

Toril Anne Elstad

**Participation in a 'Low Threshold'
Community Mental Health Service:
an Ethnographic Study
of Social Interaction, Activities
and Meaning**

Thesis for the degree of Philosophiae Doctor

Trondheim, March 2014

Norwegian University of Science and Technology
Faculty of Social Sciences and Technology Management
Department of Social Work and Health Science



NTNU – Trondheim
Norwegian University of
Science and Technology

NTNU

Norwegian University of Science and Technology

Thesis for the degree of Philosophiae Doctor

Faculty of Social Sciences and Technology Management
Department of Social Work and Health Science

© Toril Anne Elstad

ISBN 978-82-326-0114-1 (printed ver.)
ISBN 978-82-326-0115-8 (electronic ver.)
ISSN 1503-8181

Doctoral theses at NTNU, 2014:95

Printed by NTNU-trykk

ACKNOWLEDGEMENTS

First of all I wish to thank all the service users and mental health professionals with whom I participated during this research for interesting conversations which have taught me a lot, and for sharing your views and experiences. Without you this thesis would not have been possible.

Many thanks go to my supervisors Kristjana Kristiansen and Arne Henning Eide for their interest in the concept of participation and social aspects of mental health, and for feedback and important critical comments. Thanks also to the Norwegian University of Science and Technology, SVT Faculty, Department of Social Work and Health Science for providing my PhD education as well as an inspiring environment during my PhD-process. As there are too many names to mention, your Head of Department Riina Kiik represents you all.

Thanks to Sør-Trøndelag University College (HiST) for supporting this research financially. Special thanks to Dean Anne Tveit and all my colleagues at the Faculty of Nursing for a supportive and inspiring work environment, and to Toril Havn Sæther for technical assistance with this manuscript. Many thanks to my colleagues at the Diploma course and Master programme in mental health work: Sissel Alsaker, Ann-Kristin Bratlie, Julia Hagen, Birthe Loa Knizek, Wenche Malmedal, Skender Redzovic, Espen Sagsveen, Rickard Skjong and Wigdis Sæther, and to former colleagues in recent years: Vesna Forbergskog, Trond Lundby, Anne Moe, Berit Nicolaysen and Lillian Skillingstad. To Wenche and Sissel: thank you also for interesting discussions and mutual support during our time as fellow PhD-students.

Thanks for collaboration in the mental health area also go to my colleagues at the Faculty of Health and Social Work and the research area 'Participation' (HiST); to Arve Almvik, Heidi Haug Fjone and Ove Hellzén (co-author in paper 4) at the Faculty of Health, Nord-Trøndelag University College; Reidun Norvoll, at the University of Oslo; Per Bernhard Pedersen at the Norwegian Directorate of Health and to Gundi Johannsen, University College Syd, Denmark.

My gratitude and sincere thanks for on-going support and a meaningful daily life go to my family: my husband Einar and children Michael, Hanna and Martin, my daughter-in-law Anne and my two grandsons Gabriel born in 2010 and Nikolai born in 2012, to my mother Anny, in memory of my father Thoralf and to my brother Stein Ivar and sister Nina.

Trondheim, March 2014,

Toril Anne Elstad

Summary

Participation in a ‘low threshold’ community mental health service: an ethnographic study of social interaction, activities and meaning

An overall aim of this thesis was to contribute with knowledge about social interaction, activity and user participation in low threshold community mental health services, what participation in such settings meant for service users in daily life and how professionals in the same service experienced their mental health work and professional roles. Other aims were that findings from the empirical study should contribute to the further developments of community mental health work and a broader understanding of ‘participation’ as a theoretical concept and perspective applied to mental health work and rehabilitation. The empirical study had an ethnographic design; conducted as fieldwork within a low threshold community mental health service for eighteen months. Research methods were participant observation, individual interviews with service users and focus group interviews with professionals.

An increase in psychiatric hospitals in the first half of last century, followed by a reduction of such institutions during the second half has been an international trend. Such developments have practical consequences in daily life for many who live with mental health problems. Services with an open, flexible organisation, offering a mix of professional- and peer-support have, thus, been encouraged as part of a ‘recovery oriented’ approach in some countries. In Norway, such services have recently also been recommended as a strategy of health promotion in the mental health area. Findings from this study suggests that a mix of professional and peer-support provides opportunities for receiving social support, as well as for active participation and mutual relationships among service users in daily life. For informants in the study, participation and mutual support enhanced self-confidence and experiences of recognition. Attending the service based on their own felt needs helped many to also participate in the wider community. Professionals described knowledge and experience as important for a flexible, low threshold approach in mental health work. This service organisation permitted more egalitarian relationships with users, than work in institutions.

The study contributes with knowledge about participation in the mental health area, and how both social support and challenges may enhance participation by providing

opportunities for mutual recognition for people with mental health problems. Social exclusion and experiences of mental distress are barriers to such experiences and community mental health services should support peoples' possibilities for sustaining a life situation in the community.

Sammendrag

Deltakelse i et lavterskeltilbud innen kommunalt psykisk helsearbeid: en etnografisk studie av sosial samhandling, aktiviteter og opplevelser av mening

Et overordnet mål for denne avhandlingen har vært å bidra med kunnskap om sosial samhandling, aktiviteter og brukermedvirkning i lavterskeltilbud innen kommunalt psykisk helsearbeid, hva deltakelse i slike settinger betyr for tjenestebrukere i deres dagligliv, og hvordan fagansatte i den samme tjenesten opplever sitt arbeid og sin fagrolle. Andre målsetninger har vært at funn fra den empiriske studien skal bidra i den videre utviklingen av kommunalt psykisk helsearbeid og en bredere forståelse av *deltakelse* som teoretisk begrep og perspektiv på området psykisk helsearbeid og rehabilitering. Studien har en etnografisk design; gjennomført som feltarbeid i et lavterskeltilbud innen kommunalt psykisk helsearbeid i 18 måneder. Forskningsmetodene var deltakende observasjon innen tjenestetilbudet, individuelle intervju med tjenestebrukere og fokusgruppeintervju med fagansatte.

En økning av psykiatrisk sykehusbehandling i første halvdel av forrige århundre og en påfølgende reduksjon av institusjonsbehandling i siste halvdel har vært en internasjonal trend. Slike endringer får konsekvenser for mange som lever med psykiske helseproblemer. Tjenester med en åpen, fleksibel organisering, som tilbyr både støtte fra fagansatte og brukere seg i mellom, har blitt anbefalt som en del av en «recovery-orientert» tilnærming i psykisk helsearbeid i enkelte land. I Norge anbefales lavterskeltilbud som en helsefremmende strategi, også på psykisk helse-området. Funn fra denne studien viser at en blanding av profesjonell hjelp og brukermedvirkning gir tjenestebrukere muligheter for både å motta sosial støtte og delta aktivt; noe som kan bidra til en utvikling av gjensidige relasjoner i dagliglivet. For flere informanter i denne studien bidro deltakelse og gjensidig støtte til økt selvtillit og opplevelser av å bli anerkjent. Å benytte tjenesten basert på egne behov bidro også til økt deltakelse i lokalsamfunnet for mange. For fagansatte var fagkunnskap og erfaring viktig for utøvelsen av psykisk helsearbeid med en fleksibel, lavterskel tilnærming, og en slik tjenesteorganisering muliggjorde mer likeverdige relasjoner med brukerne enn fagrollen i institusjoner.

Studien bidrar med kunnskap om hvordan en blanding av sosial støtte og utfordringer kan øke aktiv deltakelse og tilby muligheter for gjensidig anerkjennelse for mennesker som lever med psykiske helseproblemer. Sosial eksklusjon og psykisk stress kan hindre slike erfaringer og lokalbasert psykisk helsearbeid bør støtte menneskers muligheter for å opprettholde sin livssituasjon i lokalsamfunnet.

TABLE OF CONTENTS

Aknowledgement.....	i
Summary	iii
Sammendrag	v
Table of contents	vii
List of papers	ix
Participation in a ‘low threshold’ community mental health service: An ethnographic study of social interaction and meaning.....	1
1. INTRODUCTION.....	1
1.1 Mental health problems and mental distress.....	4
1.2 Studying participation in a community mental health service context.....	6
1.3 Research aims and central research questions	8
1.4 Structure of the thesis	10
2. BACKGROUND.....	11
2.1 Deinstitutionalisation.....	11
2.2 Ideologies behind deinstitutionalisation	12
2.3 Community mental health services in Norway.....	14
2.4 Summary.....	16
3. THEORETICAL PERSPECTIVES AND CONCEPTS.....	18
3.1 Social aspects of mental health and illness	18
3.2 Theoretical perspectives of social interaction	20
3.3 Social integration, social inclusion and participation.....	21
3.4 Participation, disability and mental health	23
3.5 Participation and the need for recognition.....	25
3.6 Theoretical resources for the study’s methodological approach	26
4. METHODOLOGY.....	29
4.1 Methodological approach	29
4.2 Ethnography	30
4.3 Research design.....	32
4.4 Study context and settings	33
4.5 Research process and role as researcher	33
4.6 Data collection and participants	34
4.7 Data analysis.....	37
4.8 Methodological considerations.....	39
4.9 Ethical considerations.....	42
5. FINDINGS FROM THE RESEARCH	44
5.1 Summaries of papers 1 – 4	44
5.2 Overall findings	49

6. DISCUSSION	52
6.1 Social support, activities and user participation	53
6.2 Participation in the service and in daily life	54
6.3 Mental health work and the professional role	55
6.4 Participation and recognition.....	57
7. CONCLUSIONS AND IMPLICATIONS	59
REFERENCES.....	61

Paper 1

Paper 2

Paper 3

Paper 4

Appendix

Papers 1 - 4

LIST OF PAPERS

1. Toril Anne Elstad. Participation, activities and social interaction in ‘low threshold’ community mental health centres (*submitted and undergoing review: Scandinavian Journal of Disability Research*)
2. Toril Anne Elstad and Kristjana Kristiansen (2009). Mental health centres as ‘meeting-places’ in the community: exploring experiences of being users and participants. *Scandinavian Journal of Disability Research*, 11 (3): 195-208.
3. Toril Anne Elstad and Arne Henning Eide (2009). User participation in community mental health services: exploring the experiences of users and professionals. *Scandinavian Journal of Caring Sciences*, 23: 674-681.
4. Toril Anne Elstad and Ove Hellzén (2010). Community mental health centres: A qualitative study of professionals’ experiences. *International Journal of Mental Health Nursing*, 19: 110-118.

Participation in a ‘low threshold’ community mental health service: an ethnographic study of social interaction, activities and meaning

1. INTRODUCTION

This thesis is about social interaction, activities and user participation within a low threshold community mental health service, what participation in such settings mean for service users and how professionals in the same service experience and describe their mental health work and professional role. During the past fifty to sixty years some fundamental changes have taken place in the field of psychiatry and mental health work in Norway, as in several other countries in the ‘western world’. Following an increase in the number of psychiatric hospital beds in the first half of last century, mental health services have been gradually restructured towards what has become known as ‘community care’ (Pedersen & Kolstad 2009, Prior 1993, Ramsdal 2013). Further developments of community mental health services that support user participation, as well as independence and active participation in daily life, have been encouraged, both internationally (WHO 2001b, WHO 2005, WHO 2007) and in Norway (Helse og omsorgsdepartementet 2013, Sosial og helsedirektoratet 2005, Sosial og helsedirektoratet 2006). Such developments are important for many who live with mental health problems, as support from mental health services often play a part in their daily lives. These changes also suggest new roles for people with mental health problems; from being mainly treated as patients, towards participation as service users and to experience agency and control in their own life situations (Corrigan *et al.* 2008, Craig 2006, Sayce 2000).

Changes in service organisation as those described above have been accompanied by changes in mental health policy and ideology: from a mainly biomedical approach, towards a focus on social interaction as well as aims of social integration, social inclusion and, more recently, ‘participation’. Such developments also influence on the practice of mental health work and professionals’ roles; towards meeting people’s needs for support as well as to encourage their active participation, both as service users and in

their daily life situations in the community (Anthony *et al.* 2002, Elstad & Hellzén 2010, Hydén 2004, Petersen 2009, Ramon & Williams 2005, Sterling *et al.* 2010). Social scientific and humanistic perspectives on mental health and illness also highlight the need to reduce barriers for social inclusion in society and support participation in daily life in the community for people with mental health problems (Borg & Karlsson 2013, Elstad & Norvoll 2013, Norvoll 2013). Recent developments in the community mental health area in several countries, has been services with a flexible and accessible organisation, which often offer a mix of professional- and peer-support (Conradson 2003, Hall & Cheston 2002, Kristiansen 2000, Parr 2000, Parr 2008, Whitley *et al.* 2008, Whitley *et al.* 2012). In Norway, further developments of such 'low threshold' services have been encouraged as a strategy of health promotion and prevention of mental health problems (Dalgard *et al.* 2011, Helse og omsorgsdepartementet 2013, Helsedirektoratet 2010).

The present empirical study has been conducted within a low threshold municipal community mental health service in a Norwegian city. This service, which has an accessible and flexible approach, consists of three centres called 'meeting-places'. People choose how to attend these centres and they are not registered as patients. Thus, this study's informants among the service users are a heterogeneous group of people, who share the following characteristics: all are adults who voluntarily visit community mental health centres, based on their experiences of mental health problems and felt needs for support and company in their daily life situations. These centres have been studied as examples of a new type of community mental health service, which offers their users opportunities for receiving social support as well as active participation. My intention has not been to evaluate or compare these settings, but to use all three centres as a research context in order to provide variation in the data collected.

Diagnoses or psychiatric treatment were neither the approach of the service chosen as research context nor the focus for this social scientific study. Most key informants did, however, speak about having previous experiences as patients in psychiatric hospitals, some for several years (Elstad & Eide 2009, Elstad & Kristiansen 2009). The professionals who work within this service practice their mental health work through

face-to-face interaction with service users on a day-to-day basis. Communication through social interaction between professionals and service users is central to clinical mental health work. I therefore included professionals who work in this service as informants, as their experiences and views could contribute to an enhanced understanding of how mental health work and the professional role in low threshold community mental health services is carried out and experienced. The workforce in this service is multi-professional; represented by the areas of occupational therapy, nursing, social work and social education (Norwegian: vernepleie) during this study.

Themes for the theoretical approach and research questions for the empirical study have been developed from my interest in the social aspects of mental health and illness, community mental health service developments, and how mental health work can support people who live with mental health problems in their daily life situations. These interests are based on my previous experiences from practising as a mental health nurse and from teaching mental health work, as well as from previous theoretical studies and research in the field of health science (Elstad 1999). This thesis' research project has an empirically oriented, practice-near approach to studying participation and meaning (Sharkey & Larsen 2005), based on service users' and professionals' actions, interaction, experiences and understandings within a community mental health service context. Links to the concept of participation as applied to daily life and to Honneth's (1995) theory of recognition were developed during the field study and the process of data analysis (chapters 3-4). In studying health-related issues, health science often draw upon theories from such areas as sociology, social psychology, as well as theories from the relevant clinical field. In my general approach to the research themes and research questions, I position myself within this tradition of social scientific health studies and health services research.

My research approach has been within an ethnographic tradition of studying people's face-to-face social interaction and activities, as they naturally occur in particular situations and settings. In ethnography, exploring everyday life, social interaction and people's experiences of meaning from an inside perspective is central (Rock 2009, Sharkey & Larsen 2005). This traditional ethnographic approach has a range of theoretical influences, such as critical theory, phenomenology and hermeneutics. A common theoretical

perspective guiding studies of social interaction in particular settings is symbolic interactionism (Blumer 1967), which is also my general approach, as described in chapter 3. An early 'naturalistic' tradition has been criticised for the belief that through close observations within a field of inquiry, researchers are able to 'tell it like it is'. Ethnography with a social interactionist approach has, however, developed in a direction where people's social construction of their culture is also central (Fangen 2004, Hammersley & Atkinson 2007, Norvoll 2006). Broad research themes related to the social aspects of living with mental health problems influenced the study design, and observations during fieldwork fed into the further data collection and theoretical study during the research process (Delamont 2007, Hammersley & Atkinson 2007, Lofland *et al.* 2006, Silverman 2005). The research methodology and data collection will be described in more detail in chapter 4.

My choice of an ethnographic approach in the empirical study has been based on theoretical perspectives and previous research, which will be presented in chapters 2 and 3. An interest in knowledge development from studying practice and the meaning this has for those who act and interact has also been inspired by my own previous research; while conducting a quantitative study of social interaction and reported quality of life among people with mental health problems (Elstad 1999). In addition, my previous experiences from clinical mental health work, as well as from teaching nursing, social education (in Norwegian: vernepleie) and, at present, multi-professional mental health work have influenced on the design and research questions.

1.1 Mental health problems and mental distress

The percentage of the population in Europe reported to have had a mental illness during the previous year has been estimated to be about 32 % (Dahl & Friestad 2013). Similarly, in studies from Norway this reported percentage has varied between different studies, ranging from 10 % up to 33 %. The percentage of the population in Norway who acquire some form of mental illness during their lifetime (i.e. the lifetime prevalence) has been reported to be from 25 % to 52 % and these figures also vary between different studies (Helsedirektoratet 2013). Such figures cover a whole range of mental health problems and conditions, some of which can have serious negative impacts on people's functioning in

their daily life situations and on their quality of life. Mental health problems are, however, understood from several perspectives and from biomedical, psychological, humanistic and social scientific traditions (Borg & Karlsson 2013, Boyd 2008, Ekeland 2011, Haugsgjerd *et al.* 2009, Norvoll 2013, Rogers & Pilgrim 2005, Skårderud *et al.* 2010). Across such disciplines there is a general agreement that mental health and illness have important social dimensions (Bø & Schiefloe 2007, Dalgard *et al.* 1995, Elstad & Norvoll 2013, Hydén 2005, McKenzie & Harpham 2006).

Experiences of mental health problems are often accompanied by reduced social contact and sometimes social exclusion. When social interaction is experienced as problematic, whether this is due to distress or stigmatising responses from others, it can lead to social withdrawal and isolation (Norvoll 2013, Granerud & Severinsson 2006, Rogers & Pilgrim 2005, Sayce 2000). Although people's needs for social contact vary, research over several decades has shown that a life situation with few social ties and a lack of supportive social relationships has negative effects on mental health in populations (Dalgard *et al.* 1995, Dohrenwend & Dohrenwend 1969, Faris & Dunham 1939, Fisher 1982, Leighton 1959, Srole *et al.* 1962). On the other hand, available social contact and support can be vital for experiencing positive mental health (Elstad & Norvoll 2013, Hummelvoll 2012). Research and theories about the social aspects of mental health and illness will be further described and discussed in chapters 2 and 3.

Distress related to mental health problems varies between people, and individuals' experiences of mental ill health often fluctuate over periods of time (Boyd 2008, Parr 2008, Skårderud *et al.* 2010). What 'psychiatric patients' or 'mental health service users' share as a group are experiences of mental health problems and/or receiving mental health services. People who share such experiences are, however, often portrayed as a homogenous group, and as if being 'patients' or 'service users' is their 'master-status' (Elstad & Norvoll 2013). Contrary to this, people who live with mental health problems can function well in daily life, but some in this situation may need extra support and relevant opportunities to use their resources (Borg 2007). This is also in line with my previous experiences from clinical mental health work. Obviously, like the rest of the

population, people with experiences as users of mental health services have different views on- and experience different needs for social support, treatment and care.

Psychiatric hospitals and other specialist mental health services offer treatment and therapy. While such approaches are important for people, for example when experiencing acute traumas or crises, supporting people in daily life requires a broader, psychosocial approach (Anthony *et al.* 2002, Corrigan *et al.* 2008, Ramon & Williams 2005, Sandlund 2004). Although themes in this thesis relate to the social aspects of mental health problems, I view different types of treatments approaches as complementary; not as opposites. Clinical approaches can, however, become problematic if treatment based on disease or illness models are applied in situations where people need and wish for support to sustain a good life in the community. In this thesis, the terms 'social' and 'psychosocial' are both used about this approach, as both these terms are also used in the literature relating to social scientific perspectives on mental health and illness.

1.2 Studying participation in a community mental health service context

Community mental health work on the ground level influences daily life for many service users. How user participation is enacted and experienced by service users and professionals within such health service contexts is therefore an important issue. Other important questions relate to what participation in low threshold community mental health services could mean for service users' experiences of mental health and functioning in their daily life situations. A further point is to acknowledge the value of the actions, relationships, experiences and views of service users and the professionals with whom they interact. Knowledge and understanding from an inside perspective are of central importance to developing clinical mental health work and community mental health services that are experienced as supportive and helpful towards enabling people with mental health problems to live fulfilling lives in their communities.

Mental health services have been, and are still undergoing processes of change. During the last few decades there has, for example been an increased emphasis on service users' rights to be involved in decisions about their own treatment and also, as a group, to have influence on service development (Sosial og helsedirektoratet 2006). These changes will

be further described and discussed in chapter 2. Here I will briefly illustrate this point with a quote from Mezzina (2005: 89), who describes a vision for mental health services, ‘from total institutions to community services and from the illness to the person’, in the following way:

We must envision horizontal organizations, with flat hierarchies, which are internally open and participatory, made up of men and women who work as professional subjects immersed in a community to which they must respond and be accountable. Their practices should be based on the recognition of the user’s contribution, either to his/her own or to everybody’s mental health. These practices must be accessible to demands and must offer flexible services based on the non-selection of users, maintaining and dealing even with the most difficult conditions within the community. Transformed knowledge, and knowledge which continues to transform itself, comes therefore from practices that ‘shoulder the burden’, and which actively aid and sustain, step-by-step, the social itinerary of the person who suffers.

A ‘low threshold’ organisation means that a service is accessible and flexible to a larger degree than more traditional mental health services. In the service studied in this empirical research, there are no intake procedures or selection based on psychiatric diagnoses or symptoms, which means that people attend the service voluntarily and according to their own felt needs. Thus, in this thesis I do not use diagnostic terms, but the broad terms ‘mental health problems’ or ‘mental distress’. These terms cover a variety of experiences, which in some of the literature have also been described as ‘psychiatric’ or ‘psychosocial’ disability (Anthony *et al.* 2002, Corrigan *et al.* 2008, Grunewald 2000, Hydén 2005, Sandlund 2005, Spaniol *et al.* 1997).

Available help and support in the community aim to make a living situation outside institutions possible for persons who live with mental health problems. Important questions for service development and mental health work remain, such as how to achieve a balance between rights to receive support towards autonomy in daily life and rights to receive professional help when needed (Wing 1990). New service developments should be accompanied by research-based knowledge that explores what users and professionals do,

seen in the light of official health policy and ideology (Prior 1993, Savage 2006, Søder 1992). It has, therefore, been argued that there is a need for studies that go behind policy aims and ‘reveal’ what they imply and mean in practical terms (Gask & Rogers 1998, Parr 2008, Pilgrim 2009). There is a need for research-based knowledge about practice and social interaction within community mental health services with a low threshold approach. Studying such often complex organisations from an inside perspective may contribute to opening up what has been described as a ‘black box’ in research (Larsen 2007). This way, such ‘practice-near’ knowledge can, potentially, contribute to mental health services research and the further development of community mental health work.

Changes in mental health policy and the restructuring of mental health services have important ideological aspects. As Prior (1993) and Søder (1992) have both discussed, policy, organisation and ideology are important frameworks that influence on mental health work. Ideology and organisational changes do not, however, tell us how social support is enacted on the ‘ground level’ in a service. It is through practice and face-to-face interaction with professionals on the ground level that service users experience whether a service is helpful (Lipsky 1980, Schön 1983). A process of restructuring the mental health service towards increased community-based services, that is taking place, have practical consequences for the daily life situations of people who live with mental health problems and need support in daily life. This is an important reason for studying participation and meaning based on their experiences (Larsen 2007, Pilgrim 2009). There is also a lack of research-based knowledge about the content of low threshold community mental health services and a need for research that can contribute to a broader understanding of what user participation and mental health work in such settings implies.

