Willumsen, 2006). Memos containing ideas, questions and assumptions, was used to a great extent during the analytic process (cf. Hallberg, 2002).

### 3.7.2 *Qualitative content analysis*

The analysis of the text in sub-studies III and IV (Papers III and IV) followed qualitative content analysis methods (Denzin & Lincoln, 1998). Content analysis is designed to classify the meaning of a text into a few categories based on their theoretical importance (Burns & Grove, 2005). It is a step-by-step approach that analyses an empirical text in a methodologically controlled manner so as to clearly present that which is central to the content (Mayring, 2000).

The analysis was inspired by Denzin & Lincoln (1998) and Graneheim & Lundman (2004). As a result, all of the focus group interviews were listened to and read several times to obtain an overview. Meaning units were identified, such as “*words, sentences and paragraphs containing aspects related to each other through their content and context*” (Graneheim & Lundman, 2004, p. 106). The meaning units were labelled, and statements from the focus group interviews were systematised by grouping together those that belonged to the same meaning units. Categories and sub-categories were identified and named. The content in each of the categories was then clarified. This process of condensing is termed abstraction (Graneheim & Lundman, 2004). The categories were validated against the transcribed interviews. Finally, the main theme and categories, sub-categories and codes developed in the analysis on the basis of data from all three focus groups were summarised.

The process of analysis involves constantly moving back and forth between the whole and the parts of the text. The analysis focused on two different levels of interpretation; explicit and latent underlying content. The categories were intended to be internally and externally heterogeneous (Graneheim & Lundman, 2004).

## **3.8 Methodological considerations**

As in all research, the central question in qualitative research is which criteria to use for assessing the ‘truth value’. Internal validity presupposes a systematic collection of data over the entire research period (Hummelvoll, 2003). Common criteria for establishing the trustworthiness of qualitative data are discussed in Polit and Beck (2004): credibility, transferability, dependability, and confirmability. In the following, these criteria are described and discussed in relation to the different sub-studies in this thesis.

### 3.8.1 *Credibility and transferability*

The credibility of the findings is dependent on the information about the research process presented by the researcher, his/her role and the arguments used for making and “defending knowledge claims” when choosing between competing

interpretations (Willumsen, 2006). Prolonged engagement is important for building trust and rapport with informants, for in-depth understanding of the culture and testing for misinformation (Polit & Beck, 2004). In this study, the researchers and co-researchers had long-term experience in the field. Credibility also involves persistent observations (Polit & Beck, 2004), which in this study concerned different perspectives of the social integration of people with mental health problems living in the community.

Triangulation can also enhance credibility (Polit & Beck, 2004). Methodological triangulation was used in this study in the form of within-method triangulation (Burns & Grove, 2005). Social integration and social networks were studied multidimensionally by means of various data collection tools and methods of analysis (Papers I, II and III). This provided the opportunity to study the phenomenon ethnographically from several perspectives. The data collected in this study have two main perspectives: a neighbour (Paper I) and a service user perspective (Papers II and III), thus making it possible to study the social integration of people with mental health problems from several angles and allowing for triangulation, which strengthens validity.

Peer debriefing can help establish credibility and provides external checks at different stages of the inquiry (Polit & Beck, 2004). Papers (I-IV) have been presented to peers on several occasions, such as doctoral seminars and workshops. The presentation of the findings to people with mental health problems and psychiatric nurses has also been important, and their comments have enhanced the credibility of the findings. In the co-operative inquiry, two forums were significant for peer debriefing. One is the project forum, where colleagues presented and discussed their research with each other, thus helping to maintain direction. The other was a reference group comprising service users, the community mental health service and institutions and representatives of the county authority. Critical questions and calls for explanation were valuable throughout the research process. Communicative validity was also ensured through discussions of published and unpublished reports with the co-researchers and the research group.

According to Silverman (2006), sampling strategies may affect the data available for analysis. The study comprised 19 participants from the neighbourhoods in Paper I, 12 and 17 people with mental health problems in Papers II and III respectively and 22 professionals in Paper IV. In qualitative inquiry, the focus is on events and incidents, and the samples are appropriate for the credibility of the study.

In Papers I-III, the data originated from a small geographical area of eastern Norway, which can be considered a weakness. However, the fact that both the individual

and the focus group interviews were held in rural and urban areas strengthens the validity of the study. In the sub-study concerning the neighbourhoods of group homes (Paper I), the population had a fairly similar social background (middle-class home owners, with children attending the neighbourhood school). Strong homogeneity in terms of background and social class within the neighbourhoods could have had a negative impact on their acceptance of the group home. There was, however, consensus among informants in the same neighbourhood, which further confirms the validity.

Because the interviews with people with mental health problems were group rather than one-to-one interviews and conducted in the familiar environment of the psychiatric day-care centres (Papers II and III), it can be assumed that the participants felt safe and free to voice their opinions. Furthermore, the participants elaborated on each other's commentaries, thus bringing more opinions to the fore, which is yet another strength of the study. A further strength is the wide range of ages and psychological problems present among the participants. A weakness of this study (Paper I) is the fact that most of the participants attended the psychiatric day-care centres or the "Mental Helse" organisation, which provided them with a meeting place for social contacts, thus influencing their views on the immediate environment. Multistage focus groups (Papers III and IV) served to strengthen validity due to the summarising of the preceding focus group discussion and feedback from the participants. This inter-subjective validation provided an opportunity to elaborate on specific topics that required clarification. Some of the participants knew each other, which reduced tension and facilitated the flow of conversation. Face validity was enhanced by comparing between all groups (Svensson, 1996).

The interaction among the group members in a group interview situation reduces the interviewer's control and can produce a somewhat chaotic recording, making it difficult to systematically hear or analyse (Kvale, 1997). Therefore, in this study, the focus groups were instructed about how to increase the clarity of the recording. Further difficulties are obtaining an idea of the frequency of a problem and preserving the anonymity of the informants. In addition, there is a risk that one or more participants in each group will dominate the discussion so that the viewpoints of other informants cannot be heard (Magnusson, 2003). This risk was taken into consideration in the present study. It is important that the moderator has training in group interviews or working with groups, as was the case in this study. The preliminary analysis and transcription of the material acquired from the multistage focus groups are read through and commented on by the observers, which contributes to validating the results. The fact that the group members comment on each other's experiences and statements also increases generalisability. In the present study, the experiences and views expressed were for the most part present in all three groups, which increases the validity of the

findings. Member checks (Polit & Beck, 2004) were an important part of the process in all of the focus groups.

Transferability refers to the extent to which the findings from the data can be transferred to other settings or groups as well as to the concept of generalisation (Polit & Beck, 2004). Due to the small sample, it would be inappropriate to claim generalisability. The purpose of this study was not to achieve empirically generalisable data, but to increase knowledge of the social integration of people with mental health problems and to develop that knowledge further by means of co-operative inquiry in two municipalities. Thick description refers to a rich description of the research during the whole process (Polit & Beck, 2004). Hopefully the description of the research in the present study will allow readers to judge the degree of transferability of the findings to other settings. The sample was extended to include additional cases, in order to expand variation in relevant settings in relation to the early findings and emergent theory.

The transferability was tested through lectures and discussions, in meetings with mental health personnel, service users and research colleagues, and at congresses, mostly held within the Nordic countries. The face validity of these discussions strengthens the findings.

### *3.8.2 Confirmability and dependability*

Confirmability refers to the objectivity or neutrality of the data (Polit & Beck, 2004). The ‘audit trail’ of this study was strengthened via the systematic collection of documentation from the findings and the analysis process, which was then presented to supervisors and colleagues. The writing and presentation of reports containing detailed documentation of the process and the findings to the participants, co-researchers and within the research group also increases the trustworthiness of the study. The information was grounded in events rather than the researcher’s personal constructions.

Dependability refers to a process that is systematic, logical and documented (Polit & Beck, 2004). An inquiry audit was performed at different stages of this study. An attempt was made to strengthen validity through the project’s research forum, where the research design and results were discussed. The research plan was evaluated before the start of the sub-projects and it was also scrutinised by the reference group during the process. The dialogue-based teaching project was frequently discussed in the research forum and at other meetings of the project group. Feedback was obtained during the process at half yearly reviews in the municipalities as well as in reports on the project.

Grounded Theory (Papers I and II) seeks to inductively generate new theories. Generating a theory from data means that most hypotheses and concepts not

only come from the data, but are systematically developed in relation to the data during the course of the research (Glaser & Strauss, 1967). Findings should be validated at regular intervals during the entire process by going back to the empirical data and comparing the analysed results with the original text. The concept of saturation is unique to Grounded Theory and strengthens the method. Theoretical saturation indicates that no additional data emerge that can be used to further develop the properties of the category (Glaser & Strauss, 1967). It is difficult to know the precise point of saturation, although the face validity of the statements from the participants and other people with mental health problems indicates that saturation was reached in this study.