1.3 Research aims and central research questions

Overall aims for this study has been to explore social interaction and activities within a low threshold community mental health service and, thus, from an inside perspective, to contribute new understandings of how social support and users’ participation are enacted. A further aim was to explore what participation in this service means for service users as part of their daily life in the community, and how the professionals experience their mental health work and professional roles. Knowledge from the study will, hopefully, also

contribute to a broader understanding of the concept of participation as applied to mental health work, and to developments of community mental health services that are helpful in supporting people with mental health problems in their daily lives in the community. Findings from the study will be analysed and discussed against background knowledge and theories about the social aspects of mental health and illness, previous research in this area and developments in community mental health work and service organisation, which will be presented in the next part of this thesis.

This introduction has provided an overview of the central themes which will be further described in chapters 2 and 3, and it also serves as an introduction to the main themes studied, which are presented in the four papers. The different parts of the study evolved as the research progressed. Thus, themes and research questions for studies 2 - 4 were developed based on the emerging findings from data collection and analyses during participant observation, which is presented in paper 1. In this way, descriptions and interpretations of the study context, including social interaction in situated activity and field conversations presented in paper 1 functions as a backdrop for the parts of the study presented in papers 2 – 4. The points below presents an overview over the central themes and research questions in the empirical study and indicates in which of the papers each theme is addressed.

Central themes and research questions:

- What characterises the localities, atmosphere, activities and social interaction within low threshold community mental health centres? (Paper 1)
- How is social support and user participation enacted within this service? (Papers 1 and 3)
- How do service users describe and understand their experiences of participation? (Papers 2 and 3)
- What does user participation in the service mean for users and professionals? (Papers 3 and 4)
- What does participation as users of the centres mean for the daily life situations of people who live with mental health problems? (Paper 2)

- How do professionals in a low threshold community mental health centre experience their mental health work and professional role? (Paper 4)

Specific aims for each of the four papers:

Paper 1: To contribute knowledge about participation in activities and social interaction within the context of an accessible, 'low threshold' community mental health service, by studying how social support in daily life is enacted and experienced.

Paper 2: To understand what meaning attending community mental health centres has for service users in their daily life situations in the community, by exploring their experiences of participation through individual interviews.

Paper 3: To shed light on the practice and meaning of user participation in a community mental health service, by exploring the perspectives of both users and professionals within a service that aims to enhance its users' active participation and influence.

Paper 4: To understand the development of mental health work and professionals' role in community mental health centres with a low threshold approach, by exploring how professionals experience their work and professional role.

1.4 Structure of the thesis

This thesis consists of a theoretical and methodological framework for an empirical study with an ethnographic approach. Chapter 2 outlines changes in mental health policy and service organisation as the background context for the empirical study. Chapter 3 presents theories about the social aspects of mental health, participation and the need for recognition. In chapter 4 the methodology, research process, research methods and ethical issues related to the empirical study are presented. Chapter 5 presents summaries of the study's four papers and the overall findings from the research. Chapter 6 contains an overall discussion and Chapter 7 presents conclusions from the study and some implications for practise and further research. The empirical research is presented in papers 1–4.

2. BACKGROUND

This part of the thesis presents background knowledge that is relevant for a broader understanding of the wider context of this study and, in this way, aims to locate the present research project and research settings within the contemporary community mental health field. An historical overview of the process known as the deinstitutionalisation of mental health services will first be described, followed by an outline of contemporary mental health policy and developments in community mental health services and mental health work.

2.1 Deinstitutionalisation

In the ‘western world’ the last century witnessed a common trend: an increase in psychiatric hospitals in the first half of the century, followed by a reduction in the number of patients in psychiatric hospitals during the second half (Bachrach 1997, Knapp *et al.* 2007, Leff *et al.* 1997, Mechanic & Rochefort 1994, Pedersen & Kolstad 2009, Prior 1993, Ramsdal 2013, Rogers & Pilgrim 2005, Sayce 2000, Scull, 1984, Thornicroft & Bebbington 1989). Earlier, psychiatric services were mainly a ‘holistic’ system where most sides of the patients’ lives were handled within psychiatric institutions (Goffman 1961, Parr 2008, Prior 1993). When ‘The Community Mental Health Centers Act’ was passed by the federal US government in 1963, the aim was to reduce the number of patients in psychiatric hospitals by 50 % in the following 10 to 20 years. By 1975 this reduction, in fact, turned out to have been 62 % (Mechanic & Rochefort 1994). This process, called the deinstitutionalisation of mental health services, which started in the USA, soon also became a trend in several European countries (Knapp *et al.* 2007).

In Norway, the number of patients in psychiatric hospitals for adults was reduced from an average of about 9000 in the years 1960–1970 to just under 3000 in 2003 (Hagen & Ruud 2004). In a government White Paper on plans and aims for mental health services in Norway (Sosial og helsedepartementet 1996/97), the move towards community-based care is further emphasised, also stating that treatment in psychiatric hospitals shall be temporary and only represent one part of several available mental health services. The municipalities’ responsibility for community mental health services is also pointed out.

A redirection of mental health services from a mainly hospital-based system towards care in the community has been welcomed internationally. However, from the USA, where the process of deinstitutionalisation started, Bachrach (1997) has described that there are wide varieties in the quality of community care, both between and within states.

As Parr (2008) has discussed, social exclusion of people with serious mental illness also exists within local communities. Could a lack of support in the community reduce opportunities for living outside psychiatric institutions for some? Warnings raised about the process of deinstitutionalisation have mainly been related to worries about insufficient care in the community, especially for those who need such support the most (Munk-Jørgensen *et al.* 1992, Pilgrim & Rogers 2003, Rosen 1992). As in several other countries, today's mental health services in Norway have been described as complex and fragmented (Ramsdal 2013), and it has been reported that many people who live with mental health problems experience a lack of continuity in their services (Rådet for psykisk helse 2008). During the last two decades a need for coordination of services for people with complex needs due to long term illness or disabilities have, therefore, been highlighted (Helse og omsorgsdepartementet 2009, 2013).

2.2 Ideologies behind deinstitutionalisation

Changes from a hospital-based system towards community mental health services represent a shift from psychiatric treatment towards also supporting people's function in their daily life situations. In his well-known book *Asylums*, Goffman (1961) described the negative effects of 'total institutions' based on fieldwork in a psychiatric hospital in the USA in the mid 1950's. A critique of psychiatric hospitals and other institutions from a human rights perspective, revealing inhuman treatments and a lack of civil rights for patients, has been understood as one of the main forces behind this shift in policy and reorganisation of services. However, as Prior (1993) has pointed out, the reasons for these changes are probably more complex. Other explanations for the deinstitutionalisation of services and a move towards community care have been related to improved treatment, particularly the new anti-psychotic medications that were available from the 1950's, as well as to improved welfare programmes in some countries. Changing ideologies and

beliefs about the nature of mental illness among mental health professionals and wishes to reduce the cost of mental health services have also been discussed in the literature (Mechanic 1994, Pedersen 2002, Prior 1993, Rogers & Pilgrim 2005, Scull 1984). In a study from Norway, general changes in service provision towards more short-time treatment, along with an increased awareness of patients' preferences among the staff, were also identified as plausible explanations for these structural changes (Hagen & Ruud 2004).

Aims of social integration, social inclusion and participation, which will be more thoroughly presented in chapter 3, can also be seen as an influence on the movement towards care in the community. These developments could also indicate a general change from a one-sided belief in hospital treatment and medical psychiatry towards a view of long-term mental illness as disability. Such a turn has been widely discussed in the literature on mental health and mental health services (Grunewald 2000, Hydén 2005, Prior 1993). Isolated psychiatric institutions were first called 'asylums' and later renamed 'psychiatric hospitals'. 'Asylum' means shelter or sanctuary and, according to Prior (1993), in the 1950's a belief in sanctuary seemed to be replaced by the belief that social integration into the community was possible for people with mental illness. In order to be socially integrated one at least has to be present in the community. This presence does not, however, necessarily mean that one is included in social networks and supportive relationships (Bø & Schiefloe 2007, Gustavsson 1993, Kristiansen 1993, Parr 2008).

Ramon and Williams (2005) describe mental health systems as being 'at the crossroads', and call for a psychosocial perspective with a focus on psychological issues, social interaction and people's social environments. A central issue that has been discussed is how services and mental health work can support community integration and genuine citizenship for people with mental health problems (Bergem & Ekeland 2006, Rogers & Pilgrim 2005, Sayce 2000). According to Knapp *et al.* (2007: 11), "The most general overarching challenge is to continue to move Europe's mental health systems out of the age of containment and confinement and into an era of opportunity and choice". Many who live with mental health problems need help in daily life. A challenge when practising community mental health work can be to balance between supporting independence and

on the other hand, provide the necessary help to function in daily life which, in turn, also can lead to increased dependence (Moe 2009, Wing 1990).

2.3 Community mental health services in Norway

The Norwegian White Paper on mental health policy (Sosial og helsedepartementet 1996/97) describes the local municipalities' responsibility for housing and community care for people with mental health problems, as well as aims of increased social integration, quality of life and user participation in mental health services. From 1998–2008 the White Paper was followed up by a national mental health programme, aiming to reorganise these services further in the direction of community care through substantial increases in the funding (Sosial og helsedepartementet 1997/98). Recent evaluation studies have documented that these changes have had positive impacts on "... access and equity, quality and efficacy, fairness, patients' rights, protection, participation and treatment outcome" (Pedersen & Kolstad 2009: 14, 18).

Norwegian mental health policy states that the main focus for mental health services shall be on service users' needs, and that active user participation and involvement are central aims for these services (Sosial og helsedepartementet 1996–97, Sosial og helsedepartementet 1997–98, Sosial og helsedirektoratet 2006). It has, however, been identified that these aims were not included or clearly stated in all the plans for mental health services in Norwegian municipalities (Helgesen 2004). The organisation of community mental health services has also been found to vary between the municipalities and these services have, thus, also been discussed as still not being sufficiently developed to meet all policy requirements (Kalseth *et al.* 2008, Myrvold & Helgesen 2009, Ramsdal 2002). Ramsdal (2013) describes services for people with mental health problems as a complex and constantly changing phenomenon which, along with the complexity of 'mental health problems' in itself, makes descriptions and analyses of mental health services problematic. This also makes it difficult to develop a 'holistic' service.

A recent approach in mental health work has been developments of 'low threshold' services, which have accessible and flexible organisations and offer support in daily life, often through a mix of professional and peer support. Such services have traditionally

been developed as part of a public health strategy of ‘harm reduction’ in services for people with drug dependency (Drucker 1995, Johansen & Myhre 2005, Ådnanes *et al.* 2008). Internationally, however, such services have also been developed as part of what is known as a ‘recovery-oriented’ approach in mental health services (Whitley *et al.* 2008, Whitley *et al.* 2012). These developments are described more thoroughly in paper 1. Guidelines for community mental health services from the Norwegian Directorate for social and health affairs (Sosial og helsedirektoratet 2005) have recommended further developments of ‘low threshold’ community mental health services, in order to offer people who live with mental health problems the safety of available help when needed. As the Norwegian Institute for Public Health points out, perspectives from the area of health promotion should also be included in the mental health field (Dalgard *et al.* 2011). A publication from the Norwegian Directorate for Health (Helsedirektoratet 2010) recommends further developments of low threshold services as part of health promotion strategies and prevention of mental health problems. Available social support has also been described as central for health promotion, as it can represent important resources for experience meaning through developing a sense of coherence in one’s life situation (Antonovsky 1993, 1996).

The shifts in mental health policy and service organisation that have been outlined here also indicate changing roles for both service users and professionals towards more collaborative relationships. ‘Partnership’ models encourage service users to take more responsibility and mental health professionals to reduce their ‘expert roles’ (Elstad & Hellzén 2010, Petersen 2009). While some studies have found that ‘paternalistic attitudes’ still prevail among professionals working in the mental health field (Lilja & Hellzén 2008, Roper & Happell 2007), Hagen and Ruud (2004) found that professionals working in psychiatric hospitals in Norway rated the need for treatment and care outside psychiatric hospitals to a much higher degree in 2003 than had been measured earlier. This result was related to a raised awareness of these alternatives among professionals and discussed as possible signs of changes in ideology towards community care or, on the other hand, as an abduction of responsibility. Important questions do, however, remain, such as whether the organisation of community mental health services actually does encourage changes towards collaborative relationships between service users and professionals, and to what degree these services are responsive to their users’ needs.

Knowledge about social activity and interaction between users and professionals is important in order to better understand the new developments in mental health work on the 'ground level'. Mental health professionals shape mental health policy into practice through their 'face-to-face' interactions with service users (Lipsky 1980). Mental health work is a broad term that signals changes from an overall focus on psychiatric hospital treatment, towards including community-based mental health services as a field of practice. Other changes have also occurred in the field of mental health, such as developments of multi-professional mental health work which, for example in Norway, has led to a common post-registration course in mental health work for health and social workers. Such developments have also contributed to a broader theoretical understanding and a more eclectic approach in mental health work (Almvik & Borge 2006, Myrvold & Helgesen 2009, Ramsdal 2013, Sosial og helsedirektoratet 2005).

Few qualitative studies exist of participation in activities and social interaction in the context of contemporary community mental health centres with a low threshold approach. There are, however, some studies from community mental health services in other countries that share similarities with this study's research context, such as a low threshold approach and a mix of professional and peer-support (Conradson 2003, Hall & Cheston 2002, Kristiansen 2000, Parr 2000, Parr 2008, Philo *et. al* 2005, Sørensen 2012, Truman & Raine 2002, Whitley *et. al* 2008, Whitley *et. al* 2012). This theme is elaborated on in paper 1.

2.4 Summary

Overall societal structures, as well as mental health policy and ideology, are frameworks surrounding and influencing on service organisation and mental health work (Prior 1993). Although this perspective is beyond the scope of the empirical research in this thesis, I have presented some background knowledge about major changes that have taken place in mental health policy, service organisation and the ideologies of mental health work in many countries in the 'Western world', including Norway. Based on my initial studies of documents and other literature related to mental health service developments, I have therefore presented a historical outline of a process of 'deinstitutionalisation' of mental

health services that has taken place in several countries internationally. Overall, this process has been characterised by a movement away from a mainly hospital-based mental health system, towards aims and developments of community mental health services. This process, along with contemporary aims of increased community integration, social inclusion and participation, represents the wider background ‘surrounding’ the community mental health service that was chosen as the research context for this study. I have also presented some central features of more recent developments within contemporary community mental health services in Norway, in order to further contextualise the present empirical study. This theme is described in more detail and discussed in paper 1.

Before describing how the empirical research was carried out, the next chapter presents theoretical perspectives and concepts related to the social dimensions of mental health and illness. Some of these perspectives and research findings functioned as theoretical resources for the development of research questions and design of the empirical study, while others emerged as relevant based on observations and the process of data analysis during fieldwork.

3. THEORETICAL PERSPECTIVES AND CONCEPTS

The overall theme of this thesis is what people do and how they interact in a 'low threshold' community mental health service. Further topics, which were developed during the first part of the field study, are what attending the service means for service users in their daily life situations, what active user participation in the service means for users and professionals, and how professionals experience their mental health work and professional role. In this chapter I will present previous research, theories and concepts related to the social aspects of mental health and illness and to a social interactionist perspective (Blumer 1969, Goffman 1961, Goffman 1967, Mead 1967). My previous clinical experience and research in the mental health field, as well as a general interest in the social aspects of mental health and illness inspired the initial research questions and development of the empirical study. The concept of participation as it is applied in the area of rehabilitation and Axel Honneth's theory of recognition (1995) are presented next. The relevance of these theoretical perspectives emerged and was developed during the process of analysing and interpreting the empirical material during the field study.

3.1 Social aspects of mental health and illness

Since the 1930's a consistent research finding has been that there are links between increased levels of mental illness in populations and less robust social ties in local communities, as well as low social support in personal networks (Cobb 1976, Dalgard *et al.* 1995, Dohrenwend & Dohrenwend 1969, Faris & Dunham 1939, Fisher 1982, Leighton 1959, Rogers & Pilgrim 2003, Srole *et al.* 1962). It has also been established that several aspects of the 'content' and functions of people's social networks, such as social support and positive relationships, are beneficial for psychological well-being and experiences of a positive quality of life, while social isolation have adverse effects on mental health (Berkman *et al.* 2000, Ferlander 2007, Kawachi & Berkman 2001, Oliver *et al.* 1996, Sayce 2000).

People with mental health problems, as a group, are often stigmatised in society (Goffman 1963, Huxley & Thornicroft 2003, Scambler 2009). Stigmatising responses from others, along with experiences of mental distress, may lead to social exclusion and difficulties in

establishing social contact and sustaining relationships with family, friends and neighbours (Allman 2013, Corrigan *et. al* 2009, Ekeland & Bergem 2006, Elstad 1999, Elstad & Norvoll 2013, Granerud & Severinsson 2006, Lingsom 2008). The results of such processes can be degrees of social isolation, which in turn may lead to a lack of hope and meaning, as well as low self-esteem, a lack of motivation and reduced possibilities to develop and sustain social skills (Boyd 2008, House 1988, Hummelvoll 2012, Rogers & Pilgrim 2005, Sayce 2000, Skårderud *et. al* 2010, Wing 1990). Whether being present in the community leads to social contact and the development of social relationships or, on the other hand, to social withdrawal and isolation also depends on how inclusive local communities and neighbourhoods are (Bricout & Gray 2006, Granerud & Severinsson 2003). ‘Community’ is a broad term, which can relate to geographical locations as well as to fellowships based on common interests (Bricout & Gray 2006, Cornwall 2008). Cohen (1985), for example, relates ‘community’ to people’s experiences of belonging and as resources for meaning and identity formation.

Social support can provide feelings of safety and motivation and, thus, encourage participation and social inclusion (Bø & Schiefloe 2007, Wing 1990). Social relationships can also be non-supportive or oppressive, and to be alone can be experienced as positive. Clinical literature in the mental health field, for example, describes how overstimulation in the form of ‘high expressed emotion’ can in itself lead to mental distress (Skårderud *et. al* 2010, Warner 1994). This way, periods of social withdrawal can sometimes function as a protection from disturbing symptoms of mental distress, and social environments with few stressful events could, thus, be of central importance for people who live with mental health problems. However, long periods of social isolation have been found to threaten people’s experiences of being a ‘whole person’ with a positive social identity (Allman 2013, Elstad & Norvoll 2013, Jenkins 2008). According to Wing (1990), for people who experience problems with functioning in daily life, a one-sided focus on autonomy may lead to reduced support and social withdrawal. On the other hand, receiving care and treatment without an influence can increase one’s dependency on others. To have control and influence in one’s life situation and available resources that confirm life as meaningful has been found to be valuable for positive mental health (Antonovsky 1993, 1996).

3.2 Theoretical perspectives on social interaction

Almost a century ago, George Herbert Mead lectured about the importance of social interaction and mutual relationships for identity-formation and feelings of self-worth. These lectures were later published based on notes written down by his students (Mead 1934/1967). According to Mead, social relationships and interaction in organised social environments are vital for the development of identity. Self-consciousness and identity are developed during processes of social experiences and common activity and "... develops in the given individual as a result of his relations to that process as a whole and to other individuals within that process" (Mead 1967: 135). 'Mind' is also expressed through social processes and experience, and depends on our ability to take on the perspectives of others. In order to experience ourselves as a subjective 'I', we must first develop a 'me' through being objects for others, and developing a 'self' in the fullest sense depends on an awareness of the attitudes of others towards ourselves, as well as on the common social activity which we engage in. This is "... the essential basis and prerequisite of the fullest development of that individual's self" (Mead 1967: 155).

In line with Mead, Goffman (1961) described identity as a subjective experience of one's own personality, which develops through social interaction. Goffman did not, however, present people as passive recipients of roles given by others, but claimed that the 'proof' of the existence of our unique, personal selves is produced through 'common, ceremonial acts' (Jacobsen & Kristiansen 2002: 43). In Goffman's theory, mutual trust is established through face-to-face interaction in concrete social situations. Through rituals of politeness and respect, such as greetings, people recognise one another and confirm one another's dignity (Goffman 1967). Being ignored, on the other hand, threatens our experiences of being valuable individuals. Based on a field study of a psychiatric hospital in the USA almost sixty years ago, Goffman (1961) described a total institution segregated from the outside world, with a custodial practice towards the patients. Stripped of all symbols of their personal identity, the patients were forced into a morally degrading career. In a field study from Norway, Løchen (1967) identified a tension between democratic ideals and realities in a psychiatric hospital, resulting in a 'diagnostic culture' where patients' communications were understood as symptoms of their mental illness. Based on a more recent ethnographic study of the practice of seclusion in psychiatric hospitals, Norvoll

(2006) highlighted dilemmas between treatment and control, and identified a need for increased ‘social responsivity’ to the patients’ individual needs and wishes.

3.3 Social integration, social inclusion and participation

Aims related to supporting people with long term mental health problems has shifted from mainly focusing on individual treatment, towards also aiming to contribute to these groups’ social integration, inclusion and participation. Today, these concepts are often used side by side (Allman 2013). When applied to supporting so called ‘marginalized groups’ in society, all three concepts are commonly used in relation to efforts to reduce social exclusion and social isolation. The Oxford guide to the English language (1989: 380, 385, 440), gives the following definitions of these three concepts: to *integrate* means to ‘combine (parts) into a whole’ and to ‘bring or come into full membership of a community’, to *include* means to ‘have or treat as part of a whole’ and to ‘put into a specified category’, while to *participate* means to ‘have a share’ and ‘take part in something’. In general, these concepts can all be related to being part of a community or social fellowship. In my understanding, however, participation has the strongest connotation to active agency, as it is not something that is done to people, but something a person does. To illustrate this with an example; it is possible to say that someone ‘integrates’ or ‘includes’ someone else, but one cannot say that one person ‘participates’ another.

Living in the community instead of for example in a psychiatric hospital, can be described as being integrated in society. However, to be present in a neighbourhood, that is, being integrated in a geographical sense, does not guarantee that social contact will occur or social relationships will be developed. An important aspect of the concept of social inclusion is that it has to do with experiences of belonging to one’s community and society, as opposed to feeling excluded from mainstream community life. Related to disability research, it has also been pointed out that since all human beings already are part of society, the term ‘inclusion’ should replace the term ‘integration’ (Tøssebro 1999, Ytterhus 2000). As Daly and Silver (2006) points out, one can only be excluded or included relative to other people. Social inclusion is about making room for everybody to

take part in society and this concept has, thus, also been linked to the concept of ‘participation’ (Gustavsson 2004, Madsen 2005, Tøssebro 2004).

In general, participation relates to social activity, active involvement and experiences of belonging. A vision of full participation in society is recognised as central in disability research and rehabilitation (Allman 2013, Bjørk-Åkesson & Granlund 2004, Molin 2004, WHO 2001a). Daly and Silver (2006) also highlight the importance of the concept of participation due to its emphasis of agency, against what they describe as contemporary tendencies to social isolation in society in general. To reduce social exclusion one could either bring resources to the individual to integrate her/him in ‘normal’ society, or one could intervene in the social environment and include all in society. As social inclusion depends on the environment as well as on individuals, an important question is, thus, how to build an inclusive society (Gustavsson 2004, Madsen 2005). Dijkers (2010: 5) describes the content of ‘participation’ as follows: “... issues such as the proper relationship of individual to society, biological and social standards for normality, and so forth, play a role in defining and operationalizing the concept”. Theoretical concepts such as social integration, inclusion and participation are developed within frameworks of certain ideologies of treatment and care (Prior 1993, Søder 1992).