Qualitative research based on focus group interviews requires understanding and co-operation between the researcher and the participants, so that the texts are mutually understood and evaluated. However, a text always involves multiple meanings and can be seen as interaction between the researcher and the participants, an act of communication. Qualitative content analysis (Papers III and IV) focuses on the subject and context, emphasises differences and similarities within codes and categories and includes both manifest and latent content (Graneheim & Lundman, 2004).

The final sub-study, which employed co-operative inquiry, provided some challenges from a methodological point of view (Paper IV). Focus group interviews were planned to take place on three occasions during the research process in order to evaluate whether the intervention had led to any change. The first was conducted during the initial period of the intervention, the second about halfway through the process and the third when the dialogue-based teaching was completed. The group that took part in the focus group interviews was the same as the one that participated in the dialogue-based teaching, and most of the focus group participants took part in at least two of these interviews. This continuity also served to strengthen the dependability of the findings.

One problem regarding confirmability is the fact that the dialogue-based teaching (Paper IV) was changed to a credit-earning course, which led to a core group of participants who were always present and others who attended less frequently. Another weakness of the study is that the same researcher created the research plan, carried out the intervention and undertook the evaluation. In order to minimise that effect, one co-moderator, who did not participate in the dialogue-based teaching, also provided assistance with the analysis. It remains to be seen whether positive feedback was given merely to please the researcher, or whether the changes were genuine. However, the results contained both positive and negative feedback, which tends to indicate truthfulness.

Co-operative inquiry can claim to be a valid research approach “*because it rests on a collaborative encounter with experience*” (Reason, 1994, p. 327). In this study, it can be described by means of three factors. *Participatory and holistic knowing* means moving away from the distance and separateness of objectivity. This paradigm was chosen, due to the fact that its core concepts: wholeness, complexity and participation, are valuable. Wholeness requires participation. One cannot truly conceive the structure of wholeness, unless one accepts that its meaning implies the involvement of all parts. Just as wholeness implies participation, participation in turn means *empathy* (understood as an almost complete identification with the subject in question) – and empathy implies responsibility. Complexity only becomes visible through participation in the system. In other words, being a part of the system allows one to see the complexity inherent in the whole (Reason, 1994; Hummelvoll, 2003). *Critical subjectivity* is, according to Reason (1998), a quality of one’s consciousness that helps to overcome the split between objectivity and subjectivity. This means that one neither suppresses primary, naive subjective experiences, nor allows oneself to be overwhelmed or ruled by them. Instead, the experience is consciously focused upon as part of the research process. The validity of the evaluation of this co-operative inquiry rests on self-awareness and the discriminating, critical and informed judgement of the participants (Hummelvoll & Severinsson, 2005). Critical awareness means the realisation that each one of us sees the world as his/her world – and not as *the* world. Consequently, individual experiences are emphasised.

*Knowledge in action* implies that knowledge is created *in* and *for* action – rather than *in* and *for* reflection. Therefore, co-operative inquiry, education and social action can be integrated in the research process. Reason (1988) holds that valid inquiry is based on a high degree of self-knowledge, self-reflection and co-operative criticism.

Professionals, service users and researchers all collaborated in this research strategy in order to create knowledge of relevance to practice. All the participants are both co-researchers and co-subjects (Hummelvoll, 2003). In order for the project to be successful, all participants should have an understanding of the field, as well as of the basic values that should guide practice, to which it is hoped that the research will contribute (Holte & Hummelvoll, 2004). Traditional public health research seeks to create knowledge for the sake of understanding, while co-operative inquiry seeks to develop knowledge for action. It is therefore important how the research problem is formulated and by whom, as well as for whom the results are intended (Hummelvoll, 2006). The researcher needs to be aware of the strengths and limits of pre-understanding in order to use his/her experiential knowledge to reframe his/her understanding of the situations under study (Coghlan & Casey, 2000).

In this project (Paper IV), the strengthening of the validity and quality within the focus groups was ensured by inviting the participants to read and comment on the analysis as well as to document the generated knowledge, thus acting as an 'advanced secretary' (cf. Hummelvoll & Severinsson, 2005). However, there are some limitations related to the size of the sample and participation, since the number of participants varied. The project took place over an extended period of time and required commitment from both project leaders and participants. This study was part of a larger project in which dialogue-based teaching formed the principal research approach. It is possible that participating in all parts of the project simultaneously proved too time-consuming for the participants. In spite of these limitations, the participants experienced the new knowledge as relevant for the solution of their current problems (Paper IV).

### **3.9 Ethical considerations**

All transcripts and data were rendered anonymous. The participants were assured that their anonymity and confidentiality would be protected: no information that could identify them or their place of residence was included in the final report, only their gender and age. None of the participants withdrew from the study. The Helsinki Declaration guidelines were respected (World Medical Association, 2002) as well as the guidelines pertaining to reduced capacity to give consent in health research (The National Committee for Medical Research Ethics, 2005) and the ethical guidelines for nursing research in the Nordic countries (The Northern Nurses Federation, 2003). It was important that people who are dependent and vulnerable should be protected against abuse. The dignity, rights, safety and well-being of all participants must be the overriding consideration (Tee & Lathelean, 2007).

An introductory letter (Appendices 2 & 3) containing an invitation to take part in individual or focus group interviews was sent to the potential participants via mental health teams in the municipalities and also via the Mental Helse user organisation. The reply slip was to be returned to mental health teams in the municipality. Potential informants were provided with both verbal and written information about the aims of the study as well as their right to decline participation or to withdraw at any time. A declaration of consent was signed by all participants with the exception of those in Paper IV (Appendices 4), who gave verbal consent.

In sub-study I (Paper I), group homes were selected in order to counteract stigmatisation of the residents. There could have been a risk of the residents being labelled 'psychiatric patients', if a group home had been chosen whose neighbourhood was not aware of what it was. This type of study can also increase

the risk of stigmatisation. For that reason, interviews were only undertaken in neighbourhoods where it was already public knowledge that the homes were group residences for people with serious mental health problems. Another important criterion was that the group home should be in the form of adjoining single or multi-level flats, a sub-divided house, or other similar arrangement, as individuals are less in focus in such a residence.

Circumstances which might influence the participants' capacity to freely give consent were assessed for each individual informant in the sub-studies (Papers II and III), and none of the participants were considered to have a reduced capacity to consent. The information, both written and oral, was adjusted for each group of informants (The National Committee for Medical Research Ethics, 2005). As a trained mental health nurse, the researcher possesses awareness and skill in navigating the interpersonal, relational and group dynamics that can arise (cf. Tee & Lathelean, 2007). Participating in an interview can put strain on an individual, thus attempts were made to minimise this effect by striving for a comfortable and calm atmosphere and treating the informants and what they said with respect and openness. Participants with a known vulnerability must be met on their own terms. Furthermore, the fact that individuals with not-known vulnerability could be participating underlines the value of caring during the data-collecting process (cf. Hummelvoll, 2007a). There were no questions concerning deeply personal issues. In these focus group interviews, the co-moderator acted as a support and back-up in the event of anyone having a problem during the interview. After the interviews, a mental health nurse was at hand in case any of the participants needed support.

Several participants expressed gratitude that these topics had been brought out into the open. The neighbours of the group homes had a strong need to express their experiences, as had the residents in terms of describing their living conditions and the challenge of having mental health problems, which supports the ethical justification for the study.

The research in Papers I, II and III was approved by the Regional Committee for Medical Research Ethics, Norway (Papers I & II, reg.no. 120/97 Paper III, reg.no: 03025. Appendices 2 & 3.), while Paper IV was approved by the political leadership, administration, and staff of the two municipalities. The research project was met with overall approval in the two municipalities involved.



## 4 OVERVIEW OF THE FINDINGS

In the following, the findings, which are related to the research questions, will be presented. The first section deals with the experience in neighbourhoods where people with mental health problems took up residence (Paper I). This is followed by a description of the experience of people with mental health problems of living in an apartment of their own (Paper II) and their ability to integrate into the community (Paper III). The final section focuses on how mental health professionals' knowledge of social integration can promote practical change and took the form of a co-operative inquiry (Paper IV).

### 4.1 Paper I: The new neighbour – experiences of living next door to people suffering from long-term mental illness

The main category was: *The need for information*. From the time that the construction of the group home was made known to the participants, they expressed a need for information and a wish to have a say in the process. The subcategories were: *Neighbourhood participation* (in the preparation phase), *Stigmatisation* and *Insecurity and fear* (in the orientation phase) and *Segregation tendencies* (in the normative phase). From the outset, the neighbours' attitude to the group home was directly related to their degree of knowledge about the project. A neighbourhood goes through different phases when a group home for patients with long-term mental illness is established: a preparation phase (during which the neighbours prepare themselves for what is going to happen), an orientation phase (which starts when the residents move into the newly established home) and a normative phase (the neighbours live side by side and contact between them creates a pattern which affects the neighbourhood environment).