Aims such as social integration, social inclusion and participation for people with long-term mental health problems or disabilities, all stem from existing problems of social exclusion among these groups of people (Elstad & Norvoll 2013, Norvoll 2013). Thus, ‘participation’ can be seen as a new word describing how to solve an old problem. However, when addressing issues of marginalization and social exclusion, an emphasis has been put on enhancing individuals’ personal recovery processes and their rights to have control and influence in their own life situations (Anthony 1993, Borg 2007, Borg & Kristiansen 2004). There is also a connection between the use of the concept of participation and aims of increasing individuals’ freedom of choice. Participation is about individuals’ experiences of engagement in life-situations. Thus, the concept of participation can be seen as a link between the individual and the surrounding world (Gustavsson 2004), which is also in line with my understanding.

3.4 Participation, disability and mental health

In the World Health Organization's International Classification of Functioning, Disability and Health (ICF), participation is defined as 'involvement in a life situation', and the domain of 'activity and participation' describes involvement in terms of social inclusion and access to resources in order to 'take part' (WHO 2001a). A need for a broader theoretical understanding of this concept has, however, been identified (Badley 2008, Cornwall 2008, Eide *et al.* 2008, Hammel *et al.* 2008). While the ICF was being developed, there was also an increased focus on the social aspects of disability and the impact of the contexts people live in for their opportunities to participate (Cerniauskaite *et al.* 2011, Oliver *et al.* 2006). In rehabilitation and disability research, 'participation' is commonly used in a broad sense, related to independent living and experiences of control in one's own life situation. Participation is often used as an outcome measure in rehabilitation and other services supporting persons who are less involved in community and society than others. Dijkers (2010), thus, links participation to the social model of disability, rather than a medical model, but also states that the field is still in need of a consensus definition of the concept. According to Witzø (2013: 4) understandings of participation in service delivery should be studied, since "... the interface between service providers and recipients may present opportunities and tools for participation."

As Molin (2004) has pointed out, participation according to the ICF is about involvement in a life situation, and should therefore be evaluated based on people's experiences and social interaction, and not on their abilities. In line with this, and according to Bjørk-Åkesson & Granlund (2004), participation develops through social interaction; therefore the degree of a person's experience of participation varies with different situations. In which situations a person wish to participate will also vary between people (Sayce 2000). Participation in life situations must therefore be judged by each individual. Based on different situations and social interaction, participation is, thus, mainly a process-description of everyday functioning and not a description of a steady state. Reduced levels of participation relate to people's abilities, as well as to barriers in their environments. Thus, individual and environmental factors interact in complex ways to 'produce' disability. However, according to Gustavsson (2004), the 'language of participation' has different meanings from different perspectives. The social dimensions of 'participation'

should, therefore, be further explored and supplemented by other perspectives, such as the meaning different forms of participation have for individuals. The ICF's definition of participation as involvement in a life situation (WHO 2001a) has been criticized for ignoring individuals' subjective experiences and complex interactive processes (Hammel *et. al* 2008). According to Hammel *et al.* (2008: 1458), future research should '... examine the complexity of participation at the level of diverse social relationships, groups, communities and cultures'.

As described in chapter 2, user participation is now a central aim for mental health services in several countries, including Norway (Sosial og helsedepartementet 1996–97, Sosial og helsedepartementet 1997–98, Sosial og helsedirektoratet 2006). The term 'user participation' relates to people's participation in their role as users of services. In the mental health field, the aims of 'user participation', as described in policy documents and research, have been applied to people's rights to have an influence on the services they receive, as well as to users' rights, as a group, to have an influence on mental health policy and service developments (Crawford *et al.* 2003, Hofseth 2000, Petersen 2009, Rise *et. al* 2013, Sosial og helsedirektoratet 2006, WHO 2001b). In this thesis, user participation related to users' influence in services was explored in interviews with service users and professionals during fieldwork, and is the focus of paper 3.

In the areas of rehabilitation and disability research, participation is commonly linked to everyday life. According to Sandlund (2005) there has been a change in terminology, also in the mental health field: from being described as 'long-term mentally ill', people are sometimes described as 'persons with mental disabilities'. Sandlund (2005: 63) also points out that such changes in language is important, as "... those who are ill may need hospital treatment, while those who have a disability may need support to do what they like but need help to accomplish." Supporting processes of participation and social inclusion is central to humanistic and social scientific perspectives, as well as a psychosocial and relational approach in mental health work (Borg & Karlsson 2013, Corrigan *et al.* 2008, Elstad & Norvoll 2013, Ramon & Williams 2005). In addition to supporting users' influence in mental health services, broader aims of participation in society are also highly relevant for people with mental health problems. Craig (2006: 15), for example, describes

the guiding principles of psychiatric rehabilitation as: "... goal-directed therapy managed in partnership and provided in real situations in a culture of empowerment and optimism", which "... should be the cornerstone of all mental health care."

3.5 Participation and the need for recognition

Ebersold (2007: 245) describes the links between disability and participation as a shift towards a participatory model, and points out that "... relating the concept of participation to its affiliating effect requires an identity-based approach, caring for the bond between citizenship and social recognition." Central to the German social philosopher Axel Honneth's theory of recognition (Honneth 1995, 2003, 2007, 2012), is the vital importance of social interaction and inter-subjective relationships to individuals' identity formation and personal developments. Building on the philosophy of Hegel and on George Herbert Mead's social psychology; in Honneth's theory, 'recognition' has three main dimensions: love, rights and solidarity. Love relates to early development and rights to citizenship. Solidarity is about being recognised as capable human beings through participation, positive engagement and mutuality in situated fellowships. As the concept of solidarity in Honneth's theory is linked to concrete experiences of mutual social interaction, his theory is highly relevant to the above discussions of social interaction, meaning and mental health related to the concept of participation.

Honneth's (1995, 2003) social philosophy is a moral philosophy, where experiences of not being recognised are explained as arising from 'social pathologies' which lead to needs and struggles for recognition. Not being recognised equals being met with 'disrespect' (Honneth 2007), which implies that one is visually observed, but not 'really seen' as a person who deserves respect and recognition for his/her uniqueness and capabilities. People who live with mental health problems can often experience social interaction as problematic, whether this is due to feelings of distress in social situations in themselves, or from being marginalised and stigmatised by others. Stigmatising responses, marginalisation or simply being overlooked can give rise to experiences of violation, or what Honneth (2007) calls 'disrespect', which can lead to social withdrawal and social isolation. However, according to Honneth (1995, 2003, 2007), experiences of disrespect can also give rise to a need for recognition, and this need, arising from experiences of

being marginalised in society, may in turn lead to struggles for recognition. In this way, Honneth's theory highlights a need for inter-subjective relationships of recognition in which people mutually confirm one another's identity (Goffman 1967, Mead 1967).

Relationships of recognition may have the capability of enhancing people's opportunities for 'self-realisation', and Mead's (1967) social psychological theory also links experiences from social interaction and relationships to identity formation. According to Oliver *et al.* (2006), meaningful participation can enhance connectedness and belonging, and valued participation may foster resilience, positive mental health and well-being. Being able to contribute to others and receive recognition for this contribution leads to experiences of self-worth, which are central to personal growth, identity formation and positive mental health (Antonovsky 1996, Jenkins 2008). In the areas of mental health work and therapy, research on communication between professionals and service users on the individual level has identified 'acknowledgement' as important (Schibbye 2002, Vatne & Hoem 2007). Mutuality in relationships has been identified as central to experiencing participation for people with diagnoses of schizophrenia (Yilmaz *et al.* 2009), and to be met as capable human beings has been identified as important for people's processes of recovery from mental health problems (Anthony 1993, Borg & Kristiansen 2004, Borg 2007, Deegan 1996, Sterling *et al.* 2010).

3.6 Theoretical resources for the study's methodological approach

I introduced this chapter by presenting literature and findings from research on the social aspects of mental health and illness, which I have found relevant for the present study. In the social scientific literature as it is applied to the mental health field, the concepts of social integration, social inclusion and participation are central. These concepts sometimes overlap and are not easily defined. I have, however, presented some examples from the literature in order to identify and clarify some similarities and differences between them. Research over several decades has documented that a socially isolated life situation can have severe negative effects on people's self-confidence, while supportive social contact and relationships have been found to have central value for experiences of positive mental health. In order to better understand such mechanisms, I have presented some central theories and research from social science that inspired this study. George Herbert Mead

and Erving Goffman's theories have a social interactionist approach, and are often linked to the perspective of 'symbolic interactionism' as developed by Blumer (1969). In this perspective, people's shared activities in face-to-face relations are central, as is the belief that 'social actors' engage with one another and the environment based on their interpretations and understanding.

Common to the theoretical perspectives presented in this chapter is that social interaction and relationships are central for mental health. As social actions and identities make sense in context, such phenomena should also be studied and analyzed in their social context. According to Goodson and Vassar (2011), qualitative research is essential when aiming to get close to and explore a social group and to understand their actions and experiences related to particular research themes. In ethnographic research, both participation and meaning is often studied. 'Meaning' relates to people's subjective experiences (Sharkey and Larsen 2005), which means that this approach could provide valuable knowledge about people's experiences from participation. Rock (2007: 26) places this form of interactionism "... on the borders between micro-sociology and social psychology". Ethnography has been described as a particularly useful approach when researchers need to understand complex phenomena and the perspectives of a group of people, as it allows for rich descriptions and a deep understanding (Hammersley & Atkinson 2007). The term 'ethnography' has an assortment of meanings and it is not often used in a wholly orthodox way, as it does not fall under only one epistemological belief (Goodson & Vassar 2011). Essentially, ethnography is a field-orientated activity that has cultural interpretations at its core, although the levels of those interpretations vary. In ethnographic research it is common to gather multiple forms of data based on different forms of research methods, such as observations, interviews and documents.

In this empirical study the intention has been to explore how people with mental health problems attend a low threshold community mental health service and what this means to them, as well as to study social interaction and activity and how the professionals experience their mental health work and role in this type of service. There is a lack of research on what people do within the context of contemporary community mental health centres with a 'low threshold' approach. The ethnographic research process is usually

open and flexible, in order to discover new ideas and insights, both from an insider (emic) and outsider (etic) position (Cresswell 2007, Fangen 2004, Hammersley & Atkinson 2007). Typically the researcher observes people in face-to-face interaction, engaged in situated activity, and explores what meaning participating in social situations has for the informants. Based on the aims and intentions of the study and from the theoretical position described in this chapter, I have chosen an explorative, ethnographic approach, with a general research process that has been described as ‘grounded theorizing’ (Alvesson & Skoldberg 2008, Charmaz 2000, Hammersley & Atkinson 2007). In the next chapter I will describe how the empirical research was carried out and discuss the methods and overall methodological approach, as well as ethical issues related to the study.

4. METHODOLOGY

Overall research aims for this study have been to contribute with knowledge about what people who attend a low threshold community mental health service do together with other service users and professionals, and what their participation means to them, in their daily life situations. Another aim has been to add to our knowledge about the practice of mental health work in low threshold community mental health services by exploring professionals' experiences from their work and professional role in such settings. This way, knowledge developed from the study can contribute to a broader understanding of the concept of participation (WHO 2001a), by adding perspectives from the community mental health area. This chapter describes the methodology and design of the study and presents an overview of the data-collection methods and process of analysis, as well as a discussion of methodological and ethical issues. To acknowledge my own role in the data production and interpretations, as well as to add transparency to how the study was carried out, I will also describe my role as researcher during the research process (Fangen 2004, Hammersley & Atkinson 2007, Sharkey & Larsen 2005, Silverman 2005).

4.1 Methodological approach

The theoretical part of this thesis has presented background knowledge about the social aspects of mental health and illness. As identified and described in the previous chapters, there is a need for further research-based knowledge about the 'content' of community mental health services (Gask & Rogers 1998, Larsen 2007, Pilgrim 2009). Thus, I have approached the data from an open-ended, social interactionist approach, where a range of theoretical perspectives has served as theoretical resources (Hammersley and Atkinson 2007). As there are few qualitative studies conducted within contemporary 'low threshold' community mental health services, I chose a methodological approach that allows for data collection from different sources. Thus, to study the research questions, I chose an ethnographic approach, addressing the study's research questions through a field study within a service consisting of three mental health centres called 'meeting-places'. Within this tradition, my intention has been to conduct the research in a way that is sensitive to the 'natural setting' which serves as the study's context, and to disturb the ordinary routines and daily life in the setting as little as possible. This way my intention has been to

explore common activity, social interaction and the participants' experiences of meaning as it naturally unfolds, as well as how it is described and experienced by different actors in the setting (Alvesson & Skoldberg 2008, Hammersley & Atkinson 2007).

4.2 Ethnography

Ethnography has been, and still is, the central research approach in social anthropology (Geertz 1984, Lofland *et al.* 2006, Spradley 1980), but from the 1920's, this approach was also applied to case studies of life in the cities in the USA, particularly by the 'Chicago School' in sociology. Since the 1960's ethnography has also spread to other disciplines, including health science (Atkinson *et al.* 2007, Hammersley & Atkinson 2007, Savage 2000, Sharkey & Larsen 2005, Silverman 2007). A central research method within the ethnographic approach is participant observation in specific contexts. This research is usually conducted over long periods of time, aiming to shed further light on issues that emerge during the course of the research process. These emerging issues are then further explored, often through qualitative interviews. Thus, according to Pope and Mays (1995: 42), ethnography "... can reach the parts other methods cannot reach". Ethnography is considered as particularly relevant in contexts where a lack of research-based knowledge has been identified (Savage 2006). In health care, ethnography is seen as valuable for studying interventions or services that are complex and difficult to standardise and, therefore, often appear as a 'black box' in research (Larsen, 2007, Savage 2000). Knowledge from an inside perspective, based on views and experiences from service users and professionals can, thus, be of value in community mental health.

An overall aim of ethnography is to describe participation and social interaction within 'real-life' contexts, and to explore people's experiences and what these mean to them (Creswell 2007, Delamont 2007, Hammersley & Atkinson 2007, Sharkey & Larsen 2005). Data collection and analyses are usually parallel, with the researcher moving from general descriptions based on early field observations, to more focused observations, and often also interviews. Within the ethnographic tradition, data are collected in 'natural settings', that is "... those that has not been specifically set up for research purposes (such as experiments or formal interviews)" (Hammersley & Atkinson 2007: 4). This commonly also implies that the researcher interferes as little as possible in the course of events and

activities within the study context which, according to Librett and Perone (2010), is what distinguishes ethnography from other methodologies. Common to ethnographic studies is an explorative, flexible approach, where the researcher ‘follows the data’ in an iterative process where data collection and analysis feed into each other (Sharkey & Larsen 2005: 169). Broad theoretical interests and themes, which Geertz (1973) has named ‘forshadowed problems’, often serve as theoretical resources or starting points and a guide to the research (Hammersley & Atkinson 2007, Silverman 2005).

An approach where researchers are open towards emerging empirical findings in addition to their theoretical questions is also central to a grounded theory approach (Glaser & Strauss 1967). In qualitative research, theorising based on analysis and interpretations of emerging empirical findings can, however, also be applied as a broad research strategy; not necessarily as a detailed data-collection method (Charmaz 2000, Hammersley & Atkinson 2007, Jacobsen 2005). My research strategy has been in line with this approach while conducting a field study within natural settings, participating in and observing social situations and interviewing people who participate and interact (Lofland *et al.* 2006). In ethnography, in using different research methods the aim is commonly to present a holistic picture of settings (Savage 2006), which is also central to case study research (Antoft & Salomonsen 2007, Flyvebjerg 2001, Yin 2003). According to Antoft and Salomonsen (2007: 29), case studies aim to “... set the particular characteristics and interesting phenomena of the organization of social life under the magnifying glass.” As the literature mentioned here shows, there is considerable overlap between research approaches labelled as ethnography, naturalistic research and case studies.

In my approach I have explored the emerging empirical findings through qualitative interviews with service users and focus group interviews with professionals during the field study. In line with ethnography, all interviews were developed from preliminary analysis of my own field notes and conducted within the research context. In drawing upon different qualitative research methods, my intention has been to include a variety of perspectives. In individual interviews, a study’s informants present their understandings through describing their subjective experiences (Fangen 2011). Likewise, focus group interviews are based on informants’ presentations of their views in discussions (Kitzinger 2005). On the other hand, deciding which observations to write down in a field diary

implies that a selection is made by the researcher (Goodley 1999). Thus, interviews can capture meanings that are otherwise hidden for the researcher and, vice versa, participant observation makes it possible for the researcher to include more than just the informants' subjective views. This way ethnography may, potentially, include different voices and meanings in a dialogic manner (Holstein & Gubrium 1995, Goodley 1999).

4.3 Research design

This research project was designed in the tradition of qualitative, ethnographic research with a naturalistic approach (Delamont 2007, Hammersley & Atkinson 2007, Lofland *et al.* 2006, Sharkey & Larsen 2005, Seale *et al.* 2007, Silverman 2005). The phenomena studied are, thus, naturally occurring social interaction in particular settings and the meanings informants attach to their participation. Studies of documents on policy and service developments, along with information rounds, were carried out during 2004. The main fieldwork was conducted from January 2005 until June 2006. Observations, theoretical study and early analysis influenced the further research process by inspiring new research questions. Starting from broad themes and questions about the characteristics of the context, activities, social interaction and meaning of participation (paper 1), field conversations and observations of variations in users' attendance, made me decide also to explore what users' participation meant to them as part of their daily life situations (paper 2). Similarly, focusing on the meaning of 'user participation' in interviews with users and professionals (paper 3) was based on different opinions voiced about this issue during 'house meetings' and conversations. Observations that the professionals' practice in many ways seemed to be different from mental health work in more traditional services made me decide to explore how they experienced their work and professional role (paper 4).

By using multiple data sources and research methods, my intention has been to broaden the knowledge base and add to the study's trustworthiness. Policy documents describing aims for mental health services internationally, nationally and locally provided background knowledge for the study. Participant observation and conversations steered by naturally occurring activities (Spradley 1979, Wadel 1991) provided an overview of the settings, activities and social interaction. A central focus in the study was on service users'

actions and experiences. Mental health work in this service was conducted through regular face-to-face interaction between professionals and users. Thus, the experiences of professionals were also included, as this could add valuable information about mental health work in a low threshold service.

4.4 Study context and settings

Social support has been identified as important to positive mental health, and people with mental health problems are often vulnerable to social isolation (chapter 3). Thus, to enhance social inclusion and community integration, mental health policy in many countries encourages the development of services that provide social support in daily life and service users' influence on the services they receive. In line with this, the aims for the service that was this study's research context are to provide social support for people living with mental health problems, to function as stepping stones towards rehabilitation for some and to enhance user participation. Background knowledge linking the present study to contemporary community mental health service developments and research has been outlined in chapter 2 and in paper 1 of this thesis. The three centres studied, which are all part of the municipal community health service in a Norwegian city, are described in more detail in paper 1. These centres have a multi-professional workforce. People choose how to attend, and there are no intake procedures or medical records kept about service users. Participation in activities and decision-making is encouraged, but not a prerequisite for using the centres. The centres' accessible, 'low threshold' approach represents a new type of organisation within community mental health, which has elsewhere been called 'semi-institutional places' (Parr 2000, 2008). Knowledge developed from a study of practice within these settings can also be relevant knowledge for developments of community mental health work elsewhere. In qualitative research, this depends on a study's 'transferability', which is mainly based on the researcher's interpretations (Antoft & Salomonsen 2007, Fangen 2004).

4.5 Research process and role as researcher

In chapter 3 I have presented theoretical resources for the research methodology and analyses in this study. My Masters' degree in health science was based on quantitative research related to social integration and quality of life for people with long-term mental

illness (Elstad 1999). This research and the accompanying theoretical studies led to my further interest in the social and psychosocial aspects of mental health and illness and how mental health work is enacted and relationships developed in services that aim to support people in their daily life situations. My work experience when starting this study was from fifteen years of practice in mental health nursing, working in psychiatric hospitals, day care units and a community mental health service and more than ten years of teaching mental health work.

Low threshold community mental health services were new to me, as I started the field study ten years after I had worked as a psychiatric nurse. I experienced that my previous work role and sharing some knowledge with the informants, helped me to gain entrance to the field and establish contact with informants. Some service users said that knowing I was a psychiatric nurse made them feel safe enough to be interviewed by me. My clinical experience also meant that I did not have to spend time learning about the basics of mental health work. Being middle aged, with a working class background and speaking the local dialect could also be the reason why one informant among the service users said she felt relaxed because I was “just an ordinary woman”. The presence of a researcher will always have some impact on the milieu. My approach was as far as possible, to avoid disturbing the natural ‘everyday life’ at the centres. I chose to be present only during the hours when users were present, and I did not adopt a role in specific activities. In my experience, this position helped me to avoid entering a ‘staff role’. I experienced that the open and flexible organisation of the service, with people constantly coming and going, made it quite easy to adopt a role as visitor. At the same time I was conscious about presenting myself to people that were new to me, briefly explaining that I was there doing research and, thus, to learn and write about what was going on in these centres.

4.6 Data collection and participants

In addition to theoretical study and literature searches in scientific databases, during the spring of 2004 I studied documents relevant to the research project. This included a systematic reading of documents describing international trends and aims for mental health services published by the World Health Organization (WHO 2001a, 2001b, 2005, 2007), documents describing Norwegian mental health policy (Helse og

omsorgsdepartementet 2009, Helsedirektoratet 2010, Sosial og helsedepartementet 1996/97, 1997/98, Sosial og helsedirektoratet 2005, 2006), as well as the local municipal mental health plan and brochures describing the service where the study was carried out. These documents provided me with valuable background knowledge about the wider research context, although I did not carry out a scientific document analysis.

By June 2004 the study was approved by the relevant regional committee for medical research ethics, the Norwegian Social Science Data Services (NSD) and the medical officer in charge of the service. During the autumn of 2004, guidelines for entering the field were discussed with those responsible for the local community mental health service, and I conducted information rounds at the centres. This also served as forums for asking questions about the research, and as a way for me as a researcher to be introduced into the milieu and to gain knowledge about their activities. Following this, the users and professionals were informed about the study in a written hand-out and in meetings at the centres before the start of the field study.

Participant observation

From January to December 2005, I conducted participant observation regularly for three hours three days per week, alternating between the three centres for three fortnightly periods at each centre. This adds up to a total of 18 weeks and all together 162 hours. I wrote field notes in my office immediately after each visit. From May to December 2005 I also conducted individual interviews with five women and five men who were all regular users of the centres. Four of these informants were also re-interviewed (Elstad & Kristiansen 2009). In February and March 2006, I conducted two focus group interviews with a group of six professionals, while gradually reducing the periods of participant observation. During this period I visited each centre once in addition to conducting the group interviews. I also participated in one social event at each centre: a Christmas party, a jubilee and a 'jumble sale'. All together I conducted about 190 hours of participant observation within the milieu of the centres from January 2005 to June 2006, not counting the individual and group interviews. In November 2006 I attended one meeting for users and staff at each centre, where I shared some preliminary findings from my early analyses, and asked for comments. I also answered questions about the

research and checked whether there were discrepancies between my understandings and those of the users and professionals. This procedure kept the research process relatively open, and comments and discussions were useful for my further analyses.

My participation was mainly in the day-to-day social life and ordinary 'small-talk' at the centres, and in some regular meetings for both users and staff. I did not participate regularly in particular activities, but attended these when it was natural, most often when I was invited by one of the service users. In specific activities I was, thus, an observer learning about what people were doing at the centres and what this meant to them. During 'house meetings' I was an observer, without participating in discussions or the planning of activities. This approach helped me to avoid entering a 'staff role', and I experienced my role as researcher as resembling that of 'observer as participant', the way it has been described and discussed by Hammersley and Atkinson (2007: 82). Immediately after each period of observation I returned to my own workplace, where I wrote down field notes consisting of concrete descriptions, my own reflections and often notes on methodology and theory (Hammersley & Atkinson 2007).

Individual interviews

In an information round after six months of participant observation, users were told that if they wished, they could be interviewed individually about what participating at the centre meant in their daily lives, and to share their views about user participation at the centres. Those who wished to be interviewed contacted me directly at the centre, or via one of the professionals. The inclusion criteria were to be a regular user of one of the centres and to have an interest in sharing this experience. I experienced that the first eight interviews gave rich information about the study themes, but added two more interviews in order to achieve a balance between women and men and to include service users from all three centres. All the interviews took place in a separate room at each centre. Five women and five men, all regular users of the centres, were interviewed, with the main questions being: "What does it mean to you in your daily life to participate at the centre?" and "What does user participation imply and mean at this centre?" During the individual and group interviews, I asked for clarifications and checked out my understanding of the informants' meanings, which has been described as an early step in the analysis (Kvale 1996). The

informants were invited to read through the transcript from their interview. Seven informants read through the interview and four were re-interviewed (paper 2).

Focus group interviews

In focus group interviews, a topic is explored in depth through discussions between a group of people who have been selected based on their knowledge and experiences with the research question (Halkier 2008, Kitzinger 2005, Lerdal & Karlsson 2008). This method was therefore chosen as data collection method in order to study professionals' experiences of their mental health work and professional role in a low threshold service. A contact person at each centre was therefore informed that I was interested in interviewing a group of professionals. As I wanted the group to consist of people with experience of this type of work, who also had previous experience of working in institutions, the criteria for inclusion were 1): to be working at one of the centres at present, 2): to have worked there for one year or more and 3): to have previous work experience from an institution, preferably a psychiatric hospital. The intention was to recruit people experienced in community mental health work, who could reflect upon their work role and relationships to the service users. Thus, the group consisted of five women and one man, two from each centre, with an upper secondary or university college education from the professions of occupational therapy, nursing and social education (Norwegian: vernepleie). All the informants knew each other and were known to me through my fieldwork. The focus group interviews were conducted in a separate room at one of the centres, and both interviews lasted for about two hours and were audio-taped and transcribed by me. The main themes and research questions related to their experiences from mental health work and the professional role at the centres, as well as to the practice of user participation.

4.7 Data analysis

Participant observation and all the interviews in this study were conducted within the research context, and the themes and research questions explored in the interviews were developed from observations during fieldwork. My overall approach to data collection and analysis has, thus, followed general principles common to ethnographic studies: starting with broad, theoretical themes as resources and then gradually focusing on specific questions based on the emerging empirical material (Hammersley & Atkinson 2007, Pope

et. al 2000, Silverman 2007). This way, the data analysis continued throughout the research in a process of going back and forth between data collection and analysis, searching for patterns which could be linked to research questions and theories. This study's approach is similar to the inductive research process of Grounded theory as it was developed by Glaser & Strauss (1967), but without following their detailed procedures. Such an approach is described as 'Grounded theorising' (Charmaz 2000, Hammersley & Atkinson 2007). Central to Glaser & Strauss (1967) was to develop new substantial theory from the empirical material. However, as described by Hammersley and Atkinson (2007), in research where the analysis is grounded in the empirical material it is also common to develop new understandings by discovering the relevance of theories from other areas. During this study's research process, emerging analytic themes were linked to theories, based on my interpretations, such as interpreting a link between empirical findings and the concept of participation in a broad sense, as well as to Honneth's (1995) theory of recognition.

This study's ethnographic approach with a social interactionist perspective meant that I approached the data analysis within the framework of a particular context and its' subjects, studying social interaction, activity and meaning (Hammersley & Atkinson, Graneheim & Lundman 2004, Sharkey & Larsen 2005). As a consequence, I wanted to search for themes in the data material, identifying, analysing and interpreting meaning based on the text from observations and interviews. As in Grounded theory, I developed codes and categories 'bottom up' from the empirical material (Kvale & Brinkman 2009, Tjora 2012). This approach is also central in qualitative content analysis. I have, thus followed an approach within qualitative interpretive content analysis as described in more detail by Graneheim & Lundman (2004). When analysing the text from field notes, as well as transcripts and notes from interviews, I first read the text closely several times to get an overview and familiarity with the content. Next I searched for its' experience-near (manifest) content and then the higher order (latent) meaning of the text. This text was highlighted and developed into sub-themes, which were grouped together and developed into higher-order themes. Finally the text was re-read to ensure that these themes adequately represented the content.

4.8 Methodological considerations

The ethnographic approach employed in this study allowed for relatively close contact with the informants over an extended period of time and to observe social interaction and activities and explore the experiences and views of both service users and professionals within the research context. The data are, thus, experience-near and from a type of service that has been little researched (Larsen 2007, Pilgrim 2009). Different qualitative methods have contributed to this ethnographic approach, and the perspectives of both service users and professionals have been explored. Studying situated activity, social interaction and meaning from different perspectives, aimed to contribute to a broader understanding of what people do together in these settings and how they experience their participation. I do not claim the findings to be representative of low threshold community mental health services in general. The study does, however, provide an example of some important aspects of the 'everyday life' in a low threshold community mental health service, which could be relevant to other similar services elsewhere (Fangen 2004). I chose to study a low threshold community mental health service with aims of providing social support as well as active user participation and I used all three centres as a research context as this would provide variation and in the data. I did not focus on differences between the three settings, as this was beyond the scope of the study. Such data could, however, have added valuable knowledge for the further development of such low threshold services.

The study shares some characteristics with a traditional 'naturalistic' approach, as participant observation and interviews have been conducted in a 'natural setting', aiming to disturb the daily routines as little as possible. I do, however, acknowledge that the researcher's presence always has some impact on informants and social situations in a research setting. The original 'Naturalistic approach' common to early studies from the Symbolic interactionist tradition (Blumer 1969) has been criticised for overlooking that people actively create meaning in their daily lives (Gubrium and Holstein 1997). Another critique has been directed towards the use of multiple methods, for example combining interviews with observations. Silverman (2007: 291) for example, claims that "... in cultural research, which focuses on social reality, the object of knowledge *is* different from different perspectives. And the different points of view cannot be merged, into a single, 'true' and 'certain' representation of the object." This critique by Silverman is,

however, in my understanding, directed towards viewing triangulation of methods as a validity measure, along with viewing 'member checking' as respondent validation. In my approach I follow approach described by Hammersley and Atkinson (2007) of using different theories as resources in order to have an open approach to data collection, as well as collecting data from different sources and by different qualitative methods, as this can help to make sense of the data, especially when studying complex settings that have been little researched.

Choosing a broad, interactionist approach implies collecting a rich and varied data material. In this study, being close to many different informants over a fairly long period of time has also been important in order to describe concrete situations and try to understand questions related to people's actions, interaction and meaning. This approach also seems to have facilitated the inclusion of service users who wished to contribute with their views based on their experiences, but who, according to some informants (paper 2), would not have volunteered to be interviewed unless they had spent some time with the researcher beforehand, as in this study. In choosing an open, flexible empirical approach, I also wanted to avoid letting one particular theory steer the research process from the outset of the study. I considered this as important when conducting a study within a service with an open, flexible low threshold organisation, which is an example of a community mental health service where little research exists. Other ethnographic approaches could, however, have facilitated more focused observations and in-depth theoretical analyses, by for example testing existing theories, focusing on power-relations and/or critically analysing people's discourses (Atkinson *et. al* 2009, Hammersley & Atkinson 2007).

This study also has some limitations related to my role as researcher. My pre-understanding, based on fifteen years of mental health nursing will have influenced on the research. Due to my familiarity with the mental health field in general I may, unconsciously, have overlooked interesting phenomena that I experienced as 'trivial'. A researcher without these experiences could have observed details that I took for granted. Thus, on the one hand, my background and pre-understanding could stand in the way of a necessary analytic distance. On the other hand, sharing knowledge with the informants is

an important part of the researcher's understanding, which may assist in the process of becoming a natural participant in the environment (Adler & Adler 1987, Wadel 1991). Flyvebjerg (2004: 429), for example, states the importance of the researcher's knowledge of the context. Citing Giddens (1982), he holds that valid descriptions of social activities depend upon knowledge shared by observer and participants.

My clinical background and experience from mental health work will have influenced on other perspectives of the study. For example, although I do recognise that strong aspects of control exists in psychiatric and mental health systems, I also view clinical mental health work as aiming to support people's function and relieve suffering (Norvoll 2006). My perspective in this study has been to explore and analyse the informants' actions and experiences of meaning and not to evaluate the service. Researchers choosing a different approach could have been more critical in their analysis and presentations. This study was conducted by one researcher. A research team could have represented a broader approach and, thus, more nuanced findings. Other studies, such as critical service evaluations from a more distanced position, would have seen other perspectives. In qualitative research it is recognised that the researcher's background and methodological choices are part of the research, which makes reflexivity and transparency important (Hammersley & Atkinson 2007). What is observed does, however, also depend on what the context and situations encountered allow for.

The open organisation of the centres studied made it possible to conduct participant observation in a non-intrusive manner, which was also a requirement by the medical officer in charge of the service, as well as by the regional committee for medical research ethics. Along with my efforts not to enter a staff role, this contributed to a relatively 'careful' approach during participant observation. I was, for example, careful not to ask too many questions about individual service users' daily lives, as this might have been experienced as too personal or intrusive. Such issues were, however, illuminated by service users and staff in their responses to themes and open-ended research questions during the individual and focus group interviews.

In ethnographic research there is a danger of ‘going native’ (Geertz 1973), which implies becoming a full participant and identifying with those studied to such a degree that reflecting on and discussing the phenomena studied in the light of theories, experiences and the outer context become difficult. This is, however, a challenge when carrying out fieldwork in general, whether the researcher is familiar with the area studied or not. In my experience, periods away from the field during processes of analysis, as well as discussions with my supervisors, helped me to maintain an analytic distance and also contributed to a broader perspective.

4.9 Ethical considerations

The study was approved by the regional committee for medical research ethics (REK) of mid-Norway and the Norwegian Social Science Data Services (NSD). The medical officer in charge of the municipal health service permitted access to the research settings. All who were interviewed individually or in focus groups gave their written informed consent. In qualitative research it is important to consider not only standard procedures for research ethics, but also ethics in practice (Guillemin & Gillam 2004, Kristiansen 2007, Ryen 2007). A central challenge in ethnographic research is to be close enough to obtain an ‘insider’ perspective and, thus, to be able to give an experience-near account, without losing the ‘outside’ perspective and analytic distance (Geertz 1973). During participant observation, informants are simultaneously partners in conversations and activities and ‘used’ for information. Thus, close contact between researcher and informants poses special challenges, such as the risk of giving descriptions that informants find alienating, offensive or irrelevant (Jacobsen & Kristiansen 2004). Researchers must, therefore, be conscious of their power position when describing situations based on their social interaction with the informants (Barron 1999). On the other hand, when the researcher is in close contact with the informants over a lengthy period of time, persons who are often overlooked may feel enabled to share their views and experiences (Davidson *et al.* 2001).

The Regional committee for medical research ethics, as well as the medical officer in charge of the municipal health service had both emphasized that the research must be carried out in a non-intrusive manner, which was an important principle that I followed throughout the research process. Throughout the study it was, thus, an important principle

for me that people should be informed of the opportunity, but not feel 'pressurised' to be informants. During the study, some service users said that knowing I was a psychiatric nurse made them feel safe enough to be interviewed. As the study was conducted in an open organisation where people decide when and how to attend, the principle of informed consent was challenging. It was not possible to know in advance who would be present during my field observations. After initial information rounds, written information about the project and how to contact me was put up on information boards. New visitors were continually informed by the professionals, who were asked to inform me if any users should object to my presence, in which case I would refrain from attending at certain times. No objections to my presence were put forward. In all the interviews, rules for written, informed consent and the right to anonymity were followed.

5 FINDINGS FROM THE RESEARCH

Within an ethnographic approach, this study has utilised different qualitative research methods in order to explore, understand and develop knowledge about how social support and users' participation in a community mental health service were enacted, what their participation meant for service users and how professionals experienced their practice and work role. The different parts of the study are presented in four papers. In this chapter I will first sum up the main findings from each paper and then present an overview of the overall findings from the study.

5.1 Summaries of papers 1 - 4

Paper 1

Toril Anne Elstad. Social support and active participation: a qualitative field study within 'low threshold' community mental health centres (*submitted and undergoing review: Scandinavian Journal of Disability Research*).

Aims: To contribute knowledge about the 'content' of community mental health centres with a low threshold organisation, by observing and exploring how social support and active participation were enacted and what their participation meant for service users.

Method: Participant observation was conducted over an extended period of time. Following initial observations of the centres' locations and atmosphere, further observations focused on the activities, social interaction and service users' descriptions of their experiences while participating in the settings. The unit of analysis was the complete field diary.

Findings: The centres had an 'integrated' location in the community and their atmosphere was observed to be 'home-like', with a clear focus on creative activities and socialising. Through an accessible, low threshold approach, the centres provided users with on-going social support and opportunities for participation in activities and decision-making about the content of the service. Sharing of practical advice was identified as a central feature of social interaction. Being with others who shared experiences of mental health problems was important to many service users. In this way the centres functioned as available

resources and on-going support in daily life. Some used the centres regularly, often participating in and contributing to social activities. Others visited occasionally, for company, to ‘relax from tension’ or to seek advice and support from the professionals. Although information and advice about how to find opportunities for active rehabilitation were available, this issue was observed to be less focused on than the on-going social activities at the centres. The main themes identified in the analysis were: ‘available resources in daily life’, ‘participation in social activities’, ‘peer support and mutuality’ and ‘social inclusion and rehabilitation’.

Conclusions: Community mental health centres can function as on-going support and available resources for sustaining a life situation in the community for people who live with mental health problems. Combining professional and peer support provides people with opportunities to receive help and support, as well as to participate in and contribute to mutual activities. How ‘low threshold’ services can function as stepping stones towards rehabilitation for some of their users should, however, be more clearly defined and further developed as practice. This includes a clearer focus on coordination with other health and social services in the community that also support psychosocial rehabilitation and processes of recovery from mental health problems.

Paper 2

Toril Anne Elstad and Kristjana Kristiansen (2009). Mental health centres as ‘meeting-places’ in the community: exploring experiences of being users and participants. *Scandinavian Journal of Disability Research*, 11 (3): 195–208.

Aims: To explore service users’ experiences of participation, and what attending community mental health centres means to them as part of their daily life situations.

Method: Five women and five men, all regular users of the service, were interviewed individually during fieldwork within the service. An open, thematic interview guide focused on the research themes and also facilitated a follow-up on the interviewees’ own responses.

Findings: The emerging themes from the data analysis centred on what participation at the centres meant for the informants personally. This was related to feelings of safety, belonging and increased confidence, as well as to the informants’ daily life situations and

community participation. Being able to choose when and how to attend the service was important to all those interviewed. To have environments with a friendly, welcoming atmosphere available, where you could also participate in activities and receive positive feedback, enhanced self-confidence. To feel like an equal and not as a 'case' was emphasised by some. This included meeting others in the same situation and the mutual sharing of positive experiences and social activities, as well as illness experiences. Most informants described that participating in the service also supported their participation in their local community. To manage to attend was described as 'mastery', when related to experiences of anxiety and depression, and some also described attending their centre as having prevented admissions to a psychiatric hospital. Others described their participation at the centres as training, and as a learning process that was helpful towards their participation in the wider community. All the interviewees described the staff as important due to their professional knowledge, which enabled them to maintain an inclusive milieu and to support and give advice to individual service users. Expressions such as 'here there are no losers', 'here I don't have to put on a mask' and 'here they know I'm not only like that' about behaviour related to mental distress highlighted the need to receive recognition as persons, not just service users.

Conclusions: This study sheds light on how accessible and flexible community mental health services can contribute to feelings of confidence, safety and social belonging. For some, their participation can also function as a 'training ground' towards inclusion in their community. The need for a place to escape from the strains of daily life in the community and a lack of opportunities for participation and recognition in the wider society are also highlighted.

Paper 3

Toril Anne Elstad and Arne Henning Eide (2009). User participation in community mental health services: exploring the experiences of users and professionals. *Scandinavian Journal of Caring Sciences*, 23: 674–681.

Aims: To explore and shed light on the meaning of user participation as practice in a community mental health service that aims to enhance its users' influence, based on the views and experiences of both users and professionals.

Method: Experiences of and views about the meaning of user participation were explored in individual interviews with ten service users and in two focus group interviews with six professionals in the same service. The data from all these interviews were the unit of analysis.

Findings: The informants in this study all valued user participation in the service, and most highlighted the importance of maintaining an inclusive environment that facilitated an influence for all service users. Both users and professionals also described reluctance by some of the users to participate in meetings and decision-making about the service. Some related this to experiences of mental health problems and distress. Users and professionals did, however, highlight some different perspectives of user participation. Service users mainly focused on decision-making related to the social milieu and the planning of activities at the centres. The professionals focused more on user participation as a democratic right and as collaboration, and highlighted a dilemma between motivating active user participation while also respecting the users' right to decide how to attend the service. The professionals' role as motivators was pointed out as important by most users. It was, however, equally important that they could choose themselves how and when to use the service. Those who were not active themselves during meetings and discussions still appreciated this opportunity, as well as being represented by other users. Some users did, however, worry in case a focus on user participation might lead to reduced help and too much responsibility, and according to the professionals, it is necessary to define user participation in the service more clearly.

Conclusions: Developing service users' influence through participation is important, not only on the political and organisational levels, but also in the contexts where users and professionals meet and are expected to collaborate. Community mental health services with accepting and inclusive social milieus can provide service users with opportunities to have an influence on some level: from individual choices about how to attend, through to active participation in service development or as user representatives.

Paper 4

Toril Anne Elstad and Ove Hellzén (2010). Community mental health centres: a qualitative study of professionals' experiences. *International Journal of Mental Health Nursing*, 19: 110–118.

Aims: To contribute to a broader understanding of the practice of mental health work in community mental health centres with a multi-professional workforce and an open accessible organisation, by exploring how professionals experience their work and professional role.

Method: As part of an ethnographic research project, two focus group interviews were conducted with one group of six experienced professionals from three community mental health centres, which are part of the municipal health service in a Norwegian city.

Findings: The group of informants highlighted the complexity of community mental health work and the need to have a broad, flexible approach towards supporting people with mental health problems in their daily life situations. Support was often about problem-solving, whether this was related to practical matters or to emotional or social issues in daily life. Meeting each individual as a person as well as facilitating social interaction between the users was discussed as important factors for enabling social inclusion and participation for all the service users. Focusing on individual users' resources through activities and, in this way, enhancing their self-esteem, was seen as another important part of their mental health work. Their relationships with service users were experienced as more egalitarian than working in institutions, and this new work role was described as 'liberating'. However, although they experienced that professional knowledge and skills were important in their work situations this was not always acknowledged by professionals in other services. The group discussed this as a possible consequence of a low status attached to working in low threshold services.

Conclusions: A low threshold organisation and flexible approach in community mental health services may facilitate developments of collaborative relationships between service users and professionals. The findings from this study do, however, suggest that there may be a lack of knowledge about the practice of mental health work in services that aim to provide professional help as well as encourage active participation from service users.

5.2 Overall findings

Findings from this study contribute with knowledge which adds to an understanding of participation in a low threshold community mental health service and the meaning their attendance as service users have for people with mental health problems in their daily life situations. Other findings relate to how support and user participation is practiced through social interaction between service users and professionals, and how professionals experience their mental health work and professional role. This way, findings from the study contribute with knowledge which is relevant for the further developments of theoretical perspectives of participation in mental health work and rehabilitation. Low threshold community mental health services have in recent years been developed internationally (Whitley *et. al* 2012). In Norway low threshold services have been further recommended as part of a strategy of health promotion (Helsedirektoratet 2010), but few studies of practice within such services exist.

My initial theoretical perspectives and research questions were related to social interaction in activities and the meaning of user participation within the service. During the first part of the study, participation related to people's daily life situations also emerged as central, based on preliminary analysis of data from field conversations and individual interviews with service users. What attending the service meant for their experiences of participation in daily life was a central theme in field conversations and interviews with key informants. Training to "take part in the world outside" was also emphasised as a main aim for the service by the professionals. Mutual sharing of practical advice related to daily life in their homes and the local community was a central part of the social conversations at the centres. When service users attended events in the wider community together, this meant that they had something to talk about with others, also outside this setting. This also enhanced participation outside the centres at other times for many, and for some this on-going support had prevented admission to psychiatric hospitals.

To attend the service according to their own choice was of central value to all users interviewed. This meant that it was possible to receive support without being subjected to control and surveillance. Thus, the low threshold approach of the service provided people with mental health problems opportunities for receiving help and support, as well as to

take on more active roles. For some, managing to attend the service was described as ‘mastery’ in itself, seen in light of their mental health problems. Some attended the centres due to their felt needs for social support and company, others were leading- and planning activities, and a few took on roles as user representatives. There were also some service users who were worried in case user participation could lead to reduced professional help and too much responsibility. Needs for support or challenges varied between people and also fluctuated over time for individuals. Variations in service users’ wishes for influence were pointed out by the professionals, who also emphasized that what user participation in the service means in practice needs to be more clearly defined. The professionals described how they sometimes experienced a dilemma between on the one hand encouraging user participation in the service and on the other hand respecting service users’ rights to be able to decide not to be actively involved.

What participation at the community mental health centres meant for individual service users was often related to feelings of belonging and enhanced self-confidence. A central finding across observations and interviews was a strong emphasis on the importance of the social milieu. This was linked to feeling supported and safe in a psychological sense. For many, their active participation in the service and participation in the wider community depended on available social support and help from mental health professionals. The importance of keeping these centres free from conflict and maintaining a relaxing atmosphere was emphasized by all service users interviewed. To facilitate social contact between service users and encourage social inclusion for all was seen as a central aspect of their mental health work by the professionals. Overall aims for this service were to provide social support in daily life as well as to function as stepping stones towards rehabilitation. Active rehabilitation, for example towards obtaining a job was, however found to be less focused on than support in daily life.

Based on observations and field conversations, and also highlighted in individual interviews with service users, was an emphasis on the importance of having a place where one could spend time with others who shared experiences of living with mental health problems. For some, to be able to contribute to, as well as be supported by, others who ‘knew what it was like’ was important. This was related to sharing positive experiences and advice as well as illness experiences, and to developing mutual relationships and

sometimes friendships. Conversations with service users who only ‘dropped in’ only occasionally and said this was important in order to ‘relax from strain’ further supported this finding. Other examples from more regular service users were about not having to feel ashamed of, for example, being young and receiving a disability pension. As one service user put it: “here there are no losers.”

The group of professionals interviewed described how mental health work in a low threshold service required a flexible work role, where knowledge, experience and skills in mental health work were important. One of the informants among the professionals described their work role as being ‘consultants in everyday living’. All informants did, however, mention that this was not always acknowledged by professionals in other services. This issue was discussed as a low status attached to work in low threshold services, as well as a possible consequence of their collaborative relationships with users and, thus, a reduced ‘expert role’ compared to more traditional mental health services. A collaborative approach in their relationships with service users was described as liberating. Professionals’ knowledge and skills combined with their ‘ordinariness’ was also found to be highly valued by the service users (papers 2 and 3).