In Figure 2, the relationships between the core category and the sub-categories are presented in visual form. When the neighbours received the *news - knowledge of the group home*, they reacted with *insecurity* and *fear*, as they had been influenced by previous experiences, by impressions from the media, the fact that mental health problems can seem frightening and did not know how to behave towards people with such problems. This insecurity led to activity, *neighbourhood*

participation, where neighbours discussed how the new group home might affect them, their families and the neighbourhood in general. They attempted to contact public authorities for the information they needed in order to prepare themselves. In other words, they expressed a *need for information*.

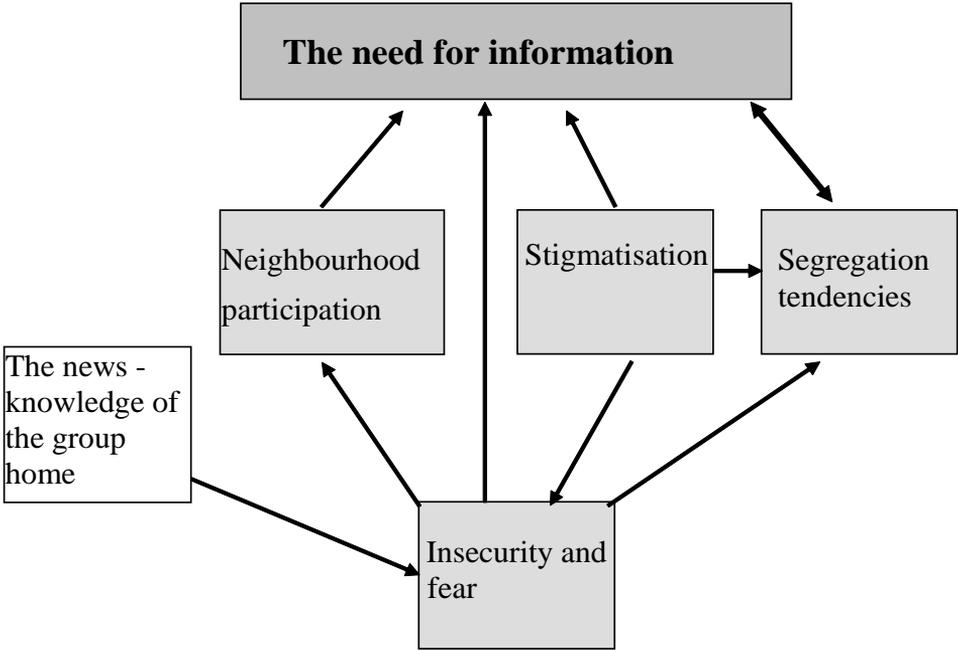


Figure 2: Schematic diagram of the neighbourhood’s experiences of the establishment of a group home for people with mental health problems.

After the establishment of the group home, the neighbours acquired experience of the residents. The intention was that the new neighbours would become a natural part of the environment. However, deviant behaviour soon became prevalent, as reported by nearly all of the participants, which led to *stigmatisation*. The neighbours experienced a “difference” they did not understand. The new residents did not conform to accepted social norms. One or two of the residents in each group home exhibited a strong degree of deviant behaviour, which gave the participants a feeling of *insecurity* and *fear* and influenced their attitudes towards all the residents. Because many of them dressed in a strange manner, they were very visible. Several of the participants perceived social behaviour which seemed alien to them. The neighbourhoods experienced both difficult and frightening episodes, and the neighbours felt that no one was responsible for the group home residents, which led to insecurity and fear. They had a need to understand what was going on in their neighbourhood as well as a *need for information* about their new neighbours, and what steps could be taken to prepare for their arrival. Contact difficulties accentuated the stigmatised behaviour of the group home residents who were perceived as choosing to isolate themselves from

the rest of the neighbourhood. Insecurity was evident in many areas, such as in the reactions of the group home residents, the participants' reactions and those of their family members, friends and neighbours. More information about the residents made the neighbours feel more secure.

The segregation tendencies category indicated that there was no hope of integration in the neighbourhood. The need for information, the insecurity and fear in addition to the stigmatised behaviour led to a tendency towards segregation. The neighbours only wanted superficial contact and kept their distance from the group home residents. At most, they were willing to exchange greetings and 'small-talk about the weather', which was compounded by declining levels of social interaction in the neighbourhood in general. Insecurity and fear also led to the informants keeping a watch for the group home residents. Some became meticulous about locking the door and had instructed their children how to behave towards the group home residents. Because of the encounters the informants had had with their new neighbours and the impression that they were lonely and excluded from the neighbourhood community, the participants questioned whether an institution or district where more people with mental health problems lived together would not be a better arrangement.

#### **4.2 Paper II: Preserving integrity – experiences of people with mental health problems of living in their own home and of their new neighbourhood**

The core category identified was *preserving integrity*, which describes the importance of maintaining dignity and being seen as a whole person by means of setting limits to what others know about oneself as a person. The participants wished to appear as a whole person, with positive and negative sides, not as a psychiatric patient. Integrity plays a part in controlling how safe the individual feels in his/her own home or immediate environment. Without autonomy or control over what other people are told about one's life, strengths and weaknesses, one may experience a lack of integrity.

This study also identified three sub-categories: *The need for control over information*, *Symmetric contact* and *My home is my castle*. The violation of human dignity caused by being perceived as different or being met with prejudice on account of mental illness made information control essential. Several of the participants who had negative experiences of other people knowing about their mental health problems had a strong desire to keep information about their psychological state private. They had experienced that mental illness is shameful, which made it difficult to gain acceptance. The participants' self-image had been affected by the lack of acceptance of mental health problems in society.

The participants were aware that communication opens the door to interaction, thus reducing rumour and fear in the neighbourhood. Some of them stated that “information can be given to neighbours if I have control over the information”. However, a few pointed out that there is now a greater openness about mental problems than previously. Some of the participants had experienced that openness was positive – telling people about their problems had brought positive reactions and made them feel respected, which in turn helped them to build self-respect and accept their own problems, thus leading to improved quality of life.

Similarity is central in the *symmetric contact* category. The participants related that it can be difficult to communicate with other people. They regarded their homes as an essential foundation for a secure and independent life and considered that a social life and companionship with other people were also important. Their closest and most common relationships were with people who also had psychological problems or who had previously suffered in this way. This endows the relationship with a balance that is not present in other relationships. The participants indicated that similar circumstances, such as living on a pension, similar ways of facing challenges and similar values are of decisive importance, more so than similar age, hobbies and interests. Similarity gives the participants a feeling of safety, which must be present in human contacts in order for friendship to develop. A psychiatric day centre in the community was important for most of the participants, as it provided them with the opportunity to communicate with people with similar problems, to participate in activities encompassing hobbies, vocational training, excursions or parties, and last but not least, to vent their joys and problems with people in the same situation or with professional personnel. Several of the participants who had no contact with their neighbours wished to have such contact and wanted help to achieve it. They stressed that if help to befriend their neighbours was to be offered, it should be provided shortly after moving in. Because the participants had experienced insufficient acceptance of their mental health problems, it became important to maintain their integrity by controlling the information given to other people about them. Information control was thus a necessary condition for the informants’ ability to become equal citizens and have the opportunity to develop social contacts.

“*My home is my castle*” emphasises the importance of having a home of one’s own, which offers highly valued freedom and independence. None of the participants wanted a home far removed from ordinary neighbourhoods, despite the fact that several of them had experienced problems integrating into a neighbourhood community. A number of the participants mentioned the feeling of safety and comfort associated with having their own home. Freedom and the feeling of independence from family and the healthcare system were important for the residents, as only in this way could they take responsibility for, and control of, their lives, thus achieving enhanced quality of life. Independence also

meant mastering the challenges and demands of daily life, such as controlling symptoms and dealing with problems related to household chores. A household assistant was experienced by some of the participants as a helping hand towards an independent life.

### **4.3 Paper III:**

#### **The struggle for social integration in the community – the experiences of people with mental health problems**

The findings of Paper III are characterised by the main theme *Living with shame and fear of exclusion* and three sub-categories: *Loneliness*, *Struggling for equality* and *Being neglected*, in which the participants described their experiences of being marginalized or less active in the community. Contact with other people and a sense of well-being in their local environment influenced their level of contentment. They wanted to test and utilise new strategies, particularly those that had proved useful as a catalyst for promoting reciprocal relationships. The desire for personal development by acquiring knowledge and accepting challenges was evident, as was the need for a great deal of self-initiative. In the process of integrating into the community, they sought support from family, friends and the health services.