During the research process, new research questions studied were developed from findings during participant observation, which means that there is some degree of overlap between the four papers. Before discussing the findings, I will here provide an overview of where findings related to the different research questions are presented. What characterises the localities, atmosphere, activities and social interaction within low threshold community mental health centres is presented in paper 1. How social support and user participation is enacted within this service is presented in papers 1 and 3. How service users describe and understand their experiences of participation is presented in papers 2 and 3. What user participation in the service means for users and professionals is presented in papers 3 and 4. What participation as users of the centres mean for the daily life situations of people who live with mental health problems is presented in paper 2. How professionals in a low threshold community mental health centre experience their mental health work and professional role is presented in paper 4.

6. DISCUSSION

In this chapter findings related to the central themes and research questions will be discussed. The ethnographic approach applied to studying social interaction and meaning in this study (chapter 4), contribute with knowledge from an inside perspective, based on the experiences and views of both service users and professionals. Individual interviews with service users and focus group interviews with professionals were applied in order to further explore new research questions and themes that emerged as interesting from early analyses based on observations. Thus, an explorative, flexible approach to studying naturally occurring activities, social interaction and experiences has provided knowledge about practice within a type of community mental health service that has been little researched. By exploring practice based on participant observation and field conversations, as well as individual and group interviews, findings from the study contributes with knowledge from the ground level in an area that has been described as a ‘black box’ in health services research (Larsen 2007, Pilgrim 2009). As background for the study, its’ wider context is described based on studies of documents on history, ideology and plans for further mental health service developments internationally and nationally.

The concept of ‘mental health problems’ covers a variety of experiences, but difficulties relating to social interaction and relationships with others are known to be central (chapter 3). In this study, the meanings of social support and participation are linked to Axel Honneth’s (1995, 2003, 2007) theory of recognition. To receive recognition through mutual relationships is central to developing experiences of self-worth and confidence, which also promotes experiences of positive mental health (Antonovsky 1996). The findings identify how social support and participation can provide opportunities for contributing to others and, thus, receive recognition, for people who live with mental health problems. A lack of opportunities for recognition in the wider society for some is also highlighted (paper 3). The study contributes with knowledge towards a broader understanding of the psychosocial aspects of participation as related to rehabilitation and disability research. This can contribute to further developments of services that support people with mental health problems in their daily lives.

People who live with mental health problems should not be viewed as if ‘psychiatric patient’ or ‘mental health service user’ is their ‘master status’ (Elstad & Norvoll 2013). It is therefore important to distinguish between ‘participation’ in daily life, as the concept is often applied in rehabilitation and disability research (Gustavsson 2004, WHO 2001a) and ‘user participation’ as the concept is generally used in health services research. For many who live with mental health problems, both these aspects of participation are meaningful, as attending a mental health service can be part of their daily life situations for periods of time. Both these aspects of the concept have been explored here: user participation as influence within a community mental health service context (paper 3) and experiences of participation in this service linked to everyday life (paper 2). Thus, in addition to illuminating user participation as practice in community mental health centres, the study contributes with knowledge to this field by relating and linking the findings to the concept of participation in daily life in a broader sense.

6.1 Social support, activities and user participation

The process of ‘deinstitutionalisation’ of mental health services has practical consequences for the daily life situations of people who live with mental health problems and experience a need for support in their daily life situations. Social support and positive relationships are known to be beneficial for mental health (Antonovsky 1987, Kawachi & Berkman 2001), while social isolation and exclusion are known risks related to severe and long term mental illness (Huxley & Thornicroft 2003, Rogers & Pilgrim 2003, Sayce 2000). The World Health Organisation has therefore called for further developments of community mental health services, stating that such services will lessen social exclusion (WHO 2007).

Recent developments in the area of community mental health include low threshold services with a mix of professional and peer-support. Available and flexible services could function as health promotion (Helsedirektoratet 2010, Parr 2000). Although their organization vary internationally, such settings in local communities share aims of providing social support in order to enhance social inclusion in the community and active participation in decision-making within services. A lack of research-based knowledge from the perspectives of service users and professionals who interact within

such settings has been identified (chapter 2). In the areas of rehabilitation and disability research a need for further knowledge about the meaning of participation as well as to develop participation further as a theoretical concept has been identified (Cornwall 2008, Eide *et al.* 2008, Gustavsson 2004, Hammel *et al.* 2008).

Supporting social inclusion, community participation and users' influence within community mental health services implies developing new roles for people with mental health problems, towards active participation as service users and increased agency and control in their daily

life situations (Corrigan *et al.* 2008, Craig 2006). Attending the centres studied, users could receive on-going social support in daily life as well as opportunities for participation in activities and decision-making about the content of the service. A mix of professional and peer-support provided opportunities for receiving social support and practical advice in daily life as well as help with more personal issues. This was important for all service users interviewed. Based on people's felt needs, the centres functioned as resources in daily life.

6.2 Participation in the service and in daily life

Although service users' participation in the wider community has not been studied directly, this study sheds some light on this issue through the individual interviews. Overall, service users described the community mental health centres in very positive terms, both during field conversations and in individual interviews. This finding is in line with studies from low threshold community mental health services in some other countries (Biegel *et al.* 2013, Conradson 2003, Kristiansen 2000, Whitley *et al.* 2008, Whitley *et al.* 2012). People who live with mental health problems can meet barriers to participation in the wider community which reduces their opportunities for experiencing recognition in the wider society. The low threshold approach of this service meant that people could choose when and how to attend. According to Antonovsky (1993, 1996), a 'sense of coherence' enhances health promotion. This is not only an individual issue, but includes knowing that resources are available.

To access a service based on one's own choice and felt needs for support and company, as well as having opportunities for active participation in the service can encourage agency. This way, people have opportunities to use their resources, develop mutual relationships and be seen as persons, not only psychiatric patients or service users. Gustavsson (1993) discusses the importance of mutual relationships for being chosen as a friend. Being with others who shared experiences of mental health problems was important to service users in this study. This is in line with other studies from the area of mental health (Kristiansen 2000, Sayce 2000) as well as research based on the experiences of people living with other disabilities and chronic illness (Alsaker & Josephsson 2011, Gustavsson 1993, Philo *et al.* 2005). Being with others who 'know from experience' can have a value in itself (Philo *et al.* 2005). In this study, a place where mental health problems were common was important as this meant that it was unnecessary to explain behaviour related to mental distress. Available professional help and peer-support in daily life can support community integration by enabling people with mental health problems to sustain a life situation outside institutions.

Aims of social inclusion imply that efforts should be made to increase participation in the wider society, such as vocational rehabilitation (Anthony *et al.* 2002, Corrigan *et al.* 2008, Craig 2006). Aims for the service studied are to provide social support and to function as stepping stones towards rehabilitation for some service users, as well as to enhance user participation in the service. Information and individual support was available, but the issue of rehabilitation was not observed to be central during social activities. On the one hand, seeing social inclusion solely as employment represents a limited view (Parr 2008). Work is, however, important both for economic reasons and for increased social inclusion in society. Thus, a clearer focus on vocational rehabilitation in this service can be helpful for many service users.

6.3 Mental health work and the professional role

Different from what is common in more traditional mental health services, people choose how to attend this service, without any intake procedures. Participation in activities is not a prerequisite for using the centres, but active participation as service users is encouraged. This way, the centres' open and accessible approach represents a new type of organisation within the mental health field (Parr 2000, Parr 2008, Whitley

et. al 2008, Whitley *et. al* 2012). Knowledge about mental health work in a low threshold service is therefore important for the further developments of community mental health work. Community mental health services aiming to provide social support in daily life have been described as ‘recovery-oriented’ (Whitley *et al.* 2008, Whitley *et al.* 2012) and such services, with a psychosocial approach in mental health work, have been encouraged (Ramon & Williams 2005, WHO 2007). Such developments also has an influence on the practice of mental health work and professionals’ roles, towards encouraging people with mental health problems’ active participation both as service users and in their daily life situations in the community (Anthony *et al.* 2002, Elstad & Hellzén 2010, Hydén 2004, Petersen 2009, Ramon & Williams 2005, Sterling *et al.* 2010).

Communication through social interaction between professionals and service users is central to clinical mental health work (Hummelvoll 2012, Skårderud *et. al* 2010). Mental health work in this service was conducted through regular face-to-face interaction between professionals and service users. A focus on user participation in the service was found to encourage experiences of belonging as well as a more collaborative approach between users and professionals (papers 1 and 3). This is in line with findings from other studies from low threshold services (Conradson 2003, Kristiansen 2000, Whitley *et. al* 2008, Whitley *et. al* 2012). Professionals working in this service experienced a collaborative approach in mental health work with service users as liberating. They did, however, describe a dilemma between encouraging users’ self-determination in how to attend the service and, on the other hand, respecting their rights to be able to decide not to be actively involved.

For many who live with mental health problems, support from mental health professionals play an important role in daily life. In the social scientific literature, discussions about people with mental health problems attending mental health services or fellowships based on illness or disability has been criticized as segregation or “ghettoization”. Sayce (2000), however, points out that people with mental health problems should be allowed to find out and decide for themselves what is experienced as supportive in their life situations. Developing mental health work and services that are

supportive without segregating people from daily life is a central challenge. 'Partnership models' in mental health work encourages mental health professionals to reduce their 'expert roles', as well as support service users' agency in daily life (Corrigan *et al.* 2008, Craig 2006, Elstad & Hellzén 2010, Petersen 2009, Sayce 2000).

Professionals' experiences and views contribute to an enhanced understanding of mental health work in low threshold community mental health services. Such mental health work differ from work in psychiatric institutions by aiming to offer support in daily life; not treatment for mental illness. Ramon and Williams (2005: 15) have described a new role for mental health workers as requiring "... emotional closeness, a 'hands on' approach, and the demonstration of interest in those everyday affairs which matter to the service user." According to Schøn (1983), an everyday life approach implies paying attention to the contextual circumstances of people's lives, instead of having a focus on technological rigor.

6.4 Participation and recognition

This study contributes with knowledge from the perspective of service users and professionals who interact within a community mental health service that has been developed during processes of deinstitutionalisation of mental health services. 'Ex-patients' from psychiatric hospitals have been found often to be socially excluded in the community (Parr 2008, Prior 1993). For many who live with mental health problems social support in daily life is central for enabling participation in the community. As one service user put it, referring to her symptoms of mental distress: "here they know I'm not only like this". Service users also gave examples such as not having to feel ashamed about receiving a disability pension and feeling relaxed enough to dare to take part in something. And as one informant said in an interview: "here there are no losers." Thus, contact with others who shared experiences of mental health problems seemed to mean more than a search for 'asylum' from the outside world. To have a place where one can feel ordinary was important, which is in line with studies of people with other types of disabilities (Alsaker & Josephsson 2011, Philo *et. al* 2005).

Based on data analysis from participant observation and interviews with service users, Axel Honneth's theory of people's need for recognition emerged as central to my understanding of the meaning of participation. This was based on observations which I interpreted as a need to be met as persons who could contribute to others, and this way not only be seen as service recipients. Honneth's (1995, 2003, 2007) theory of recognition highlights the importance of social interaction and being recognised as capable human beings through mutual relationships for identity formation and personal development. According to Goffman (1967) and Mead (1967), reciprocal relationships and face-to-face interactions in concrete social situations are of central importance for feelings of self-worth and identity formation. To contribute to others has been identified as important for experiencing participation (Yilmaz *et. al* 2009).

Linking social support to the concept of participation and theories of recognition provides a broader understanding of how participation through social interaction and activities can enhance positive mental health. This thesis, thus, contributes with knowledge to an on-going discussion of how the concept of participation can be further theoretically developed (Björk-Åkesson & Granlund 2004, Cornwall 2008, Eide *et al.* 2008, Hammel *et al.* 2008).

7. CONCLUSIONS AND IMPLICATIONS

Knowledge from the area of mental health work contributes to a broader understanding of the concept of participation by adding perspectives on the psychosocial aspects of participation based on both service users' and professionals' experiences. A need to develop a broader theoretical understanding of participation has been discussed. By exploring and linking participation to Axel Honneth's theory of needs for recognition, this study contributes to the theoretical understanding of the meaning of participation from a mental health perspective.

In mental health work and service development it is important to recognise the fluctuating nature of mental health and illness and to be flexible and responsive to service users' needs. Different forms of community care, contributions from user organisations and low threshold services offering on-going support in daily life are all valuable parts of this picture. After the deinstitutionalisation of mental health services a need for support combined with opportunities for active participant roles is essential. Being a 'service user' is only one part of a person's life situation. A 'disability approach' in mental health work and models from the area of rehabilitation can be useful for supporting people with mental health problems that reduce their functioning in daily life. Further knowledge about practice and social interaction within such services is needed, as well as how such support can enhance social inclusion for people with mental health problems in communities and society at large.

Knowledge from this study contributes to a broader theoretical understanding of the concept of participation as applied to mental health work and rehabilitation. Further research which contributes to a broader theoretical understanding of participation is needed. Developments of community mental health services that aims to support people with mental health problems in their daily lives in the community should be further researched. This should include studies of the practice of mental health work and developments of the professional role in low threshold community mental health services internationally. Studies evaluating and comparing different community mental health services with a low threshold organisation are also needed.

REFERENCES

Adler, P. A. & Adler, P. (1987). *Membership Roles in Field Research*. Newbury Park CA: Sage Publications.

Allman, D. (2013). The Sociology of Social Inclusion. DOI: 10.1177/2158244012471957. Downloaded February 19th 2013 from: <http://sgo.sagepub.com/content/3/1/2158244012471957>

Almvik, A. & Borge, L. (Eds.) (2006). *Psykisk helsearbeid i nye sko*. Bergen: Fagbokforlaget.

Alsaker, S. & Josephsson, S. (2011). Stories stirring the quest of the good: narratives of women living with chronic rheumatic conditions. *Scandinavian Journal of Disability Research*, 13(1): 53-70.

Alvesson, M., & Skoldberg, K. (2008 2nd ed.). *Tolkning och Reflektion: vetenskapsfilosofi och kvalitativ metod*. Lund: Studentlitteratur.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11-23.

Anthony, W., Cohen, M., Farkas, M. & Gagne, C. (2002, 2nd ed.). *Psychiatric Rehabilitation*. Boston MA: Boston University, Centre for Psychiatric Rehabilitation.

Antoft, R. & Salomonsen, H. H. (2007). Det kvalitative casestudium – introduksjon til en forskningsstrategi. I: Antoft, R., Jacobsen, M. H., Jørgensen, A. & Kristiansen, S. (red.), *Håndværk og horisonter. Tradition og nytænkning i kvalitativ metode* s. 29-57, Odense: Syddansk universitetsforlag.

Antonovsky, A. (1993). Complexity, Conflict, Chaos, Coherence, Coercion and Civility. *Social Science and Medicine*, 37(8): 969-974.

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International*, 11(1): 11-18.

Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (Eds.) (2007). *Handbook of Ethnography*. Los Angeles, London, New Delhi, Singapore, Washington DC: Sage Publications.

Bachrach, L. (1997). Lessons from the American experience in providing community-based services, In: Leff, J. (Ed.), *Care in the Community: Illusion or Reality?* pp. 21-36, Chichester, New York, Weinheim, Brisbane, Singapore, Tokyo: John Wiley & Sons.

Badley, E. M. (2008). Enhancing the conceptual clarity of the activity and participation components of the International Classification of Functioning, Disability and Health. *Social Science and Medicine*, 66: 2335-2345.

- Barron, K. (1999). Ethics in qualitative social research on marginalized groups. *Scandinavian Journal of Disability Research*, 1(1): 39-49.
- Bergem, R. & Ekeland, T. J. (2006). Psykisk sjuke som medborgarar. *Tidsskrift for Velferdsforskning*, 9(1): 26-38.
- Berkman, L. F., Glass, T., Brissette, I. & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Social Science and Medicine*, 51: 843-857.
- Biegel, D. E., Pernice-Duca, F., Chang, C. W. & D'Angelo, L. (2013). Correlates of Peer-Support in a Clubhouse Setting. *Community Mental Health Journal*, 49(3): 249-259.
- Björk-Åkesson, E. & Granlund, M. (2004). Delaktighet – ett centralt begrepp i WHO's klassifikasjon av funksjonstillstånd, funksjonshinder och helsa (ICF). I: Gustavsson, A. (red.): *Delaktighetens språk*, s. 29-48, Lund S: Studentlitteratur.
- Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*, Berkeley: University of California Press.
- Borg, M. (2007). *The Nature of Recovery as Lived in Everyday Life: Perspectives of individuals recovering from severe mental health problems*, Doctoral thesis. Trondheim: Norwegian University of Science and Technology.
- Borg, M. & Karlsson, B. (2013). *Psykisk helsearbeid. Humane og sosiale perspektiver og praksiser*. Oslo: Gyldendal Akademi.
- Borg, M. & Kristiansen, K. (2004). Recovery-oriented professionals: Helping relationships in mental health services. *Journal of Mental Health*, 13(5): 493-505.
- Boyd, M. A. (2008 4th ed.). *Psychiatric Nursing. Contemporary Practice*. Philadelphia, Baltimore, New York, London, Buenos Aires, Hong Kong, Sydney, Tokyo: Wolters Kluwer. Lippicott, Williams & Wilkins.
- Bricout, J. C. & Gray, D. B. (2006). Community Receptivity: The ecology of disabled persons' participation in the physical, political and social environments. *Scandinavian Journal of Disability Research*, 8(1): 1-21.
- Bø, I. & Schiefloe, P. M. (2007). *Sosiale landskap og sosial kapital*. Oslo: Universitetsforlaget.
- Cerniauskaite, M., Quintas, R., Boldt, C., Raggi, A., Coeza, A., Bickenbach, J. E. & Leonardi, M. (2011). Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalization. *Disability and Rehabilitation*, 33(4): 281-309.
- Charmaz, K. (2000). Grounded Theory. Objectivist and Constructivist Methods. In: Denzin, N. K. & Lincoln, Y. S. (Eds.), *Handbook of Qualitative Research (2nd ed.)*, pp. 509-535, Thousand Oaks California: Sage Publications.

- Cobb, S. (1976). Social Support as a Moderator of Life Stress. *Psychosomatic Medicine*, 38(5): 300-314.
- Cohen, A. P. (1985). *The Symbolic Construction of Community*, London: Tavistock Publ.
- Conradson, D. (2003). Spaces of care in the city: the place of a community drop-in centre. *Social and Cultural Geography*, 4(4): 507-524.
- Cornwall, A. (2008). Unpacking 'Participation': models, meanings and practices. *Community Development Journal*, 43(3): 269-283.
- Corrigan, P. W., Mueser, K. T., Bond, G. R. & Solomon, P. (2008). *Principles and Practice of Psychiatric Rehabilitation. An Empirical Approach*. New York: The Guilford Press.
- Corrigan, P. W., Larson, J. E. & Rusch, N. (2009). Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry*, 8: 75-81.
- Craig, T. (2006). What is psychiatric rehabilitation? In: Roberts, G., Davenport, S., Holloway, F., Tattan, T. (Eds.). *Enabling Recovery: The Principles and Practice of Rehabilitation Psychiatry*, pp. 3-15, London: Gaskell (Royal College of Psychiatrists).
- Crawford, M. J., Aldridge, T., Bhui, K., Rutter, D., Manley, C., Weaver, T., Tyrer, P. & Fulop, N. (2003). User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. *Acta Psychiatr Scand*, 107(6): 410-414.
- Creswell, J. W. (2007, 2nd ed.). *Qualitative Inquiry & Research Design. Choosing Among Five Approaches*. Thousand Oaks, London, New Delhi: Sage Publications.
- Dahl, e. & Friestad, C. (2013). Sosial ulikhet of psykisk helse. I: Norvoll, R. (red.). *Samfunn og psykisk helse. Samfunnsvitenskapelige perspektiver*, s. 149-165. Oslo: Gyldendal Akademisk.
- Dalgard, O. S., Døhlie, E. & Ystgaard, M. (red.) (1995). *Sosialt nettverk, helse og samfunn*. Oslo: Universitetsforlaget.
- Dalgard, O. S., Schjelderup Mathisen, K., Nord, E., Ose, S., Rognerud, M. & Aarø, L. E. (2011). *Bedre føre var ... Psykisk helse: Helsefremmende og forebyggende tiltak og anbefalinger*. Rapport 2011: 1. Oslo: Nasjonalt folkehelseinstitutt.
- Daly, M. & Silver, H. (2008). Social exclusion and social capital: A comparison and critique, *Theory and Society*, 37: 537-66.
- Davidson, L., Stayner, D. A., Stacey, L., Smith, P. & Sledge, W. H. (2001). Phenomenological and participatory research on schizophrenia. In: Tolman, D. L. & Brydon Miller, M. (Eds.): *From subjects to subjectivities*, pp. 163-179, New York: University Press.

- Deegan, P. (1996). Recovery as a Journey of the Heart. *Psychiatric Rehabilitation Journal*, 19(3): 91-97.
- Delamont, S. (2007). Ethnography and participant observation. In: Seale, C., Gobo, G., Gubrium, J. F. & Silverman, D. *Qualitative Research Practice (2nd ed.)*, pp: 203-217. Los Angeles, London, New Delhi, Singapore: Sage Publications.
- Dijkers, M. P. (2010). Issues in the Conceptualization and Measurement of Participation: An Overview. *Arch Phys Med Rehabilitation*, 91(9): 5-16.
- Dohrenwend, P. B. & Dohrenwend, B. P. (1969). *Social Status and Psychological Disorder: A Causal Inquiry*. New York, London, Sydney & Toronto: John Wiley & Sons.
- Drucker, E. (1995). Harm reduction: A public health strategy. *Current Issues in Public Health*, 1: 64-70.
- Ebersold, S. (2007). Affiliating Participation for Active Citizenship. *Scandinavian Journal of Disability Research*, 9(3-4): 237-253.
- Eide, A. H., Jelsma, J., Loeb, M., Maart, S. & Toni, M. K. (2008). Exploring ICF components in a survey among Xhosa speakers in Eastern & Western Cape, South Africa. *Disability and Rehabilitation*, 30(11): 819-829.
- Ekeland, T. J. & Bergem, R. (2006). The Negotiation of Identity among People with Mental Illness in Rural Communities. *Community Mental Health Journal*, 42(3): 225-232.
- Ekeland, T. J. (2011). *Ny kunnskap – ny praksis. Et nytt psykisk helsevern*. Rapport 2011: 1. Skien: Nasjonalt senter for erfaringskompetanse innen psykisk helse.
- Elstad, T. A. (1999) *Sosial integrasjon blant mennesker med alvorlige psykiske lidelser*. NIS-rapport 2/99, Trondheim: SINTEF Unimed helsetjenesteforskning.
- Elstad, T. A. (Submitted, Paper 1). Participation, activities and social support in 'low threshold' community mental health centres (in review *Scandinavian Journal of Disability Research*).
- Elstad, T. A. & Eide, A. H. (2009). User participation in community mental health services: exploring the experiences of users and professionals. *Scandinavian Journal of Caring Sciences*, 23: 674-681.
- Elstad, T. A. & Hellzén, O. (2010). Community mental health centres: A qualitative study of professionals' experiences. *International Journal of Mental Health Nursing*, 19: 110-118.
- Elstad, T. A. & Kristiansen, K. (2009). Mental health centres as 'meeting-places' in the community: exploring experiences of being service users and participants. *Scandinavian Journal of Disability Research*, 11(3):195-208.