A sense of loneliness was dominant for most of the participants, which varied from all-encompassing loneliness to having contact with family and friends, but still experiencing many hours of solitude. The majority considered such isolation extremely difficult to cope with. Lack of a job or regular daytime activity and being alone in the house or apartment resulted in several hours of loneliness during the day. They reported that their days passed slowly and that time had little meaning. The experience of being different is closely related to various factors: feeling that one is not needed, inability to be gainfully employed, the feeling of not contributing to society, low income, and a sense that contact with others only occurs via health professionals.

A person who has mental health problems cannot do or say much that is not in line with ‘mainstream’ views, as it is likely to lead to misinterpretation. The participants reported being looked down upon or ignored due to having been in a psychiatric institution. Limited financial resources affected their ability to interact in their social network and emphasised the image they had of themselves as different as well as their feeling of being excluded from society.

Relationships with other people and meaningful activities on a routine basis provided a solid foundation and enabled the participants to feel as a whole person and equal. The most important objective is for the participants to return to the

work force, as it provides an income. It also allows the individual to compare him/herself with colleagues. Another significant aspect is the need to feel important to someone. The participants wanted a companion, preferably someone close to their own age, with whom they could share common interests, in order to help them identify with others and thus establish more lasting relationships. Those who had a job or were active in a club or organization gave the impression of having a meaningful existence and experienced loneliness to a lesser degree. Family and family ties were important to the participants, as they were considered less demanding. However, family ties could also be problematic. Approximately half of the informants reported conflict in their family relationships.

The participants stated that health care professionals ignored their wishes and attempts to expand their social network, particularly in psychiatric institutions. Several believed that their professional support teams were unaware of the significance of family and relationships in their lives. The participants claimed that it was not in their best interest to be too outspoken or appear too knowledgeable when receiving treatment. Problems were not recognized when a person was able to express him/herself with ease and clients felt that being knowledgeable and articulate could actually be a disadvantage, as it makes the difficulties appear less obvious. They described encountering “false empathy”, which they considered degrading and humiliating.

#### **4.4 Paper IV: Knowledge about social networks and integration: A co-operative research project**

The main theme in this study was: *The potential of experiential knowledge-based competence*. The categories which characterise this theme are: 1) *increased knowledge*; 2) *awareness of social interactions*; 3) *cross-disciplinary professionalism*; and 4) *potential for changes in practice*. The theme and categories influenced and strengthened each other in the interactive process, where the dialogue and focus were on social integration. By the end of the project, all participants expressed that they had increased their theoretical knowledge considerably as well as obtained social network intervention tools. The knowledge gained enabled them to develop and implement new skills in community mental health work.

Dialogue-based teaching enhanced the participants’ professional competence as a result of systematic reflection and indicated that their working methods were firmly grounded in scientific knowledge and theory. They learned from each other by discussing experiential and academic knowledge and considered client narratives especially valuable. Dialogue-oriented teaching gave the participants increased insight into how they understood themselves as professionals, as well as how they understood other individuals, both clients and colleagues. They

found that their problem-solving became more creative and their thinking broader and stated that they discovered new methods to use when working in the community.

One effect of dialogue in smaller groups was that the participants became well acquainted. They contributed their own professional perspectives and discovered that, in spite of their different competencies, they had much in common. Sharing opinions by means of dialogue-based teaching allowed them to become closer. They reported similar experiences and made joint suggestions for interventions. Cross-disciplinary co-operation arises spontaneously from the knowledge dialogue. Understanding, dialogue and solidarity among the participants enhanced confidence, which increased the tendency to use each other's expertise. Participating in cross-disciplinary dialogue makes one realise that cross-disciplinary co-operation is essential for solving problems. The dialogue altered their way of viewing themselves and others.

The participants reported that they had redefined their work in the community and had thus become more aware of the border-residents' status and challenges at least from a theoretical perspective. The participants had a preconception that social integration was essential for the clients' quality of life and were interested in social network strategies and the opportunities inherent in social integration, although few had experience of specific methods. The essence of experiential knowledge is that there are many possible ways of helping clients to expand their social networks. The experiential knowledge thus gained may contribute to health-promotion strategies such as social integration. Thereby, the professionals can provide a stronger sense of belonging to the local community for people with mental health problems. Significant changes took place between the initiation of the dialogue-based teaching as well as between the first and last focus group interviews. The participants had become more creative and aware of social networks. New possibilities for improving the clients' social integration were discussed as well as more proactive use of existing possibilities. The participants in this study gained professional and cross-disciplinary confidence although, to date, the knowledge has still not been fully implemented in practice. The participants have all experienced that a change in working practice takes time. Much of their work with the clients is aimed at trying to motivate them to take part in activities of interest. Through activities, the clients obtain social practice and the opportunity to try out new ways of being together. The focus here is on client-managed activities.

There was potential for changes in practice. Most of the participants had tried to identify ways to increase their clients' social contacts, such as by creating new meeting points. Network maps and informal mappings of clients' social networks were the methods most frequently employed by the participants. Furthermore, the

participants stated that participation in the dialogue-based teaching encouraged them to test network-building strategies that they had considered in the past, but rarely put into practice. In the urban municipality, where the culture department was especially active, a number of different methods for strengthening social networks and improving social integration had been used. The most important task for the participants was to help the clients to find something to get up for in the morning and in this regard they considered that work was particularly important. An activity or job where someone was expecting them and where they could engage in a meaningful activity was a requirement for bringing people with mental health problems back into a more ordinary societal role. Clients were matched with others in different activity groups over a longer period of time. The participants expressed that similar circumstances and experiences with mental health problems gave the clients a unique bond. This common experience creates a bond from which friendship can later develop. In the co-researchers' experience, creating friendships required a large investment of time for most clients. Participants from the rural community were even more aware that they should have worked harder to promote better social integration and networks for their clients, instead of concentrating on helping them with their physical symptoms. Social network interventions, loneliness and clients' social networks had previously only been superficially addressed in consultations.

One of the goals of this project was to present concrete suggestions for social integration initiatives or models, which could be used in the two municipalities. Creative suggestions came from both communities, and the ideas were further developed in small groups as well as in both the dialogue-based teaching sessions and the focus group interviews. Participants from the urban municipality developed suggestions for adventure groups for young people in danger of exclusion from ordinary social life. Young adults without jobs or studies lack opportunities for social interaction. A lack of structure and meaning in their existence, and a feeling of being a border-resident, can lead to mental health problems. It is important to start preventive measures before their mental health problems and feelings of social exclusion become too great. The tentative target age is 18-30 years. The project's aim was to establish social network groups with activities related to the members' interests, in co-operation with other voluntary organisations in the community. An environment where personal experiences and individual contributions are in focus could support such young people in developing their own resources and provide them with a feeling of social integration. This group could give its members something to share with others. The goal should be to develop the group into a voluntary organisation, or to become a part of a pre-existing voluntary organisation. Another goal should be to increase the group members' confidence in their own personal resources, in order to encourage them to start work or continue their school career. These groups are now up and running.

In the rural municipality, a plan for an activity centre was developed, which involved obtaining a house or small farm and building on ideas from other activity centres and co-operative projects. The project was given the working title “Green Fingers Farm”. Residents who are not involved in ordinary working life and feel themselves to be outsiders should have a more active life in order to combat loneliness and depression. This applies to the long-term unemployed and those in receipt of a disability pension. Inspired by the “Fountain House” concept of co-operative and sheltered workplaces, official support for the idea of a small farm project has grown. The farm will be characterised by a high level of client involvement and a low participation threshold. A start has now been made with the setting up of a centre on a small scale.



## 5 INTERPRETATION AND GENERAL DISCUSSION

The essence of social integration for people with mental health problems is being empowered to rebuild a valuable and meaningful life. The role of mental health workers in this process is to help people see what is possible and then to assist them by supporting their choices (cf. Bertram & Stickey, 2005). This chapter discusses the findings from Papers I-IV in the light of the research questions.

### **5.1 People with mental health problems re-establishing in a local environment and their social integration**

The first research question was: *How have people with mental health problems affected their neighbourhood after re-establishing in the community?* The answer to this question is summarized by the main findings of this study: neighbours of group homes for people with mental health problems experienced insecurity, fear and uncertainty as a result of frightening and stigmatised behaviour as well as complications in their contact with the residents, which led to exclusion and segregation in the form of distancing or watching. There was a great need for information. One main question raised by the informants was: “Is an institution not a better alternative for this group?”