- Elstad, T. A. & Norvoll, R. (2013). Sosial eksklusjon og inklusjon. I: Norvoll, R. (red.). *Samfunn og psykisk helse. Samfunnsvitenskapelige perspektiver*, s. 118-148. Oslo: Gyldendal Akademisk.
- Fangen, K. (2004). *Deltagende observasjon*. Bergen: Fagbokforlaget.
- Fangen, K. (2011). Deltagende observasjon. I: Fangen, K. & Sellerberg, A. M. (red.). *Mange ulike metoder*, s. 37-56. Oslo: Gyldendal Akademisk.
- Faris, R. E. & Dunham, H. W. (1939). *Mental Disorders in Urban Areas: An Ecological Study of Schizophrenia and Other Psychoses*, Chicago: University of Chicago Press.
- Ferlander, S. (2007). The Importance of Different Forms of Social Capital for Health. *Acta Sociologica*, 50(2): 115-128.
- Fisher, C. S. (1982). *To Dwell among Friends - personal networks in town and city*, Chicago: University of Chicago Press.
- Flyvebjerg, B. (2001). *Making Social Science Matter. Why social inquiry fails and how it can succeed again*. Cambridge: Cambridge University Press.
- Flyvebjerg, B. (2007). Five misunderstandings about case-study research. In: Seale, C., Gobo, G., Gubrium, J. F. & Silverman, D. (Eds): *Qualitative Research Practice*, pp 390-404. Los Angeles, London, New Delhi, Singapore: Sage Publications.
- Gask, L. & Rogers, A. (1998). Bridging the gap: Mapping a new generation of primary mental health care research, *Journal of Mental Health*, 7(6): 539-541.
- Geertz, C. (1973). *The Interpretation of Cultures*. New York: Basic Books.
- Geertz, C. (1984). 'From the native's point of view'. On the nature of anthropological understanding. In: Scweder, R. & LeVine, R.: *Culture Theory. Essays on Mind, Self and Emotion*, pp. 123-136. New York: Cambridge University Press.
- Giddens, A. (1982). *Profiles and Critiques in Social Theory*. Berkeley: University of California Press.
- Glaser, B. & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine Publishing Company.
- Goffman, E. (1961). *Asylums. Essays on the Social Situations of Mental Patients and Other Inmates*. Harmondsworth: Penguin Pelican Books.
- Goffman, E. (1963). *Stigma. Notes on the Management of Spoiled Identity*, New York: Penguin Books.
- Goffman, E. (1967). *Interaction Ritual. Essays on face-to-face behaviour*. New York: Pantheon Books.

- Goodley, D. (1999). Disability Research and the 'Researcher Template': Reflections on Grounded Subjectivity in ethnographic research. *Qualitative Inquiry*, 5(1): 24-46.
- Goodson, L. & Vassar, M. (2011). An overview of ethnography in healthcare and medical education research. *Journal of educational Evaluation for health Professions*. DOI: 10.3352/jeehp.2011.8.4.
- Graneheim, U. H. & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24: 105-112.
- 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): 602-613.
- 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.
- Grunewald, K. (Ed.) (2000, 2. utg.). *Psykiska handikapp – möjligheter och rättigheter*. Stockholm: Liber Forlag.
- Gubrium, J. F. & Holstein, J. A. (1997): *The New Language of Qualitative Method*. New York: Oxford University Press.
- Guillemin, M. & Gillam, L. (2004). Ethics, reflexivity and 'ethically important moments' in research. *Qualitative Inquiry*, 10(2): 261-80.
- Gustavsson, A. (1993). Livet i 'Integrasjonssamfunnet' – en analyse av nærhetens sosiale betydning. I: Sandvin, J. T. (red.), *Mot normalt? Omsorgsideologier i forandring*, s. 203-243. Oslo: Kommuneforlaget.
- Gustavsson, A. (Ed.) (2004). *Delaktighetens språk*, Lund: Studentlitteratur.
- Hagen, H. & Ruud, T. (2004). *Pasienter i psykisk helsevern for voksne*, Rapport 3/04, Trondheim: SINTEF Helse.
- Halkier, B. (2008). *Fokusgrupper*. 2. utgave. København: Samfundslitteratur.
- Hall, S. & Cheston, R. (2002). Mental Health and Identity: The Evaluation of a Drop-in Centre. *Journal of Community and Applied Social Psychology*, 12: 30-43.
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J. & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19): 1445-1460.
- Hammersley, M. & Atkinson, P. (2007, 3rd ed.). *Ethnography. Principles in Practice*. London: Routledge.

- Haugsgjerd, S., Jensen, P., Karlsson, B. & Løkke, J. A. (2009, 3. utg.). Perspektiver på psykisk lidelse – å forstå, beskrive og behandle. Oslo: Gyldendal Akademisk.
- Helgesen, M. (2004). *Brukerinvolvering i psykisk helsearbeid i kommunene*. NIBR-notat 2004: 136. Oslo: Norsk institutt for by- og regionforskning.
- Helse og omsorgsdepartementet (2009). *Samhandlingsreformen. Rett behandling – på rett sted – til rett tid*. St. meld. Nr. 47 (2008-2009). Oslo: Helse- og omsorgsdepartementet.
- Helse og omsorgsdepartementet (2013). Kap. 10: Psykisk helse, I: *Prop. 1 S (2013- 2014). Tilråding fra regjeringen*. Oslo: Helse og omsorgsdepartementet.
- Helsedirektoratet (2010). Fokus: Lavterskeltilbud. *Psykisk*, 01/10. Oslo: Helsedirektoratet.
- Hofseth C. (2000). *Brukermedvirkning i psykiatrien – fra politikk til praksis*. Oslo: SINTEF Helse og rehabilitering.
- Holstein, J. A. & Gubrium, J. F. (1995). *The active interview*. Thousand Oaks California: Sage Publications.
- Honneth, A. (1995). *The Struggle for Recognition. The Moral Grammar of Social Conflicts*. Cambridge UK: Polity Press.
- Honneth, A. (2003). *Behovet for anerkendelse*. København: Hans Reitzels Forlag.
- Honneth, A. (2007). *Disrespect. The Normative Foundations of Critical Theory*. Cambridge UK & Malden USA: Polity Press.
- Honneth, A. (2012). *The I in We. Studies in the Theory of Recognition*. Cambridge UK & Malden USA: Polity Press.
- House, J. S. (1987). Social Support and Social Structure. *Sociological Forum*, 2(1): 135-146.
- Hummelvoll, J. K. (2012, 7. utg.). *Helt – ikke stykkevis og delt. Psykiatrisk sykepleie og psykisk helse*, Oslo: Gyldendal.
- Huxley, P. & Thornicroft, G. (2003). Social inclusion, social quality and mental illness. *British Journal of Psychiatry*, 182: 289-290.
- Hydén, L. C. (2005). *Från psykiskt sjuk till psykiskt funktionshindrad*, Lund: Studentlitteratur.
- Jacobsen, M. H. & Kristiansen, S. (2002). *Erwing Goffman. Sociologien om det elementære livs sociale former*, København: Hans Reitzels Forlag.
- Jacobsen, M. H. & Kristiansen, S. (2004). Den moralske dimensjonen i deltagende observasjon. *Sosiologi i dag*, 34(1): 5-30.

- Jacobsen, M. H. (2005), Quo Vadis, Grounded Theory? I: Jacobsen, M. H., Kristiansen, S. & Prieur, A. (red., 2. utg.), *Liv, fortælling, tekst. Strejftog i kvalitativ sociologi*, s. 77-107, Aalborg: Aalborg Universitetsforlag.
- Jenkins, R. (2008, 3rd ed.). *Social identity*. London & New York: Routledge.
- Johansen, N. B. & Myhre, H. (2005). *Skadereduksjon i praksis – Del I*. Oslo: Kompetansesentret, Rusmiddelstaten i Oslo.
- Kalseth, J., Pettersen, I. & Kalseth B. (2008). Psykisk helsearbeid i kommunene – tiltak og tjenester. Status 2007/2008 og utvikling i Opptrappingsplanperioden. Sintef rapport A8823. Trondheim: SINTEF helse.
- Kawachi, I. & Berkman, L. F. (2001). Social ties and mental health. *Urban Health*, 78(3): 458- 467.
- Kitzinger, J. (2005). Focus group research: using group dynamics to explore perceptions, experiences and understandings. In: Holloway, I. (Ed.), *Qualitative Research in Health Care*, pp. 56-70. Berkshire UK & New York: Open University Press.
- Knapp, M., McDaid, D., Mossialos, E. & Thornicroft, D. (Eds.) (2007). *Mental health policy and practice across Europe: the future direction of mental health care*, Maidenhead UK: Open University Press.
- Kristiansen, K. (1993). *Normalisering og verdsetjing av sosial rolle*. Oslo: Kommuneforlaget.
- Kristiansen, S. (2000). Interaction patterns among users of a Danish community care centre. *International Social Work*, 43(3): 325-336.
- Kristiansen, S. (2007). Etikk og feltarbeid – utfordringer og dilemmaer i kvalitativ sosiologisk praksis. I: Antoft, R., Jacobsen, M. H., Jørgensen, A. & Kristiansen, S. (red.), *Håndværk og horisonter. Tradition og nytænkning i kvalitativ metode*, s. 226-248. Syddansk universitetsforlag.
- Kvale, S. (1996). *InterViews*, Thousand Oaks – London – New Delhi: Sage Publications.
- Kvale, S. & Brinkmann, S. (2009, 2nd ed.). *Det kvalitative forskningsintervju*. Oslo: Gyldendal.
- Larsen, J. A. (2007). Understanding a complex intervention: Person-centred ethnography in early psychosis. *Journal of Mental Health*, 16(3): 333 – 345.
- Leff, J. (Ed) (1997). *Care in the Community – Illusion or Reality?* Sussex: John Wiley & Sons.
- Leighton, A. H. (1959). *My Name is Legion. The Stirling County Study of Psychiatric Disorder and Sociocultural Environment*. New York: Basic Books.

- Lerdal, A. & Karlsson, B. (2008). Bruk av fokusgruppeintervju. *Sykepleien Forskning*, 3(3): 172-175.
- Librett, M. & Perone, D. (2010). Apples and oranges: ethnography and the IRB. *Qualitative Research*, 10(6): 729-747.
- Lilja, L. & Hellzén, O. (2008). Former patients' experiences of psychiatric care: A qualitative investigation. *International Journal of Mental Health Nursing*, 17: 279-286.
- Lingsom, S. (2008). Invisible Impairments: Dilemmas of Concealment and Disclosure. *Scandinavian Journal of Disability Research*, 10(1): 2-16.
- Lipsky, M. (1980). *Street-level Bureaucracy. Dilemmas of the Individual in Public Services*. New York: Russel Sage Foundation.
- Lofland, J., Snow, D., Anderson, L. & Lofland, L. H. (2006, 4th ed.). *Analyzing Social Settings. A guide to qualitative observation and analysis*. Belmont CA: Wadsworth Cengage Learning.
- Løchen, Y. (1976). *Idealer og realiteter i et psykiatrisk sykehus. En sosiologisk tolkning*. Oslo: Universitetsforlaget.
- Madsen, B. (2005). *Socialpedagogik – Integration og inklusion i det moderne samfund*. København: Hans Reitzel.
- McKenzie, K. & Harpham, T. (2006). *Social Capital and Mental Health*. London & Philadelphia: Jessica Kingsley Publishers.
- Mead, G. H. (1934/1967). *Mind, Self and Society. From the standpoint of a social behaviourist*. Chicago: University of Chicago press.
- Mechanic, D. (Ed.) (1994). *Inescapable Decisions- The Imperatives of Health Reform*, New Brunswick & London: Transaction Publishers.
- Mechanic, D. & Rochefort, D. (1994). Deinstitutionalization of the Mentally Ill- Efforts for Inclusion, In: Mechanic, D. (Ed.), *Inescapable Decisions- The Imperatives of Health Reform*, pp. 165-212. New Brunswick & London: Transaction Publishers.
- Mezzina, R. (2005). Paradigm Shift in Psychiatry: Processes and Outcomes. In: Ramon, S. & Williams, J. E. (Eds.), *Mental health at the crossroads: the promise of the psychosocial approach*, pp. 82-93. Aldershot: Ashgate Publishers Limited.
- Moe, A. (2010). *Praksis som kunnskapskilde. En studie av brukeres og hjelperes erfaringer* Doctoral thesis, Trondheim: Norwegian University of Science and Technology.
- Molin, M. (2004). Delaktighet inom handikappområdet – en begreppsanalys. In: Gustavsson, A. (Ed.): *Delaktighetens språk*, s. 61-81. Lund: Studentlitteratur.

- Munk-Jørgensen, P., Mortensen, M. & Mortensen, P. B. (Eds.) (1992). *Socialpsykiatri: hvorfra? Hvorhen?* København: Hans Reitzel.
- Myrvold, T. M. & Helgesen, M. (2009). *Kommunalt psykisk helsearbeid. Organisering, samarbeid og samordning*, Rapport 2009/4. Oslo: Norsk institutt for by- og regionforskning.
- Norvoll, R. (2006). *Det lukkede rom. Bruk av skjerming som behandling i psykiatriske akuttposter*. Doktorgradsavhandling. Oslo: Universitetet i Oslo.
- Norvoll, R. (2013). Samfunnsvitenskapelige perspektiver på psykisk helse og psykiske helsetjenester. In: Norvoll, R. (Ed.) *Samfunn og psykisk helse. Samfunnsvitenskapelige perspektiver*, s. 38-72. Oslo: Gyldendal Akademisk.
- Oliver, J., Huxley, P. & Bridges, J. (1996). *Quality of life and Mental Health Services*. London: Routledge.
- Oliver, K. G., Collin, P., Burns, J. & Nicholas, J. (2006). Building resilience in young people through meaningful participation. *Australian e-Journal for the Advancement of Mental Health*, 5(1): 5-7.
- Parr, H. (2000). Interpreting the 'hidden social geographies' of mental health: ethnographies of inclusion and exclusion in semi-institutional places. *Health & Place*, 6(3): 225-237.
- Parr, H. (2008). *Mental Health and Social Space. Towards Inclusionary Geographies?* Malden USA, Oxford UK, Victoria AUS: Blackwell Publishing.
- Pedersen, P. B. (2002). Deinstitutionalisering av det psykiske helsevernet. I: Norvoll, R. (red.) *Samfunn og psykiske lidelser*, s. 187-204. Oslo: Gyldendal Akademisk.
- Pedersen, P. B. & Kolstad, A. (2009). De-institutionalisation and trans-institutionalisation – changing trends of in-patient care in Norwegian mental health institutions 1950-2007. *International Journal of Mental Health Systems*, doi:10.1186/1752-4458-3-28
- Petersen, K. (2009). *Brugerinddragelse i rehabilitering. En kvalitativ undersøgelse av borgerens perspektiv*, Doktorgradsavhandling. Aarhus: Aarhus Universitet.
- Philo, C., Parr, H. & Burns, N. (2005). "An oasis for us": in-between spaces of training for people with mental health problems in the Scottish Highlands. *Geoforum*, 36: 778-791.
- Pilgrim, D. (2009). Recovery from mental health problems: scratching the surface without ethnography. *Journal of Social Work Practice*, 23(4): 475-87.
- Pilgrim, D. & Rogers, A. (2003). *Mental Health and Inequality*. Houndmills, Basingstoke, Hampshire, New York: Palgrave MacMillan.

- Polit, D. F. & Beck, C. T. (2004, 7th ed.). *Nursing Research – principles and methods*. Philadelphia: Lippincott, Williams & Wilkins.
- Pope, C. & Mays, N. (1995). Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health service research. *British Medical Journal*, 311: 42-45.
- Pope, C., Ziebland, S. & Mays, N. (2000). Qualitative research in health care. Analysing qualitative data. *British Medical Journal*, 320: 114-116.
- Prior L. (1993). *The Social Organization of Mental Illness*, London, Newbury Park & New Delhi: Sage Publications.
- Ramon, S. & Williams, J. E. (Eds.) (2005). *Mental health at the crossroads: the promise of the psychosocial approach*. Aldershot: Ashgate Publishers Limited.
- Ramsdal, H. (2002). Om formingen av det kommunale psykiatريفلتet. I: Norvoll, R. (red.) *Samfunn og psykiske lidelser*. Oslo: Gyldendal Akademisk.
- Ramsdal, H. (2013). Styring og organisering av tjenestene. I: Norvoll, R. (red.) *Samfunn og psykisk helse. Samfunnsvitenskapelige perspektiver*, s. 214-242. Oslo: Gyldendal Akademisk.
- Rise, M. B., Westerlund, H., Bjørgen, D. & Steinsbekk, A. (2013). Safely cared for or empowered in mental health care? Yes, please. *International Journal of Social Psychiatry*. DOI: 10.1177/0020764012471278. Downloaded from isp.sagepub.com on March 14, 2013
- Rock, P. (2007). Symbolic Interactionism and Ethnography. In: Atkinson, P., Coffey, A., Delamont, S., Lofland, J. & Lofland, L. (Ed.), *Handbook of Ethnography*, pp. 26-38, London, Thousand Oaks California, New Delhi, Singapore: Sage Publications.
- Rogers, A. & Pilgrim, D. (2005, 3rd. ed.). *A Sociology of Mental Health and Illness*. Berkshire & New York: Open University Press.
- Roper, C. & Happell, B. (2007). Reflection without shame – reflection without blame: Towards a more collaborative understanding between mental health consumers and nurses. *Journal of Psychiatric and Mental Health Nursing*, 14: 85-91.
- Rosen, A. (1992). Community Psychiatric Services: Will They Endure? *Current Opinion in Psychiatry*, 5: 257-265.
- Ryen, A. (2007). Ethical issues. In: Seale, C., Gobo, G., Gubrium, J. F. & Silverman, D. *Qualitative Research Practice (2nd ed.)*, pp: 218-235. Los Angeles, London, New Delhi, Singapore: Sage Publications.
- Rådet for psykisk helse (2004). *Verdig liv. Velferd, medvirkning og helhet ved psykiske lidelser*. Oslo: Rådet for psykisk helse.

- Sandlund, M. (2005). Vad er psykiska funktionshinder? I: Hydén, L. C. (Ed.). *Från psykiskt sjuk till psykiskt funktionshindrad*, s. 63-82. Lund: Studentlitteratur.
- Savage, J. (2000). Ethnography and health care. *British Medical Journal*, 321: 1400-1402.
- Savage, J. (2006). The value of applied ethnography in healthcare. *Journal of Research in Nursing*, 11(5): 383-393.
- Sayce, L. (2000). *From psychiatric patient to citizen. Overcoming discrimination and social exclusion*. Houndmills, Basingstoke: Palgrave MacMillan.
- Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness*, 31(3): 441-455.
- Schibbye, A. L. L. (2002). *Et dialektisk perspektiv på eksistensiell og psykodynamisk psykoterapi*. Oslo: Universitetsforlaget.
- Schön, D. A. (1983). *The reflective practitioner: how professionals think in action*. New York: Basic Books.
- Scull, A. (1984). *Decarceration - Community Treatment and the Deviant*. Cambridge: Polity Press.
- Seale, C., Gobo, G., Gubrium, J. F. & Silverman, D. (2007). *Qualitative Research Practise*. Los Angeles, London, New Delhi, Singapore: Sage Publications.
- Sharkey, S. & Larsen, J. A. (2005). Ethnographic exploration: participation and meaning in everyday life. In: Holloway, I. (Ed.) *Qualitative Research in Health Care*, pp. 168-190. Berkshire & New York: Open University Press.
- Silverman, D. (2005 2nd ed.). *Doing Qualitative Research*. London, Thousand Oaks CAL, New Delhi: Sage Publications.
- Silverman, D. (2007). *Interpreting Qualitative Data*. Los Angeles, London, New Delhi, Singapore: Sage Publications.
- Skårderud, F., Haugsgjerd, S. & Stanicke, E. (2010). *Psykiatriboken. Sinn – kropp – samfunn* Oslo: Gyldendal Norsk Forlag.
- Sosial og helsedepartementet: St.meld. nr. 25, (1996-97). *Åpenhet og helhet*. Oslo: Sosial og helsedepartementet.
- Sosial og helsedepartementet: St.prp. nr. 63 (1997-98). *Om opptrappingsplanen for psykisk helse*. Oslo: Sosial og helsedepartementet.
- Sosial og helsedirektoratet (2005). *Veileder: Psykisk helsearbeid for voksne i kommunene*. Oslo: Sosial og helsedirektoratet.

- Sosial og helsedirektoratet (2006). *Brukermedvirkning – psykisk helsefeltet. Mål, anbefalinger og tiltak i Opptappingsplan for psykisk helse*. Oslo: Sosial og helsedirektoratet.
- Spaniol, L. R., Gagne, C. & Kohler, M. (Eds.) (1997). *Psychological and Social Aspects of Psychiatric Disability*. Boston MA: Boston University, Center for Psychiatric Rehabilitation.
- Spradley, J. P. (1979). *The ethnographic interview*. New York: Holt, Rinehart & Winston.
- Spradley J. P. (1980). *Participant observation*. New York: Holt, Rinehart & Winston.
- Srole, L., Langer, T. S., Michael, S. T. et. al (1962). *Mental Health in the Metropolis: The Midtown Manhattan Study*. New York: McGraw-Hill.
- Sterling, E. W., Silke, A. E., Tucker, S., Fricks, L. & Druss, B. (2010). Integrating Wellness, Recovery, and Self-management for Mental Health Consumers. *Community Mental Health Journal*, 46: 130-138.
- Søder, M. (1992). Normalisering og integrering: Omsorgsideologier i et samfunn i endring. I: Sandvin, J. T. (red.) *Mot normalt? Omsorgsideologier i endring*, s. 41-66. Oslo: Kommuneforlaget.
- Sørensen, N. Ø. (2012). *Det levde liv med sindslidelse – Et etnografisk forskningsstudie af borgernes sociale liv i behandlings- og sosialpsykiatri*. Frederiksberg DK: Forskningscenter for Socialt Arbejde, Professionshøjskolen Metropol.
- Thornicroft, G. & Bebbington, P. (1989). Deinstitutionalization - from Hospital Closure to Service Development. *British Journal of Psychiatry*, 155: 739-753.
- Tidemann, M. (2004). Lika som andra – om delaktighet som likverdiga levnadsvillkor. I: Gustavsson, A. (red.): *Delaktighetens språk*, s. 119-136, Lund S: Studentlitteratur.
- Tjora, A. (2012, 2nd ed.). *Kvalitative forskningsmetoder i praksis*. Oslo: Gyldendal Akademisk.
- Truman, C. & Raine, P. (2002). Experiences and meaning of user involvement: some explorations from a community mental health project. *Health and Social Care in the Community*, 10(3): 136-143.
- Tøssebro, J. (1999). Integreringsprincippet i teori och praktik. I: Tideman, M. (red.): *Handikapp – synsätt, principer, perspektiv*, s. 177-194. Stockholm: Studentlitteratur.
- Tøssebro, J. (2004). Introduksjon – integrering og inkludering, historikk og politikk. I: Tøssebro, J. (red) *Integrering och inkludering*, Lund: Studentlitteratur.
- Vatne, S. & Hoem, E. (2007). Acknowledging communication: a milieu-therapeutic approach in mental health care. *Journal of Advanced Nursing*, 61(6): 690-698.