The literature review revealed that mental health problems are a public health issue (cf. WHO, 2002). The majority of people come into contact with mental health problems through their own difficulties or those of their friends and family members. The term ‘mental health problems’ (WHO, 2001b) covers a wide range of conditions from mild depression to acute schizophrenia. Each individual’s experience of mental health problems differs and depends on various factors, such as the level and type of mental distress, his/her social network – friends, partner, family and support persons as well as his/her previous experience of mental distress or illness. Another term used is ‘mental health difficulties’ (Office of the Deputy Prime Minister, 2004), the definition of which is similar to that of mental health problems. However, it can be understood as a milder and more transient condition. The term can be interpreted as being less stigmatising and

makes the condition appear more ordinary. Due to the variety of mental health problems, both in level and types of difficulties, it makes sense not to limit the term to a group of mental health illnesses.

People's social lives are constantly changing. Contact between neighbours is influenced by the general changes in society as a whole. A central factor is mobility. People change their place of residence more often than was previously the case and most work outside the home, in another area of the town or city away from their neighbourhood. The majority of friends and family live in different neighbourhoods. People use cars to meet each other. Higher standards of living make it possible to travel more often and to be socially active outside the local environment (cf. Fyrand, 2005).

In Paper I contact between neighbours was described as decreasing. Some participants indicated a desire for only superficial interaction with their neighbours. Mobility and social activities outside the local community may be reasons for the decreasing social contact with neighbours, which in turn affects the amount of contact people wish to have with the new neighbours who have mental health problems. The study showed that there was little or no desire for contact with this group of neighbours, which is similar to the findings of Barham and Hayward (1995). This lack of reciprocity makes the possibility of a meeting difficult (cf. Pinfold, 2000), as reciprocity is essential for the ability to enter into a relationship. To increase the opportunities for a tighter neighbour network for people with mental health problems, efforts to increase reciprocity should be emphasised in all situations where interaction is important.

Information and the need for information were key issues for the neighbours of the group homes. When someone faces the unknown, he/she needs knowledge and information, in the same way as when we are frightened or insecure, or have experienced a stressful situation in which we were afraid. Information is necessary in order to understand, to make the world predictable, and to regain control and equilibrium. The neighbourhood balance is affected when a new residence is built and the effect is experienced as irreversible. In the case of a home for people with special needs, the relative uncertainty is even greater (cf. Magnusson, 2003).

Generally speaking, no one has the right or responsibility to provide or receive notification when homes change hands. For many people, mental health problems are associated with stigma (Johnstone, 2001). Furthermore, these problems are experienced as taboo-laden and leading to segregation. In addition, mental health problems are often associated with lower self-esteem and difficulties in contact with other people (cf. Nilsson, 2004). These circumstances contribute to the desire to withhold information about mental health problems. In this study,

some of the people with mental health problems who spoke about their struggle experienced rejection, which is supported by other studies (Barham & Hayward, 1995; Bengtsson-Tops, 2001; Nilsson, 2004). Is it right to share this information? In order to maintain their integrity and autonomy, people with mental health problems must have control over the information that is provided about them to others. This is an important human principle and no less so for people with mental health problems.

In order to minimise rumours and speculation and reduce insecurity, some form of information should be given when a group home for people with mental health problems is to be built. The information should be general in nature and formulated in a positive way without going into detail about the future residents. The information might, for example, try to describe what is involved in having a serious mental health problem and how it affects interaction with other people. It could also explain how contact can be established between the 'new neighbours' and the neighbourhood. The information should be presented to the new residents first and approved by them before it is disseminated. In this way, the new group homes could achieve a more positive start. Neighbours' uncertainty might be replaced by understanding and respect and the neighbourhood would be able to escape the insecurity described by the participants. The beginning of the integration process is important, a fact that was pointed out by neighbours as well as the group home residents and needs to be emphasised (cf. Elstad, 1999).

Some participants in Paper I mentioned an alternative. Those who desired closer contact with their new neighbours had been provided with the appropriate information in the form of letters or conversations with the responsible professionals. It is important to note that, also in this process, the key concept was information, along with a positive encounter. Would the encounter have been a positive one without the provision of this information?

The uncertainty and fear described by the participants led to negative reactions and segregation. It seemed that neither people with mental health problems nor their neighbours wished to have closer relationships with each other. There was mutual scepticism, which both groups explained as being due to their uncertainty about the reactions of the other group. In other studies, people with serious mental health problems were deemed to be in a state of liminality, associated with threat or unease (Warner & Gabe, 2004). Should people with mental health problems aim at becoming a natural part of the local environment, but without close relationships with their neighbours?

There were multiple causes of insecurity and fear felt by the neighbours towards the group home residents as a result of incidents which were experienced as unpleasant or frightening, as well as earlier experiences and opinions. The

neighbours' fear was detected by the group home residents, who reacted by maintaining their distance, resulting in the development of a negative spiral that is very difficult to break. It was surprising that many of the participants expressed insecurity and fear. This insecurity must be taken seriously and requires the availability of professionals. It is important to note that the insecurity and fear were mainly directed towards one or two residents of the group home. It takes a long time to establish confidence when fear and uncertainty have taken root. The professionals should discuss what social skills people with mental health problems should master before they move into their own residence.

'Border-resider' status among members who are seen as different based on history and other social factors (Drevdahl, 2002) can be discerned in all the parts of the study (Papers I-IV). This rendered the service users helpless and powerless when it came to bringing about changes in their lives. Their status of 'Border-resider' creates challenges for health care professionals and social workers to support and meet them as individuals. Mental health problems can be seen as both consequences and causes of social exclusion, both of which are evident in the present study. Mental health problems appear to lead to economic deprivation and social isolation. To respect a person's integrity and his/her personal sphere, means respecting his/her values, wishes and boundaries (cf. Andersson, 1994).

The two aspects that facilitate a meeting between people are reciprocity and the availability of meeting places, the importance of which is underlined by the present findings (Paper I). Reciprocity is necessary for achieving contact and social companionship (cf. Kawachi & Bekman, 2001) and develops when a mutual recognition of behaviour, interests and values occurs. The degree of reciprocity is an important expression of the quality of a relationship. Social contacts with a large degree of reciprocity are favourable in, for example, a supportive relationship. Reciprocity is based on a sense of security (Drevdahl, 2002). The results of this study indicate that the two groups do not have a basic sense of security in relation to each other. Professionals can actively create meeting places in the local environment, and a sense of security can be achieved by means of openness and information. This can help to stimulate more reciprocity and social contact. In order to see people as fellow human beings, we need to know them.

## **5.2 Experience of social integration for people with mental health problems**

The research question describing social integration from the service users' point of view was: *How do people with mental health problems experience social integration in the community?* The findings from the study related to this question are as follows: persons suffering from mental health problems regard their home

as important for a safe and independent life – a place where autonomy and dignity in the contact with other people can develop. Living in the community was experienced as important. The participants' social life mainly consisted of contact with other people with mental health problems. Similar life situations were more important than age, interests and hobbies. The participants had little or no contact with their neighbours outside of the group home and most of them did not wish for any. As the participants had experienced a lack of acceptance and loss of autonomy when meeting people, it was considered important to preserve their integrity by controlling the amount of information provided about their condition to other people. Individuals who suffer from mental health problems struggle with social integration within the community. One explanation is the reported experience of living with shame and loneliness. This problem is often associated with low self-esteem, anxiety and depression, hence a well-run day centre, organisation or job may decrease stigmatisation and reduce feelings of alienation. In addition, the importance of family ties was overlooked by the health professionals.

The mental health care reforms in Norway have altered the situation for people with mental health problems (The Directorate for Health and Social Affairs, 2005). Nevertheless, one can question whether the investment in community mental health has led to people with mental health problems becoming more integrated in society; the findings in this study show that they feel marginalised. People with mental health problems generally have difficulty coming into contact with others (Bengtsson-Tops, 2001; Nilsson, 2004) while those around them feel that it is difficult to have contact with them, as they are different in terms of both appearance and behaviour. According to the participants in this study (Papers II & III), when people with mental health problems live in ordinary neighbourhoods, it can be easier for the other residents to accept them, and making contact with people may also be easier. However, people with mental health problems experience that they have to 'be even more normal than others' in order to prevent stigmatisation.

The findings in Papers II and III indicate that social integration is defined as actively participating in the local community and co-operating with others. A person does not need close contact in a neighbourhood in order to feel socially integrated. If a person has no organised daytime activities, the local environment, family and other social networks will assume greater importance.