- Wadel, C. (1991). *Feltarbeid i egen kultur*. Flekkefjord: SEEK A/S.
- Warner, R. (1994, 2nd ed.). *Recovery from Schizophrenia*, London & New York: Routledge.
- Whitley, R., Harris, M., Falloot, R.D. & Wolfson Berley, R. (2008). The active ingredients of intentional recovery communities: Focus group evaluation. *Journal of Mental Health*, 17(2): 173-182.
- Whitley, R., Strickler, D. & Drake, R. E. (2012). Recovery Centers for People with Severe Mental Illness: A survey of Programs. *Community Mental Health Journal*, 48: 547-556.
- WHO (2001a). *International classification of functioning, disability and health (ICF)*, Geneva: World health Organisation.
- WHO (2001b). *Mental Health: New Understanding, New Hope, World Health Report*, Geneva: World Health Organization.
- WHO (2005). *Promoting Mental Health. Concepts, Emerging Evidence, Practice*, Geneva: World Health Organization.
- WHO (2007). *Community mental health services will lessen social exclusion, says WHO*. <http://www.who.int/mediacentre/news/notes/2007/np25/en/print.html> 15.06.07
- Wing, J. K. (1990). Meeting the needs of people with psychiatric disorders. *Social Psychiatry and Psychiatric Epidemiology*, 25: 2-8.
- Witzø, A. E. (2013). *Participation in older adults – in the context of receiving home-based services*. Doctoral thesis. Trondheim: Norwegian University of Science and Technology.
- Yilmaz, M., Josephsson, S., Danermark, B. & Ivarsson, A. B. (2009). Social processes of participation in everyday life among persons with schizophrenia. *International Journal of Qualitative Studies on Health and Well-being*, 4: 267–279.
- Yin, R. K. (2003, 3rd ed.). *Case Study Research. Design and Methods*. Thousand Oaks, London, New Delhi: Sage Publications.
- Ytterhus, B. (2000). *"De minste vil, og får det kanskje til ...". En studie av hverdagslivets segregering i inkluderende institusjoner – Barnehager*. Doctoral thesis. Trondheim: Norwegian University of Science and Technology.
- Ådnanes, M., Kaspersen, S. L., Hjort, H. & Ose, S. O. (2008). *Lavterskel helsetiltak for rusmiddelavhengige - Skadereuserende bindeledd mellom bruker og øvrige hjelpeapparat*. Trondheim: SINTEF helsetjenesteforskning.

Paper 1

Is not included due to copyright

Paper 2

Mental health centres as ‘meeting-places’ in the community: exploring experiences of being service users and participants

Toril Anne Elstad^{a*} and Kristjana Kristiansen^b

^a*Faculty of Nursing, Sor-Trøndelag University College, Trondheim, Norway;* ^b*Institute of Social Work and Health Science, Norwegian University of Science and Technology, Trondheim, Norway*

(Received 20 December 2007; accepted 28 October 2008)

The purpose of this article is to present and discuss findings from a qualitative study within mental health centres called ‘meeting-places’ in the community. Ten service users were interviewed in order to explore and gain insight into what visiting the centres might mean in the daily life situations of people who experience mental health problems. The interviewees were recruited during fieldwork within these centres, aiming to facilitate the inclusion of service users who wished to share their experiences, but who might not otherwise come forward as research participants. Three main themes were identified in the data analysis: ‘To belong and be recognized’, ‘Needs for support and challenges’, and ‘Participation and everyday life’. Flexible community mental health services can be helpful by offering support and challenges as well as possibilities for mutual relationships. However, the study also highlights a lack of opportunities for participation and recognition in the wider society.

Keywords: community mental health centres; users and participants; experiences

Introduction

The aim of this article is to present and discuss findings from a qualitative study within mental health centres which are part of the municipal health service in a Norwegian city. These centres, called ‘meeting-places’, aim to support users’ social inclusion in their community as well as to increase user-participation within the service. The main theme explored in individual interviews was what visiting these centres meant in the daily life situations of service users. The organization of the centres facilitates the role of service user as well as active participant, which differs from more traditional mental health services. User participation and social inclusion are central aims for contemporary mental health policy in several countries. The study should therefore have relevance outside of its local context.

Background context

Developing mental health services to support people in their life in the community is now a central aim internationally (WHO 2001b, 2007). Norwegian policy is in line with these recommendations, as described in a government White Paper on mental

*Corresponding author. Email: toril.elstad@hist.no

health services (SHD 1996/97). A reduction in psychiatric hospital beds and an increase in community mental health services have been major international trends across several countries for more than 50 years (Corrigan et al. 2008; Mechanic and Rochefort 1994; Pilgrim and Rogers 2005; Prior 1993; Wright, Bartlett, and Callaghan 2008). Research from Norway shows, for example, that the number of people who were registered as patients in psychiatric hospitals declined from about 9000 in the years 1960–1970 to just under 3000 in 2003 (Hagen and Ruud 2004), and two recent reports (Kaspersen, Ose, and Hatling 2007; Ose, Pettersen, and Kalseth 2007) show an increase in community-based mental health services.

Critique of segregated psychiatric institutions began with the work of for example Goffman (1961). In Norway, Løchen's work (1976) unveiled the disparity between rhetoric and reality with regard to what psychiatric hospitals were hoping and claiming to accomplish and what actually was occurring. In many countries, the deinstitutionalization of mental health services has been welcomed by different stakeholders, including user organizations, service administrators, professionals and politicians, despite often representing different viewpoints and interests. Issues related to what the better practice is, in order to reduce marginalization and enhance the inclusion of 'vulnerable groups' in society, have been widely discussed (cf. Froestad, Solvang, and Söder 2000; Tøssebro 2004). It has also been pointed out that being physically present in a locality is a pre-requisite for inclusion, but provides no guarantee of social contact and development of social relationships (Gustavsson 1993; Kristiansen 1993). A risk of social isolation in the community for people with mental health problems has also been discussed (Pilgrim and Rogers 2005; Sayce 2000). Such discussions highlight the importance of studying relationships between ideology and service users' experiences. Sandvin and Lichtwark (2005, 69), for example, refer to Söder (1982) when addressing the issue of ideology and practice:

Ideologies give certain directions for action. But ideologies are also simplifications, and for ideologies to be implemented it is necessary that these simplifications are adjusted to practical realities, which often reveals the inadequacy of the realism of ideologies. The result might be that the ideology is never implemented or that it is implemented but with a different outcome than expected.

Different forms of social ties, social networks and social capital have been studied and discussed, related to issues of health and welfare (Ferlander 2007; Kawachi and Berkman 2001; McKenzie and Harpham 2006; Putnam 2000). In social network theory, close relationships are described as 'strong ties' and more superficial social contacts as 'weak ties'. Social support is believed to be available in the strong ties between family and friends. Granovetter (1973), however, described how weak ties can build bridges to new social settings, such as finding and maintaining a job or having contact with neighbours. A lack of weak ties in the personal networks of marginalized groups in society may explain their relative lack of 'social capital', which refers to '... social participation in the activities of the formal and informal networks of civil society and/or as generalized trust' (Pilgrim and Rogers 2005, 39). In the International Classification of Functioning, Disability and Health (ICF), 'participation' is defined as involvement in a life situation (Björk-Åkesson and Granlund 2004; Molin 2004; WHO 2001a), and the notions of social capital and social inclusion appear to be intrinsically connected to participation and social interaction. Theories about experiences of recognition (Honneth 1995, 2003) also

highlight the importance of participation in social activities and the formation of mutual relationships for identity-formation and well-being.

People with mental health problems have long been described as an excluded group in society (Huxley and Thornicroft 2003; Sayce 2000; Sen 2000), and according to Bergem and Ekeland (2006), recognizing and implementing the realities of a genuine citizenship status for people with mental health problems is a central challenge for services and communities in striving towards goals of social inclusion. The Global Forum for Community Mental Health, organized by the World Health Organisation, recently sent out a message directed at reducing the social exclusion of people with mental health problems, aiming to ensure their participation in society, including an urgent need for countries to provide a network of community mental health services (WHO 2007). Community mental health centres offer settings and activities designed with the stated purpose of providing supports in daily life. However, some essential questions need further exploration, such as how people with mental health problems experience use of these community-based services, and what meaning their participation might have for their situations in the wider community.

Previous research

How people with mental health problems experience life in the community has been studied from different perspectives, and investigated by quantitative as well as qualitative research methods. Some recurrent findings from quantitative studies reveal unmet needs for social contact, relationships and activities (Bulow, Svensson, and Hansson 2002; Hansson et al. 2003; Jansson, Sonnander, and Wiesel 2003) and the importance of such factors for self-reported 'quality of life' (Borge et al. 1999; Elstad 1999; Oliver, Huxley, and Bridges 1996). Qualitative studies have reported feelings of loneliness, shame and psychological pain, fear of neglect and exclusion, passivity and needs for support but not wanting to be subjected to control (Birkeland and Kristoffersen 2004; Erdner et al. 2002; Granerud and Severinsson 2006; Green et al. 2002). Kristiansen's study of women with long-term mental health problems (2004) revealed fears of not being a good mother, issues of violence and abuse often within the service system, worries about whose version of reality is 'real', and having different perceptions of what help is helpful. Bergem and Ekeland (2004) found variations in how people with mental health problems created and sustained their identities, mentioning the need for flexible community mental health services. Borg and Kristiansen (2004) found that people with serious and enduring mental distress often recover based on their own active agency combined with non-traditional responses from service workers. Life in the community for people with mental health problems has also been studied by observations and field conversations. Reporting from a study in the USA, Estroff (1981) described how 'psychiatric clients' often had to struggle to get by. Prior (1993, 178) described the social worlds of 'ex-patients' living in local communities in Northern Ireland as '... a subworld of the disabled and the handicapped and the sick ...', a world that had only superficial contact with mainstream society.

Qualitative studies have also been conducted within community mental health services. In a Danish study, Kristiansen (2000), reported variations in individual users' attachment to community mental health centres, and in a study from Norway, Lillestø and Hanssen (2000, 57) found that users had an ambivalent relationship to community day-centres, wishing most of all to 'come back to society'. In an English

study with a geographical perspective, Conradsen (2003, 507) described 'drop-in centres' as 'spaces of care in the city'. Whitley et al. (2008), reporting from qualitative evaluation research in the USA, found that centres called 'intentional recovery communities' were important for the psychosocial needs of service 'consumers'. The most prominent theme identified in their study was the importance of feeling safe, which: '... appeared to be the bedrock upon which positive inter-personal relationships were forged and individual growth occurred' (177).

It seems sensible to argue that community services should have a wider focus than treatment and care (Corrigan et al. 2008; Grunewald 2000; Hydén 2005). Knowledge about the social and relational aspects of mental health and mental distress based on learning from those with lived experience is important in order to develop services which support community participation and inclusion. There remains, however, a lack of research-based knowledge about the content and function of contemporary community mental health services (Ramsdal 2002). The subject of this article is what functions and meaning different aspects of such services might have in daily life for people with mental health problems.

Methodological approach and rationale

The rationale for this study was to add new insights and perspectives to existing knowledge about the role of community mental health services in people's life situations from the perspective of service users living in the community. This theme was explored in individual interviews with 10 service users in a study which was developed and conducted during participant observation (Hammersley and Atkinson 2007; Sharkey and Larsen 2005). After information rounds, five women and five men volunteered to be interviewed by contacting the first author directly or via a member of staff at the centre, during periods of participant observation from May to November 2005. The intention was that this procedure should facilitate the participation of persons who wished to be interviewed, but who might not otherwise come forwards as informants. This would, again, aid in the inclusion of informants with a variety of experiences, which was important in this study in order to gain insight into experiences from community mental health centres as part of daily life.

Study context

The research reported here was conducted within three community mental health centres in a Norwegian city. In the local mental health service plan, the centres are described as 'meeting-places' for people with mental illness living in the community. As described earlier, mental health services that aim to support people in the community have been developed in many countries. It is, however, important to note that similar terms can be used about different types of organizations. The centres that provided this study's research context are part of the local municipal health services, with staff from different health- and social professions employed. All centres are situated in mixed business and residential areas: one close to the city centre, another at the outskirts of the city and the third about 10 kilometres from the city centre. Users choose how to use the centres: there are no intake procedures or applications, no medical records are kept, and 'user-participation' in decision-making and involvement in leading activities is encouraged. According to the local plan for mental health services, the aim of these centres is to help users cope with everyday

life: a step towards rehabilitation for some and/or mainly an arena for social contact for others. Some visit the centres regularly while others 'drop in' only occasionally, and individual persons' use of the centres also varies over time.

Participants and procedure

Inclusion criteria for this study were to be a user of one of the centres, and also to have an interest in sharing this experience to contribute to this study. The research participants have been given fictional names and no demographic data were noted other than gender and approximate age, which ranged between 40 and 60 years. As the focus for the study was on the experiences of those interviewed, no medical information was sought. All informants did, however, volunteer information about previous experiences as users of mental health services during the interviews.

All the interviews were conducted by the first author. An open interview guide was used, with themes relating to the following main question: 'What does it mean to you in your daily life to participate at the centre?' Some informants did not wish their interviews to be taped. As it might be perceived as intrusive, a tape-recorder was not used (Sharkey and Larsen 2005, 177). Notes taken were summarized for the informants during the interviews, asking whether the meaning of their responses had been correctly understood. This can be considered as a validity measure in qualitative interviewing (cf. Kvale 1996, 237). In subsequent interviews, four informants supplemented some issues while three others commented that the written interview reports adequately represented their experiences. Three informants were not available for second interviews. In the autumn of 2006, meetings were held at each centre, presenting and discussing preliminary themes and findings from the analysis. These procedures were conducted in order to keep the research process relatively transparent and to facilitate feedback from informants on preliminary understandings during the research process.

Ethical issues

According to established regulations in Norway, the study was submitted to and approved by the regional committee for research ethics, the Norwegian social science data service, and the local medical officer. Before commencing the study, users and staff were informed in open meetings, and written information was handed out and also posted on announcement boards at each centre. An important principle when conducting this study was to avoid putting pressure on service users by active recruitment for interviews, according to requirements from the medical ethics committee and medical officer in charge of the services and also in line with the general approach in the research project. The research process was kept relatively open, such that participating informants could review interview transcripts, and discuss emergent findings during group discussions at the centres. This contributed to a wider understanding of the informants' perspectives, and was also based on ethical reflections, since some informants might have disliked the experience of being written about, with little influence on how their expressions might be used. As described by Kristiansen (2005, 95): '... within a medical approach, subjective reports are of interest primarily to uncover signs and patterns of pathology. They are asked for, and listened to, but then fitted into diagnostic categories'.

Analysis

The data analysis was based on open-ended interviews, starting with the following question: 'What does it mean to you in your daily life to participate at the centre?' The full text from all the interviews was first read through, obtaining an overall impression of the content. Secondly, each interview was read, marking all the text containing descriptions seen to illuminate the main research question. These identified descriptions from across the interviews were then re-read several times, developing and amending main themes and categories. Finally, the complete text was re-examined and explored, searching for higher-order themes and issues (Kvale 1996). The following three categories were developed from the empirical material: (1) To belong and be recognized; (2) Needs for support and challenges; (3) Participation and everyday life. These themes do to some degree overlap. However, theme one relates to 'psychosocial' aspects of using the centres, theme two focuses more on the meaning of socializing within the centres as part of daily life, while theme three relates to relationships between participation within the service and participation in the wider community.

Findings

The purpose of this study was to explore experiences of attending community mental health centres from the perspective of people who visit such settings regularly. The main focus was on the meaning of this participation in the participants' daily life situations. Findings from the interviews are presented below, using the main themes as headings. Some background information from observations during the field study has been included, in order to contextualize the findings.

To belong and be recognized

All informants in this study emphasized the importance of having an environment where they could feel safe and relaxed, in a friendly atmosphere that was free from conflicts. Some also elaborated on the importance of how you are met. Linda, for example, told how, on her first visit, one woman who visited the centre said: 'come over and sit here beside us'. This invitation was very important to Linda: 'The two of us are now best friends'. According to Jenny, there is an awareness of how they greet and receive new users at 'her' centre. This is planned by users and centre staff. Jenny compared being at the centre where she said she felt 'like an equal' to her previous experiences of a psychiatric hospital where she had often felt 'like a complete fool' in the role of patient. Grethe described her experience this way: 'in a psychiatric hospital one is not seen as a human being, – one becomes a "case" ... but I've never experienced leaving this centre feeling that I've been ignored'. This is how she described the setting:

... it feels safe to come here, also when you have a bad day ... It was difficult to identify myself as someone who needs help from psychiatry. At the same time, the centre felt like a safe place: you can come here also when feeling ill, as long as you can manage to sit here for a while. This can actually feel like mastery, you know, just knowing that you've been here. For someone with anxiety, this is an accomplishment.

Erik spoke about his own experiences and also what the centres might mean for other users: 'You get positive feedback ... meet others in the same situation and can

share these experiences without feeling shame. Here I don't have to explain or defend that I get a disability pension'. 'Not having to put on a mask' and 'feeling less pressure to have to live up to things all the time' were also important to Erik. Similarly, others described the centres as places where you could 'loosen up' or 'be yourself'. Grethe said: 'The ordinary activities in the neighbourhood can be too demanding after coming out from a psychiatric hospital. There you can feel like a loser because you can't manage to do the simplest of things. Here at the centre, you are never a loser'. One woman gave the following example: 'Here, we all know what it's all about. If I'm feeling low-down, like I was yesterday at the shopping centre, then here they know that I am not *only* like that'.

Several informants spoke about these places as 'their' centre, for example Ivar who referred to 'his' centre this way: 'We are a close gang here at our centre. People come here to be social and for instance to celebrate our birthdays'. How to spread information to potential users was an issue discussed in meetings at the centres, and some user-representatives were observed to be actively engaged in how the centres were presented in brochures and on the internet. In the interview, Maria also spoke about the importance of information. She had heard from others that their local doctor had informed them about these centres and that visiting the centre could prevent being admitted to psychiatric hospital: 'If my doctor had informed me about the centre, it would have been useful. Doctors and other health professionals should be more aware of different opportunities and rights. There is a lack of information'.

Needs for support and challenges

When interviewed, Erik said: 'To come here can be a little like being at work. It is a kind of learning process, too. You get important experiences and dare to behave more freely'. In line with this, conversations at the centres were observed often to be about practical things, such as food prices, food recipes, how to get a bank loan, buy a flat or decorate a room. Sometimes people would give practical advice to one another. Conversations were also about previous holidays, or shared experiences like a bus trip or the centre's Christmas party. When staff participated in these settings, it was as ordinary conversation partners. These were observed to be like familiar, everyday conversations that could take place anywhere in our culture.

In the interviews, some users talked about mutual support, available companionship, and sometimes the development of friendships. David said: 'There is not much "illness-talk" at the centre, since there is a "house rule" against too much of this.' However, he also added: 'Sometimes it's necessary to talk about one's problems and the things one struggles with . . . others may have experienced the same, and this can be positive'. Both Maria and Andreas described how, in their experience, 'meeting like-minded' could mean 'finding comfort in sharing the same fate'. Similarly, Grethe said: 'Those who know how it feels can give others good ideas and help start a process that has positive effects'.

All users emphasized the need for having professional staff available at the centres. Jenny said: 'The professionals are very important . . . they are together with us and listen to us. I can ask for advice if there is some trouble in my daily life'. According to Maria: 'When you're ill you want the staff to have good professional knowledge and to understand what the matter is'. This appeared to be related to keeping the setting conflict-free and feeling safe, and also a concrete need for help and advice in one's daily life situation. Ivar said about this:

Here you are backed up in your everyday life if you need it ... It is very important that those working here have professional knowledge. Here we have the safety of knowing that there are professionals available who can handle the situation if something should happen.

Karin said: 'People here are nice. But I still don't want the users to take over. It's important that the staff takes care of things and organize activities, – otherwise it might be chaotic. The way things are here suits me fine. I need a very long time to connect to new people'.

Participation and everyday life

Responses to what participation at the centre meant in daily life in general were mainly about having somewhere safe to meet people and to have opportunities to participate in activities together with others. Alternatives were often described as being left alone, and on one's own. Linda, for example, described 'lying on the couch at home' as her alternative, adding 'that's what I used to do before'. When asked about what centre-participation meant for her, Karin answered: 'for example, one doesn't have to walk around town alone all day. It would be boring and lonely in the long run'.

Another typical response was related to reducing experiences of mental distress. Andreas said that the centre was 'very important' for him in order to get out either on his own or be together with others. For him, this social participation also served as a way of avoiding his experiences of strong anxiety. In his own words: 'When you're alone, you can get yourself into a state of anxiety and crisis. Together with others, you can train yourself not to think like this'. Jenny compared participating at the centre to her earlier experience of psychiatric hospitals this way:

It's very important to have somewhere like this to go to. Before one didn't have alternatives to hospital admission ... it was quickly in and out of hospital. Because of this centre, I haven't been inside a psychiatric hospital for ten years. It's like an anti-depressant without side effects.

Grethe likened her depression to being in a 'vacuum-land', explaining that somebody then has to help in order to 'let in air and open up a way out'. Sharing positive experiences with others at the centre could, again according to Grethe, help this way: 'Experiencing something, – then being able to tell others about it is very different from living in a vacuum. Actually, not only to tell others, but also knowing yourself that you have done something helps'. Similarly, Erik said: 'To participate socially here helps me to feel less isolated in general. In this way, to participate here can help me manage to do other things as well, outside of the centre'. According to Karin, visiting the centre also helped her to have contact with others outside of the centre. She said the following: 'I feel proud to participate here. Managing to come here also helps me to take part in other things. I get more self-confidence'.

Discussion

The purpose of this study is to illuminate different aspects of what it means to attend community mental health centres in a context of user-participation and social inclusion, based on the experiences of regular service users. A main finding from 10 individual interviews was a very positive description of these centres. On one hand,

this is not surprising, since all the study participants had chosen to visit the centres on a regular basis. It also reflects a sense of belonging, since these centres are based on both professional- and peer-support. This indicates that services focusing on user participation and social inclusion are appreciated by their users.

To belong and be recognized

To feel socially included and safe was important for all those interviewed in this study. Some related this to needs for safety and support in order to avoid or reduce experiences of mental distress. Others felt that participation at these centres could prevent (re)admissions to psychiatric hospitals. It was also important for the users to participate in an environment where one felt equal and respected. Honneth (1995, 2003) highlights needs for fellowship, where one is seen as a fellow human being and recognized for one's competencies, not merely as a person observed and tolerated. Relationships of mutual recognition provide opportunities for experiencing solidarity, social inclusion and increased self-worth. Grethe's expression: 'here you are never a loser' when speaking about the atmosphere at 'her' centre provides an illustrative example. Some of the interviewed referred to the centre as 'our place'. It was also observed that users of the centres informed potential new users about the centres. This can be understood as expressions of anticipated fellowship and belonging.

Whitley et al. (2008) found that 'intentional recovery communities' were important for the psychosocial needs of 'service consumers'. Feeling safe was vital for the development of positive relationships and individual growth, and this also allowed 'consumers' to function better in 'everyday society'. The present study supports these findings. The expressed needs for protection from the pressures of the wider community identified in this study do, however, also highlight that there are barriers to social inclusion in society for people who experience mental distress. Tøssebro (2004) has discussed the distinction between tolerance in society in general and individuals being 'tolerated'. The need for environments where one can be seen and respected; not merely 'tolerated', may indicate a lack of opportunities for experiencing true recognition as fellow citizens in society.

Support and challenges

Through talking about everyday experiences, people gave one another practical advice and feedback. Conversations that involve mutual sharing of experiences might support one's identity as someone who has something worthwhile to give to others. Such conversations can be understood as 'normalizing' and 'identity-forming', especially when staff also share experiences and reactions from their own daily lives. Mutual support may enhance self-confidence and strengthen people's identity as someone who contributes rather than being viewed solely as 'service users'. Some centre-users emphasized that participation in activities and sharing experiences at the centres helped building confidence and gave them something to talk about when meeting other people. Others emphasized opportunities for 'training' and learning to cope with everyday life. This is in line with findings suggesting that 'bridging' social capital is of particular value as it supports vertical exchange and enables people to 'get ahead' rather than just 'get by' (Usher 2006).