One of the main goals of the Mental Health Reform (The Norwegian Social and Health Department, 1998) is to take account of the needs of service users – from the perspective of their entire life situation – when determining what services to offer. People with mental health problems should be able to live as 'normal' a life as possible with a sense of well-being, increased quality of life and participation

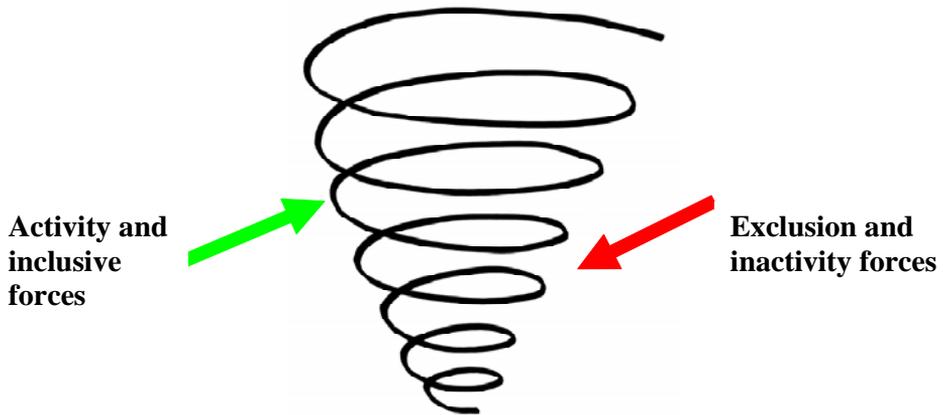
in society. Their fundamental needs should be met in the form of a suitable home with adequate support, participation in working life or another meaningful activity and belonging in a social context. A high degree of user co-operation is necessary in order to achieve this goal (cf. Beston, 2003).

Living in a group home provides a social network with reciprocity for most people with mental health problems (Paper II). The need for contact with neighbours is limited when contact with other residents in the group home is described as sufficient, as such contacts also provide help and support and contribute to establishing independence from their families and professionals. However, living in a group home labels each individual resident as a person with a mental health problem. 'The whole neighbourhood' (Paper II) knows that the group home is for people with such problems. The stigma of deviance can become more evident, making it more difficult to escape the deviant role (cf. Thesen, 2001). A lack of social competence and deviant behaviour from individual residents contribute to the neighbourhood's view of all the residents in the group home (Paper I), which can make it difficult to establish contact.

Living in a block of flats or other ordinary type of accommodation could provide a much more anonymous existence, in terms of the stigma of suffering from mental health problems (Papers II & III), making it easier to be seen as an ordinary resident. The possibility of being seen as a whole person, and not just one with mental health problems, is greater. However, for many of the participants, a more 'anonymous' existence also led to little or no contact with their neighbours. It may be difficult to make contact with neighbours in a block of flats (cf. Nilsson, 2004), which can increase the feeling of loneliness. This underlines the importance of having meeting places for social contact and a social network outside the neighbourhood.

From an inductive perspective, the informants' experiences of social integration and social networks show that the categories *Preserving integrity, symmetric contact* (Paper II), and *Living with shame and fear of exclusion, loneliness, struggling for equality and being neglected* (Paper III) affect one another and must be viewed in context. From an abductive reasoning perspective, the 'integration - disintegration spiral' provides a visual model of the inter-relations between and context of the categories (Figure 3). The spiral becomes wider when moving towards the top, which illustrates the participants' expanding options and possibilities. The lower portion of the spiral is characterised by passivity and loneliness, while the upper represents an active life. Upward movement along the spiral is expressed by heightened activity and contact with other people. The arrows pointing inwards represent forces which push up or press down. The arrows within the spiral show that an individual is constantly in motion, moving either upwards or downwards depending on which forces are strongest.

## Social integration



## Disintegration

*Figure 3: The integration - disintegration spiral*

### **Activity and inclusive forces are identified as:**

- a job
- an active life in voluntary associations and/or a mental health day centre
- a sense of defying or overcoming one's own limits
- opportunities to master new skills or gain new knowledge
- support and assistance to begin new activities, and co-existence with others
- good supportive contact with family and reciprocal friendship where contact is sufficiently frequent
- one's own home which is felt to be secure and well-suited.

### **Exclusion and inactivity forces are identified as:**

- negative feelings which are not adequately managed, such as shame, low self-esteem, alienation, and exclusion
- passivity, loneliness and a 'slow life'
- lack of connection and structure in everyday life
- conflict-filled or insufficient contact with immediate family
- insufficient income in relation to the cost of living
- lack of courage and external support for broadening one's own activities and contacts
- passive meeting places with little reciprocity.

The 'integration – disintegration spiral' can illustrate the various factors and

interpret them on a more general level for people suffering from mental health problems. The participants were represented at different points of the spiral. Those who had a job or were significantly engaged in voluntary activities were in the upper section. Social integration should be both on a personal and a local community level. Some of the participants exhibited a downward movement. Isolation was experienced both on a personal level and as exclusion from the local environment. The participants (Papers II and III) exhibited a strong desire for upward movement. The goal was active companionship with other people, where the most important factor was having some kind of daily occupation such as a job. A negative spiral effect could be counteracted by working actively with the elevating or upward-moving forces. To attain this, the participants reported that they needed help. The integration - disintegration spiral helps achieve a picture of social integration as a phenomenon and could serve as a working tool to be tested in practice.

Most of the people with mental health problems who took part in this study (Papers II & III) were satisfied with their living conditions and appeared to have an independent life, albeit with restricted forms of possibilities. The struggle to live independently is difficult and many of the participants still felt excluded from the work and leisure activities of everyday life, which led to significant loneliness and boredom and a 'slow life'. Lack of equality and employment made the participants feel neglected. The findings showed that isolation led to loneliness, even when they had contact with family members and friends. As their family and friends worked and lived their own lives, the amount of contact was limited. The feeling of loneliness was similar to that reported in other studies (Elstad, 1999; Bengtsson-Tops, 2001; Eide & Røysamb, 2002; Nilsson, 2004). According to Barham & Hayward (1995), having a meaningful life and feeling attachment to other people are closely connected. It should be noted that the informants reported that the importance of family ties was often overlooked by health care professionals. The family is one of the most important pillars of support for people with mental health problems. Mental health professionals must work actively to support families, so that they can assist the service users to lead an independent life (cf. Magnusson, 2003). In addition, experiences of loneliness and mental health problems are related to a sense of loss, defeat and the feeling of detachment from one's own social context and life (cf. Nilsson, 2004). The loneliness can be increased by the fact that people are no longer in their ordinary relationships, for instance, a working relationship, which leads to a downward movement in the integration - disintegration spiral. When people have an upward movement, they experience empowerment in their life. People's social networks are always in a state of flux. It is an ongoing process, where periods of their lives affect their social interactions. Being a member of a social group requires active participation and openness, which means that the process of social integration never ends and that our view of the world is subject to constant

change. People define their situation in terms of their own horizon (Levin & Trost, 1996; Gadamer, 1997), restricted by their own limitations.

A daily routine similar to that of most other people is an important factor for a satisfying life, and hence, organised daytime activities are essential. The most important aspect for people with mental health problems is having a job. In Norway, there has been an increase in the number of jobs allocated to people with special needs (Trommald, Christensen, & Schjeldrup, 2005), and day centres have been established in most municipalities (The Directorate for Health and Social Affairs, 2005). Nevertheless, the increase in job opportunities and centres has not been adequate in relation to the needs indicated by the present study, which points, in particular, to a lack of economic opportunities. Almost all of the participants were in receipt of a disability pension. In Norway, the number of people on such a pension is higher than in almost all other western countries, and efforts to get more people with disabilities into working life have not been as successful as envisaged (The Ministry of Labour and Inclusion, 2006).

Hydén (1997) identified three essential qualities in the work arena: i) a structuring of life in terms of time and space which most people share, which synchronises a person with the others in his/her environment; ii) social relationships arise through the shared social world of the workplace, where people and activities are organised around a common purpose. This allows a person to see him/herself through the eyes of others as well as his/her actions in relation to others; iii) both work and social relationships endow the individual with a place in society, and through that place, with a meaning-relation to themselves. These aspects of work emerged in the focus group interviews, together with the importance of increased income (Paper III). Although work will not be appropriate for everybody, most of the informants in this study retained an ambition to engage in meaningful work. Employment initiatives could be improved by including a wider range of occupations as well as voluntary work, which can be valuable in itself and an effective route to paid employment. Supported workplaces can facilitate entry into ordinary employment. Unemployment can lead to a deterioration in mental health (cf. WHO, 2005). The sense of being regarded as a person comes from feeling that one is useful and wanted (cf. Evert et al., 2003), which highlights the importance of work or other daytime activity. People with mental health problems gather in their own clubs and meeting places where they feel safer. Participants expressed that having a mental health problem is such a great strain that it is important to be able to share that experience with others and to be together with others who have the same background. This finding is similar to those of other studies (Green et al., 2002). While such contact reduces the load, it is not enough to ensure a meaningful life. It is important to work actively towards better social networks and the creation of meaningful daytime activities. Interventions that are targeted at improving social relationships are likely to have a positive impact

on self-care and occupational functioning, while overlooking such interventions has a negative impact on those aspects (cf. Evert et al., 2003). Improving social relationships can lead to an elevation in the integration - disintegration spiral. The social integration projects in the municipalities – the adventure groups and the “Green Fingers farms” – can help people to move further up in the spiral, and an evaluation with a positive outcome could encourage others to start similar projects (Paper IV).

Stigma and shame mean that one is not taken seriously, which may increase the feeling of marginalization (cf. Thesen, 2001). The sense of alienation makes it even more difficult to participate in daily life. People who are stigmatised have problems being recognised as individuals with both positive and negative characteristics. Stigmatisation leads to altered self-esteem, as well as to changes in one’s social situation. The impact of stigma on people with mental illness can result in avoidance of social contacts and attempts to conceal the true self. Stigma deprives people of their dignity and hinders their full participation in society (Johnstone, 2001). Their life experience can be described as ‘living in-between’ and as being on the margin of society (Drevdahl, 2002). One way of addressing stigma is to ensure that more information is made available to family, friends and the general public, thus enabling a better understanding of mental health problems. Families need emotional support as well as advice and guidance in order to ensure that the best possible home environment for persons with mental health problems can be maintained (cf. Lefley, 2001). In order to counter stigma and discrimination, professionals should initiate activities that emphasise the ubiquity of mental health problems, the fact that the prognosis is generally good and that people with mental health problems are rarely associated with violence. Supporting the local initiatives of non-governmental organisations can stimulate local community involvement and increase social integration. An overview of local initiatives in Norway or one of its regions can help other communities establish such programs and initiatives.

Low financial resources may affect the self-esteem of individuals with mental health problems. The participants felt that they could not afford to entertain people at home, buy birthday gifts, or go to a restaurant and/or café. Other factors that have a bearing on one’s financial resources are living alone and smoking. The participants felt helpless and powerless to create change in their lives, especially when moving down the ‘integration - disintegration spiral’. The poverty among people with mental health problems must be taken seriously by government, in order to halt the development of a low-class system. An important task for mental health professionals is to balance the efforts devoted to controlling individual risk factors and those dealing with the underlying social and economic health factors (Beaglehole & Bonita, 2004). Society must be stimulated to improve socio-economic conditions for people with mental health problems if full social

integration is to be made possible. The results of this study show how a lack of economic resources is a major barrier preventing people in a marginal position from regaining their former social position. Clothing and outer appearance are a part of human social interaction (cf. Levin & Trost, 1996) that send signals about group membership. This should be discussed with service users as a way to avoid stigmatisation.

In Norway, mental health problems have been focused upon in recent years, in part due to the Mental Health Reforms (The Directorate for Health and Social Affairs, 2005). The coming forward of celebrities who suffer from mental health problems and nationwide funding drives have helped to achieve a new openness on the subject. However, the present study shows that this openness has had little impact on the social integration of people with mental health problems, as their neighbours are still, for the most part, unwilling to engage in closer contact. The reasons for this could be the income gap, which prevents people with mental health problems from accessing the same social arenas as their neighbours and friends, and being seen as a group where individual appearance makes them stand out. Without active intervention that focuses on the social environment and individual support, people with mental health problems who move into new homes run the risk of social isolation (cf. Hardiman & Segal, 2003). Several researchers have demonstrated the existence of a tendency towards segregation (cf. Barham & Hayward, 1995). Social network characteristics influence the quality of life of persons with mental health problems (Howard et al., 2000; Bengtsson-Tops & Hansson, 2001). Those working in community mental health care need to ensure that people suffering from mental health problems experience a sense of belonging in the community, thus enabling them to develop a network and achieve social integration. The mental health reform states that the normalisation and social integration of people with mental health problems has been and will continue to be a long process (cf. Nirje, 2003).

Mental health professionals may be unable to change the attitudes of people in the community, but their stance and practices can influence the opportunities of individuals with mental health problems (Bertram & Stickey, 2005). There should therefore be a broad investment in network-strengthening initiatives in community healthcare with the continued involvement of local strategies such as those employed in this co-operative inquiry project. The integration - disintegration spiral can be a useful tool for professionals and the potential of the elevating forces should be focused upon.

Strandmark (2004) argues that the essence of good health is life force and that of poor health powerlessness. The desire for life blossoms in companionship with other people, and in the same way pain is worsened by stigmatisation. Self-image is affected by the people in our immediate environment and by society

as a whole; we value ourselves according to how others see us. The desire for activity and social companionship was a strong driving force for the participants. The municipalities' plans for meeting places must be further developed (Paper IV). The activity group and activity centre strategies that evolved could become a valuable contribution to mental health services in the municipalities (Paper IV), as people who are at risk of mental health problems will be able to find an accepting environment.

The condensed interpretation in indicates the prerequisites necessary for achieving social integration of people with mental health problems:

- i) adequate social competence
- ii) meeting places for social contact and interaction
- iii) a social network that provides sufficient time together and support
- iv) activities which give meaning to daily life
- v) sufficient income in relation to the cost of living

In this study, the participants asked for help to achieve these conditions.

### **5.3 The influence of social integration on changes in mental health professionals' practice – a co-operative inquiry strategy**

The third research question of the study was: *How does knowledge of social integration promote practical changes in mental health professionals' practice?* Findings related to this question are summarised as follows: co-operative research is a scientific approach that can be valuable in the public sector. In order to achieve the best possible results, the whole team should be involved and play an active part in all aspects of the project. Systematic reflection on practice leads to increased awareness of one's own attitudes and intervention methods, societal conditions, and the municipality's attitude to the increased social integration of people with mental health problems. Dialogue-based teaching has the potential to enhance participants' professional competence as a result of systematic reflection. The experiential knowledge thus gained may contribute to health-promotion strategies such as social integration. Thus, professionals can facilitate a stronger sense of belonging to the local community for people with mental health problems.

The final part of the study was the co-operative inquiry project conducted in two municipalities in Norway, intended to stimulate the further development of mental health professionals' skills and knowledge. In this study social integration is also seen from a public perspective, in which there is a citizen perspective containing the civil rights and doctrines of society. All citizens in a local community have

some understanding of social integration for people with mental health problems, but in most cases it formed only a small part of their life-world. Over time, some of the participants gained an additional perspective – a user or professional perspective that provided them with increased knowledge and thus a broader understanding of the concept. The present findings can be seen in this context. In the dialogue-based teaching sessions, it was important to monitor the power balance between citizen, user and professional perspectives, which interacted dialectically in situations where social integration of people with mental health problems could be investigated and mutually understood.

An important task for the professionals was to help people with mental health problems interpret their suffering, so that they can see patterns of meaning and achieve progress thanks to their new understanding (cf. Nordtvedt & Grimen, 2004). Without sensitivity to people's experiences and understanding, it is impossible to help them to interpret their situation. In order to help and understand people with mental health problems, it is necessary to have knowledge of their lives as a whole – their social networks and living conditions – and not just their symptoms and problems. This requires a multi-dimensional view of the individual. The individual service user with mental health problems cannot be treated in a social vacuum. It is important that assessment takes account of the service user's social network. Here one must raise the question of how to assess the social network (Green et al., 2002). People with mental health problems (Papers II and III), co-researchers (Paper IV) and earlier findings (Bengtsson-Tops, 2001) highlight the importance of working to improve social integration. The co-researchers who participated in the dialogue-based teaching and multi-stage focus groups were initially interested in working with social network development (Paper IV). They regarded this as an important part of their task, even if they had done little to develop the social integration of the service users. However, there were great differences among the participants. The desire to further develop their knowledge in the area of social integration gave rise to a natural division between the co-researchers and the rest of their colleagues who had not taken part in the program.

Dialogue-based teaching was one of the methods used to stimulate the co-researchers to critically evaluate their practice and discover new possibilities. The findings from Paper IV demonstrate that dialogue-based teaching had multiple positive effects. It was instrumental in the development of a deepened professional identity and provided time for reflection, through which an interdisciplinary approach to social integration evolved. A shared professional background, as well as the sense that one's own professional identity could be strengthened through interaction with one's colleagues proved meaningful. This is similar to the results of an evaluation of a four-year research collaboration project entitled *Promotive and preventive mental health care in the local community* (Beston, et al., 2007).

The number of participants in the dialogue-based teaching varied. The project took place over a long period of time and required perseverance on the part of both project leaders and co-researchers. Did the large number of sessions lead to fatigue in the group? This study was one of several in which dialogue-based teaching was the most important method. Different programs for dialogue-based teaching, seminars and focus groups took place over the course of the study. The varying number of participants in the dialogue-based teaching was due to the fact that only some members of each team took part and that, to a large degree, the co-researchers worked independently. The local project co-ordinator had a key role, both in terms of providing inspiration and acting as a pacemaker (cf. Hummelvoll, 2003).

Dialogue-based teaching led to open communication between the multi-disciplinary participants, which resulted in respect for each other's knowledge and experience and lowered the threshold for co-operation. This communicative development may lead to a ripple effect in the community, thus helping people with mental health problems to achieve increased social integration. Empowerment, participation and collaboration cannot be achieved without good communication. A more open attitude among professionals could result in a more active approach to social integration. The participants in the dialogue-based teaching sessions gained a larger repertoire of strategies, which had been tested both in research and community settings. They also developed an increased ability to utilize existing social network intervention methods. If reflexivity and knowledge for practical use are to be developed for the entire group of professionals, a majority of team members must be active participants. It was difficult for "the core group" to share their sense of ownership with their teams.

The interdisciplinary interaction which developed among the co-researchers (Paper IV) improved co-operation across professional boundaries. The users' voice was also consciously brought into the dialogue through their participation in the dialogue-based teaching and through the presentation of the findings of Papers I-III. The fact that the study was closely linked to local communities made the research especially relevant for the understanding of social integration in the participants' local areas. Learning through participation in dialogue-based teaching has contributed to the participants' ability to reflect as well as strengthening their own knowledge. It provided a theoretical base for practice and verification that one's practice is supported by research-based knowledge and theory. This finding agrees with other studies (cf. Hostick & McClelland, 2000; Kjønnsberg, 2007). The dialogue (Paper IV) led to deeper understanding and made it easier for the participants to integrate the new knowledge in their practice. Fellowship with their colleagues proved meaningful both on a personal level and in terms of the relationship with their colleagues and individual service users. The care methods used in psychiatric hospitals cannot be simply transferred

to a community setting, thus individual modification must take place, a task to which co-operative inquiry may be well-suited.

In the multi-stage focus groups (Paper IV), the participants put their experiences from their own individual practice into words and, as a result, gained a more nuanced understanding. Discussing the possibilities of new approaches to social integration contributed to the broadening of the co-researchers' repertoire of techniques in encounters with service users. These dialogues offer an opportunity to raise the participants' experiences to a higher level (cf. Hummelvoll & Severinsson, 2005). The use of multistage focus groups contributed new knowledge through action and reflection.

It appears that the co-researchers' understanding of the social integration concept in Paper IV developed over the course of the dialogue-based teaching. In the first of the focus group interviews and in the earliest of the dialogue-based teaching sessions, their description of social integration was primarily static. Their attitudes were characterised by the difficulty of influencing the service users' networks and by their own negative experiences. With each dialogue-based teaching session, more dynamic factors were added to the concept. Enhanced awareness of the concepts and a more positive and active attitude to working with social networks emerged in both the discussions and the focus groups. The co-researchers have a solid understanding of the importance of social integration in people's lives and always considered their own role as important, but the dialogues on social integration assumed an innovative character. The discussions in the focus groups indicated that the increased awareness and open dialogue made the participants more secure in their professional function. This should lead to better service for people with mental health problems.

It was a challenge that the municipalities differed significantly from each other and that there were also cultural differences between them (Paper IV). The program created knowledge for and through the co-researchers and researchers, both in terms of social integration and the implementation of co-operative inquiry in community healthcare. The relevance of co-operative inquiry is determined by whether the participants find their new knowledge relevant for problem solving – it is the practical use of the knowledge that is valuable (cf. Hummelvoll 2006). The strength of the knowledge dialogue lies in the possibility of transforming knowledge into action. Co-operative inquiry is a step-by-step process. When one has “sown the seeds” it takes time for them to mature, and the change becomes apparent only gradually. Analysis revealed that group members' understanding of their new knowledge increased over time. The seeds are the inspiration and knowledge gained through the knowledge-based dialogue. The duration of the incubation period depends on the circumstances mentioned above. These pioneering participants can spread their new knowledge among the other team

members, which may lead to action on a new level. The scope of this project was quite broad, as all staff members and not just specific teams were invited to take part. This may have a snowball effect that could lead to broader dialogues in each individual team.

A sense of ownership of the co-operative inquiry is important for the outcome (Hummelvoll, 2003). In order for knowledge to be useful in a local context, the participants must experience ownership of it (cf. Coghlan & Casey, 2000). A possible reason why the implementation of the new knowledge has been less than anticipated could be that few of the professionals in each team took part in the program. By focusing on a small part of the community health care organization (e.g. one district team), the sense of ownership of all of the participants might have been strengthened, thus leading to a more direct effect on practice. Similar findings on a sense of authentic collaboration were presented in a Norwegian study, which used co-operative inquiry (Kjønnsberg, 2007).

The participants reported that they only rarely implemented the knowledge gained in the dialogue-based teaching (Paper IV). This can be explained by several factors:

- i) The participants were unable to gain the support of their colleagues for the implementation of the new methods. In the municipalities, mental healthcare is organised into local and some task-oriented teams. The participants comprised members from all of these various teams. However, there was no team from which a majority of the members took part. For this reason, none of the teams became a natural forum for discussion on the topics raised during the dialogue-based teaching. Without a clear strategy for following up the themes raised in dialogue-based teaching and multi-stage focus groups, implementation became inadequate.
- ii) There have been few meeting points for health and social workers in which to implement experiential knowledge, and professionals who mainly work alone with clients have difficulty introducing new methods without backup from the members of their team. Even if they wanted to test the new methods and ideas that arose during the process, it was difficult to find time to discuss those ideas with their teams.
- iii) The participants reported that their working days involve many problems which require rapid interventions and left little time for health prevention.
- iv) There are several competing treatment methods in the workplace, and if other team members do not possess the participants' new understanding, conflict may result.
- v) The local project coordinators did not work closely with the other participants, which allowed little opportunity for further involvement

after the initial meetings. Opportunities to discuss how to implement the new methods were lacking. The local project co-ordinator had a key role in this task, as both a source of inspiration and a pacemaker, in order to keep the project moving along and active. Having a job similar to that of the rest of the co-researchers might have led to greater focus on the project.

- vi) Hardly any managers participated in the dialogue. Management and the local project co-ordinator must be given and take advantage of the opportunity to motivate the co-researchers to put the new knowledge to work.

With regard to implications for education and clinical community practice, co-operative research has proved a powerful tool in community mental health work. The method has the potential to strengthen both disciplinary and cross-disciplinary co-operation and knowledge as well as to articulate, illuminate and initiate the development of new strategies, thus leading to the development of a more advanced form of knowledge-in-action (Molander, 2000). A goal of Paper IV was to develop knowledge that is close to practice, in order to obtain a common knowledge base. The steps and characteristics of the practitioner's knowing-in-action (Schön, 1987) were recognised in the program.



## 6 CONCLUSIONS

- The present thesis demonstrates that the social integration of people with mental health difficulties into the community is not achieved. There is still much to be done with regard to providing sufficient community services for people with mental health difficulties.
- The results of Papers I-III strongly support that to feel socially integrated is important for people's mental health, and they emphasise the importance of social contact for developing social competence.
- Social integration is a necessary component of decentralised mental health community care.
- To achieve social integration, a person with long-term mental health problems needs to develop sufficient social competence. Neighbours to group homes require, at the very least, general information, and efforts must be made to create social contact between persons suffering from mental health and their neighbourhoods.
- Those working in community mental health care need to ensure that people suffering from mental health problems experience a sense of belonging in the community, which, in turn, enables them to develop a network and achieve social integration.
- There is a need to strengthen healthcare professionals' training in order to ensure they are aware of the stigma and the ethical problems that may arise when providing homecare, especially those having to do with preserving the integrity of people with mental health problems.
- There is a need for knowledge on the part of those responsible in the community in order to create a deeper understanding of the integration difficulties experienced by individuals with mental health problems. These difficulties should be taken into account in the planning and development of day-time activities, work, and programmes aimed at promoting social integration.
- The results from Paper IV suggest that a multi-disciplinary approach is both valuable and necessary for the process of providing adequate social integration and social networks.
- The findings in Paper IV indicate that co-operative inquiry can be beneficial in the public sector. In order to achieve the best possible result, the whole team should be involved and play an active part in all aspects of the research

project. If the groups are too large, the participants' level of engagement may suffer.

Further research could continue to explore and evaluate the practice of helping people with mental health problems integrate into communities in today's society. Also, the content of the information presented to the public could be further developed so as to better use it as a tool to aid successful social integration. Social integration should continue to be focused upon through new studies in this field.

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