For some participants in this study, contact with others who 'shared the same fate' was important, including the sharing of good advice based on 'illness-

experience'. Gustavsson's research (1993) describes how some persons with mental illness prefer the company of others who share the same experience over others who do not. This raises interesting questions about social inclusion and community integration, for example how one defines 'community', and related feelings of belongingness. As pointed out by Bricout and Gray (2006, 5): 'Communities exist both as a physical place, whether defined by local convention, political boundaries or shared perceptions and as a locus of affiliation or identification . . .'. Seen in the light of theories about social networks and social capital; can 'weak ties' that are developed within community mental health services also increase people's 'bridging social capital', leading to new experiences and activities in the wider society?

Participation and everyday life

The community mental health centres studied in this research project played a central role in the daily life of many of their users. Alternatives were often being alone and not participating together with others. Contrary to findings in a study by Lillestø and Hanssen (2000), none of the informants in this study expressed ambivalence about their participation at the centres. This difference may be related to methodology, or it can reflect differences in the study contexts, including changes in policy and organization. A Danish study (Kristiansen 2000) found variations in how people used and identified with community mental health centres. In the present study such variations were also observed. Bergem and Ekeland (2004) discussed a need for flexible community mental health services based on self-determination for the users. Findings in this study support the view that open and flexible community services may have the potential of increasing personal social networks and feelings of recognition through mutual relationships and peer-support. Such services may provide opportunities and challenges, and can also function as a safe retreat, in order to gather the strength to move on towards greater participation in community life. According to service users in this study their participation also aided in participating socially outside the community mental health service arenas. However, some of the interviewed also describe these services as places where one could get away from 'society', indicating some need for 'sanctuary' or 'asylum', often due to the experience of barriers to true social inclusion in the outside world.

Some methodological considerations

The purpose of this study has not been to generalize or evaluate, but to gain insight into different aspects of what regular use and participation in community mental health centres mean in people's daily life situations. From observations by the first author, and from comments by some of those interviewed, one can note that this inclusion procedure facilitated participation in the study of service users who might not otherwise have been interviewed. By including the views of some service users who are otherwise seldom heard, the study adds a new perspective to the knowledge-base about the experiences of mental health service users in the community.

No attempt was made to actively recruit informants. This was a pre-requisite for gaining access to the setting from those in charge of the services, and is also an important principle in research ethics, because of protecting anonymity and ensuring informed consent. It is, however, important to consider that the interviews are based on 'self-selection' among people who have chosen to use community mental health

centres, often on a regular basis, and that the inclusion of more 'peripheral' service users might have led to more critical views. People who occasionally drop in to community mental health centres have elsewhere been found to have different affiliations to the service (Kristiansen 2000).

Another important point is that all informants volunteered some information about previous treatment from other mental health services, and some compared their previous experiences to their present situations. Thus, their frames of reference would be influenced by a contrast between 'before and now'. On one hand this indicates progress in making mental health services more useful and less repressing. On the other hand, previous negative experiences may also reduce people's ambitions. Persons who use other services or participate in a user-organization may have different experiences and views.

Concluding remarks

Open and flexible community mental health services provide support which may aid in coping with life in the community for some of the users. To have professional help available without having to give up control in one's life-situation may increase feelings of security and agency, and may prevent (re)hospitalization for some. To experience mutual relationships and recognition contributes to self-confidence and well-being. Community mental health centres can also be seen as protective communities within the larger community. Without such 'protective environments', would people with severe mental health problems be left behind in institutions? Or is it the settings and supports offered by society that limit social contact? Important questions remain unanswered about the use of community mental health services and about creating opportunities for people with mental health problems to receive recognition also in the larger community. Further research into community participation and inclusion, as well as how different types of community mental health services might aid in such processes, is necessary.

References

- Bergem, R., and T.J. Ekeland. 2004. Identitet og integrasjon. Menneske med psykiske lidinger i små samfunn [Identity and integration. People with mental illness in rural communities]. *Tidsskrift for Velferdsforskning* 7, no. 2: 64–77.
- Bergem, R., and T.J. Ekeland. 2006. Psykisk sjuke som medborgarar [People with mental illness as citizens]. *Tidsskrift for Velferdsforskning* 9, no. 1: 26–38.
- Birkeland, A., and K. Kristoffersen. 2004. Opplevelse av behov for hjelp hos psykiatriske pasienter som bor i egen bolig [The experience of need for help of psychiatric patients who live in their own home]. *Vård i Norden* 24, no. 4: 15–9.
- Björk-Åkesson, E. and M. Granlund. 2004. Delaktighet – ett centralt begrepp i WHO's klassifikasjon av funktionstillstånd, funktionshinder och helsa (ICF) [Participation: A central concept in the WHO's classification of function, disability and health (ICF)]. In *Delaktighetens språk* [The language of participation], ed. A. Gustavsson, 29–48. Lund: Studentlitteratur.
- Borg, M., and K. Kristiansen. 2004. Recovery-oriented professionals: Helping relationships in mental health services. *Journal of Mental Health* 13, no. 5: 493–505.
- Borge, L., E.W. Martinsen, T. Ruud, Ø. Watne, and S. Friis. 1999. Quality of life, loneliness, and social contact among long-term psychiatric patients. *Psychiatric Services* 50, no. 1: 81–4.
- Bricout, J.C., and D.B. Gray. 2006. Community Receptivity: The ecology of disabled persons' participation in the physical, political and social environments. *Scandinavian Journal of Disability Research* 8, no. 1: 1–21.

- Bulow, P., T. Svensson, and J.H. Hansson. 2002. Long-term consequences of the reformation of psychiatric care: A 15-year follow-up study. *Nordic Journal of Psychiatry* 56, no. 1: 15–21.
- Conradsen, D. 2003. Spaces of care in the city: The place of a community drop-in centre. *Social and Cultural Geography* 4, no. 4: 507–25.
- Corrigan, P.W., K.T. Mueser, G.R. Bond, R.E. Drake, and P. Solomon. 2008. *Principles and practice of psychiatric rehabilitation. An empirical approach*. New York: The Guilford Press.
- Elstad, T. 1999. Sosial integrasjon blant mennesker med alvorlige psykiske lidelser [Social integration among persons with severe mental illness]. Trondheim, Norway: NIS-rapport 2/99, SINTEF Health Research.
- Erdner, A., M. Nyström, E. Severinsson, and K. Lutzen. 2002. Psychosocial disadvantages in the lives of persons with long-term mental illness living in a Swedish community. *Journal of Psychiatric and Mental Health Nursing* 9: 457–63.
- Estroff, S. 1981. *Making in crazy: An ethnography of psychiatric clients in an American community*. California: University of California Press.
- Ferlander, S. 2007. The importance of different forms of social capital for health. *Acta Sociologica* 50, no. 2: 115–28.
- Froestad, J., P. Solvang and M. Søder, eds. 2000. *Funksjonshemming, politikk og samfunn* [Disability, politics and society]. Oslo: Gyldendal Akademisk.
- Goffman, E. 1961. *Asylums*. Harmondsworth: Penguin Pelican Books.
- Granerud, A., and E. Severinsson. 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: 288–93.
- Granovetter, M. 1973. The strength of weak ties. *American Journal of Sociology* 78: 1360–80.
- Green, G., C. Hayes, D. Dickinson, A. Whittaker, and B. Gilheany. 2002. The role and impact of social relationships upon well-being reported by mental health service users: A qualitative study. *Journal of Mental Health* 11, no. 5: 565–79.
- Grunewald, K., ed. (2000) *Psykiska handikapp – möjligheter och rättigheter* [Psychiatric disability – possibilities and rights]. 2nd ed. Stockholm: Liber Forlag.
- Gustavsson, A. 1993. Livet i 'integrasjonssamfunnet' – en analyse av nærhetens sosiale betydning [Life in 'the integration-society' – an analysis of the social meaning of closeness]. In *Mot normal? Omsorgsideologier i forandring*, ed. J.T. Sandvin. Oslo: Kommuneforlaget.
- Hagen, H., and T. Ruud. 2004. Pasienter i psykisk helsevern for voksne [Patients in adult psychiatric services]. Trondheim, Norway: Rapport 3/04, SINTEF Health research.
- Hammersley, M., and P. Atkinson. 2007. *Ethnography*, 3rd ed. London: Routledge.
- Hansson, L., M. Sandlund, A. Bengtsson-Tops, O. Bjarnason, H. Karlsson, T. Mackeprang, L. Merinder, L. Nilsson, K. Sørgaard, H. Vinding, and T. Middelboe. 2003. The relationship of needs and quality of life in persons with schizophrenia living in the community. A Nordic multi-center study. *Nordic Journal of Psychiatry* 57, no. 1: 5–11.
- Honneth, A. 1995. *The struggle for recognition. The moral grammar of social conflicts*. Cambridge: Polity Press.
- Honneth, A. 2003. *Behovet for anerkendelse* [The need for recognition]. Copenhagen: Hans Reitzels Forlag.
- Huxley, P., and G. Thornicroft. 2003. Social inclusion, social quality and mental illness. *British Journal of Psychiatry* 182: 289–90.
- Hydén, L.C. 2005. *Från psykiskt sjuk till psykiskt funktionshindrad* [From mentally ill to mentally disabled]. Lund: Studentlitteratur.
- Jansson, L., K. Sonnander, and F.A. Wiesel. 2003. Clients with long-term mental disabilities in a Swedish county – conditions of life, needs of support and unmet needs of service provided by the public health and social service sectors. *European Psychiatry* 18, no. 69: 296–305.
- Kaspersen, S., S.O. Ose, and T. Hatling. 2007. *Psykisk helsearbeid i kommunene: Disponering av omerkede midler i kommunene 1999–2005* [Community mental health services: Use of earmarked grants in the municipalities 1999–2005]. Trondheim: Report A1216: SINTEF Health research.
- Kawachi, I., and L.F. Berkman. 2001. Social ties and mental health. *Urban Health* 78, no. 3: 458–67.
- Kristiansen, K. 1993. *Normalisering og verdsettning av sosial rolle* [Normalization and social role valorisation]. Oslo: Kommuneforlaget.

- Kristiansen, K. 2004. Madness, badness and sadness revisited: Ontology control in mental health land. In *Gender and disability research in the Nordic countries*, ed. K. Kristiansen and R. Traustadóttir. Lund: Studentlitteratur.
- Kristiansen, K. 2005. Owners of chemistry, hope and evidence. In *Resistance, reflection and change. Nordic disability research*, ed. A. Gustavsson, J. Sandvin, R. Traustadóttir, and J. Tøssebro. Lund: Studentlitteratur.
- Kristiansen, S. 2000. Interaction patterns among users of a Danish community care centre. *International Social Work* 43, no. 3: 325–36.
- Kvale, S. 1996. *InterViews*. Thousand Oaks: Sage Publications.
- Lillestø, B., and J.I. Hanssen. 2000. Pasientfellesskapets betydning for mennesker med alvorlige psykiske lidelser [The meaning of 'the patient fellowship' for people with severe mental illness]. In *Usynlighetskappen. Levekår for funksjonshemmede*, ed. T.I. Romøren. Oslo: Akribe.
- Løchen, Y. 1976. *Idealer og realiteter i et psykiatrisk sykehus. En sosiologisk tolkning* [Ideals and realities in a psychiatric hospital. A sociological interpretation]. Oslo: Universitetsforlaget.
- McKenzie, K., and T. Harpham. 2006. *Social capital and mental health*. London: Jessica Kingsley Publishers.
- Mechanic, D., and D. Rochefort. 1994. Deinstitutionalization of the mentally ill – efforts for inclusion. In *Inescapable decisions – the imperative of health reform*, ed. D. Mechanic. New Brunswick: Transaction Publishers.
- Molin, M. 2004. Delaktighet inom handikappområdet – en begreppsanalys [Participation in the disability-area – an analysis of the concept]. In *Delaktighetens språk* [The language of participation], ed. A. Gustavsson. Lund: Studentlitteratur.
- Oliver, J., P. Huxley, and J. Bridges. 1996. *Quality of life and mental health services*. London: Routledge.
- Ose, S.O., I. Pettersen and J. Kalseth. 2007. Opptappingsplan for psykisk helse: Utvikling i kommunale brukerrater og dekningsgrader fra 2001–2004 [National mental health plan: Changes in user rates and coverage ratios for municipal services from 2001 to 2004]. Trondheim: Report A1312, SINTEF Health Research.
- Pilgrim, D., and A. Rogers. 2005. *A sociology of mental health and illness*. 3rd ed. Berkshire: Open University Press.
- Prior, L. 1993. *The social organisation of mental illness*. London: Sage Publications.
- Putnam, R.D. 2000. *Bowling alone. The collapse and revival of American community*. New York: Simon & Schuster.
- Ramsdal, H. 2002. Om formingen av det kommunale psykiatrifeltet [Shaping the new field of municipal community mental health work]. In *Samfunn og psykiske lidelser*, ed. R. Norvoll. Oslo: Gyldendal Akademisk.
- Sandvin, J., and W. Lichtwark. 2005. Gradual improvement or deterioration in disguise? In *Resistance, reflection and change. Nordic disability research*, ed. A. Gustavsson, J. Sandvin, R. Traustadóttir, and J. Tøssebro. Lund: Studentlitteratur.
- Sayce, L. 2000. *From psychiatric patient to citizen. Overcoming discrimination and social exclusion*. Houndmills, Basingstoke: Palgrave MacMillan.
- Sen, A. 2000. Social exclusion: Concept, application, and scrutiny. Asian Development Bank Report, Social Development Papers 1.
- Sharkey, S., and J. Larsen. 2005. Ethnographic exploration: Participation and meaning in everyday life. In *Qualitative research in health care*, ed. I. Holloway. London: Open University Press.
- SHD: St. meld. nr. 25. 1996/97. *Åpenhet og helhet* [The Norwegian government's White Paper on mental illness and mental health services]. Oslo: Sosial-og Helsedepartementet.
- Søder, M. 1982. Om osynliggjørende av funksjonshindrades behov [On rendering the needs of disabled people invisible]. *Tidsskrift for Nordisk Forening for Pedagogisk Forskning* 3: 15–20.
- Tøssebro, J. 2004. Introduksjon – integrering og inkludering, historikk og politikk [Introduction – integration and inclusion, history and politics]. In *Integrering och inkludering*, ed. J. Tøssebro. Lund: Studentlitteratur.
- Usher, C. 2006. Social capital and mental health in the urban south, USA: A quantitative study. In *Social capital and mental health*, ed. K. McKenzie and T. Harpham. London: Jessica Kingsley Publishers.

- Whitley, R., M. Harris, R.D. Falloot, and R. Wolfson Berley. 2008. The active ingredients of intentional recovery communities: Focus group evaluation. *Journal of Mental Health* 17, no. 2: 173–82.
- WHO. 2001a. *International classification of functioning, disability and health (ICF)*. Geneva: World Health Organization.
- WHO. 2001b. *Mental health: New understanding, new hope, world health report*. Geneva: World Health Organization.
- WHO. 2007, 1 June. Community mental health services will lessen social exclusion, says WHO. <http://www.who.int/mediacentre/news/notes/2007/np25/en/print.html>.
- Wright, N., P. Bartlett, and P. Callaghan. 2008. A review of the literature on the historical development of community mental health services in the United Kingdom. *Journal of Psychiatric and Mental Health Nursing* 15, no. 3: 229–37.

Paper 3

User participation in community mental health services: exploring the experiences of users and professionals

Toril Anne Elstad MSc, RN (Assistant Professor, PhD Student),^{1,2} and Arne Henning Eide PhD (Vice President Research, Professor)^{3,4}

¹Faculty of Nursing, Sør-Trøndelag University College, Trondheim, ²Institute of Social Work and Health Science, Norwegian University of Science and Technology, Trondheim, ³SINTEF Health Research, Oslo and ⁴Faculty of Health Education and Social Work, Sør-Trøndelag University College, Trondheim, Norway

Scand J Caring Sci; 2009; 23: 674–681

User participation in community mental health services: exploring the experiences of users and professionals

Increased user participation and community integration are central aims for contemporary mental health policy in many countries. User participation in community mental health services is developed through practice; from interaction between service-users and professionals working on the ground level. Despite this, there is a lack of research exploring users' and professionals' experiences and views based on the practice of user participation. The objective of this study was to illuminate user participation in a community mental health context based on the experiences of users and professionals within the same services. A qualitative study with an explorative design was applied. Preliminary data analyses based on a field study within three community mental health centres in a Norwegian city lead to our specific focus on experiences of user participation. This theme was explored in individual interviews with 10 users and two group interviews with six professionals. This article is based on the data from these interviews. All informants valued user participation in the service and

highlighted the importance of the environment. Users and professionals did, however, highlight interesting issues of user participation from different perspectives. We developed the findings into three main themes: (i) user participation – experiences and preferences, (ii) an environment that promotes user participation and (iii) professional help, responsibility and user participation. Developing service-users' influence through participation is important, not only on the political and organisational level, but also in the contexts where users and professionals meet and collaborate. Self-determination in how to use services means that there are opportunities for receiving support without being subjected to control. Community mental health services which provide flexible, accepting environments with possibilities for both support and challenges may enhance participation and give all users possibilities to have an influence.

Keywords: user participation, community mental health, experiences of users and professionals.

Submitted 20 August 2007, Accepted 20 June 2008

Introduction

Increased user participation, which is an aim for mental health policy in several countries, signals a democratisation of the relationships between service-users and professionals. But what are the experiences of those who are expected to collaborate to make this policy work in practice? In this article, we explore how users and service-providers in the same community mental health centres experience user participation. The background for this study is our interest in the social aspects of mental health,

the experiences and views of people who live with mental health problems and relationships between users and professionals. The aim of the article is to add to our understanding of user participation by illuminating different perspectives within community mental health.

Background

The importance of social factors for mental health; both welfare conditions and social relationships, has long been established (1, 2). Research into the welfare of people with mental health problems have shown that, as a group, they are still among the most socially excluded in society (3, 4). A process of closing or downsizing psychiatric institutions has taken place in many countries in the western world. This re-organisation of services is intended to enhance social integration and inclusion for persons with mental health

Correspondence to:

Toril Anne Elstad, Sør-Trøndelag University College, Faculty of Nursing, Postmottak, N-7004 Trondheim, Norway.
E-mail: toril.elstad@hist.no

problems (5–7). A central challenge for contemporary mental health policy is to develop community services which support people in their life situation in the community. This gives persons with mental health problems increased rights and responsibilities compared to being patients in psychiatric institutions (8). Implicit in this policy are also the expectations that users of community mental health services shall be active participants. In a recent report (5–7, 9), the Norwegian Department of social and health affairs states the following about user participation in mental health:

‘Users have the right to participate and at the same time user participation has a value in itself, a therapeutic value and is a means to enhance the improvement and quality assurance of the services’. (...). ‘User participation – whether it is on the systems – or individual level – means that the user participates in shaping the service together with professionals’.

User participation, as the term is applied to the mental health area, is about users having an influence on the services they use. Believing that one has some control in one’s life situation, as opposed to feeling helpless (10) can be important for mental health and for experiencing life as meaningful. Antonovsky (11), for example, describes this as part of having a ‘Sense of Coherence’. Increasing users’ rights to have an influence on services has been described as ‘empowerment’, which has been linked to both the ideals of collective social action and to ‘individualistic consumerism’ (12). User involvement in a system has also been described as a continuum, depending on how much power the user has (13). This model incorporates individualist and collectivist traditions, ranging degrees of users’ involvement from being informed, consulted, in partnership through to having user control.

Discussions of individual vs. collective aspects of user participation can also be seen in the light of social scientific theories about relationships between lifeworld and system. Layder (14: 8), for example, claims that everyday worlds, social activity, the nature of social relationships, the organisation of settings and its wider contexts are partly independent realms which are ‘(...) fused in different ways’. How individuals’ unique experiences and interpersonal relationships are influenced by and have an influence on social situations also raises important questions for health-care research and theory. For example, how does user participation on the individual level relate to users’ right, as a group, to have influence on the organisation – and development of mental health services? Is it meaningful to rank user participation from the individual level through to the collective level, or should these perspectives be considered as separate, equally important and intertwined domains (14)?

Research and evaluations have shown great variation in how different mental health services live up to the ideals of user participation (15–17). Some studies have also found variations in users’ preferences for participation in deci-

sion-making (8, 18). Nelson and Lomotey (19) found that members of consumer-run organisations participated most often in social and recreational activities and less in ‘external’ activities. In a study by Truman and Raine (20) users of a community service appreciated working towards their personal goals, mixing with others and helping others. Connor and Wilson (21) identified person-centred care, appropriate professional training, information and peer support as valued by the users. Saeterstrand (22) found professionals’ expertise in communication and attitudes towards co-operation with users to be decisive for the implementation of user participation.

Although the term is frequently used and discussed, what user participation may imply in practice for users and professionals is, however, not always clear (23–25). Aims of user participation can be vague and may have different meanings depending on one’s perspective, which makes the degree of user participation in services difficult to evaluate (26). A report from the Mental Health Commission New Zealand (27: 6) states that a weakness in discussions about service-user participation is that it tends to focus on the service or systems level and not on individual service-users’ relationships with mental health workers while receiving a service:

(...) There is little consistency in the way policy makers, funders, providers or mental health workers think about, plan for and ensure participation. Reasons for this inconsistency include the lack of clarity and consensus about what service-user participation really means, and the contexts and competencies that are necessary to support it.

Policy documents and organisational structures are frameworks which may or may not facilitate user participation in mental health services. Knowledge based on the experiences of persons with mental health problems who are users of community mental health services is an important aspect of understanding user participation. For many persons with long-term mental health problems, being users of community services is part of everyday life. The experiences and views of the professionals with whom they interact are also important, partly because their mental health work directly affect the users in their life situation and also because this may indirectly illuminate the ideology that ‘surrounds’ the users (28, 29).

User participation as practice in community mental health is developed through interactions between users and professionals. Despite this, there is a lack of studies based on the experiences of both these groups within the same services. Bringing the two perspectives together in one study can contribute to our understanding of the conditions for user participation and the development of user participation as practice. The objective of this study is to add to our understanding of user participation by exploring the experiences of users and professionals within a community mental health service.

Method

This study was developed and conducted during participant observation as part of a field study within three community mental health centres. Observations of mental health work and users' participation within the service led to our interest in gaining more insight into the meaning of user participation from the perspectives of both users and professionals. Users' experiences were explored in individual interviews in order to illuminate the meaning of participation in community mental health centres in their daily life situations, while group interviews were chosen as method for studying professionals' experiences of user participation as part of their mental health work. Open-ended interview guides with user participation as one main theme were used in both types of interviews. All interviews were conducted by the first author from May 2005 to March 2006.

The research context

Data were collected in three community mental health centres which are part of the municipal services in a Norwegian city of approximately 150 000 citizens. These centres were chosen as a research context because, in line with current mental health policy, to enhance user participation is a central aim for the service. The centres are located within or just outside the city centre, close to shops, flats or offices. In the local municipal plan for community mental health services, the centres are described as 'meeting places' and 'low threshold services' which can be stepping stones towards rehabilitation for some users and mainly an arena for social contact for others. Users choose how and when to use the centres. Registrations made in 2002 showed that the three centres had 215 regular users and were visited each day by an average of 66 persons.

Ethical considerations

The study was approved by the regional branch of the National Committees for Medical Research Ethics. Access to the research context was given by the medical officer in charge. A principle followed throughout the study was to conduct the research in a nonintrusive manner (30). This is important, particularly in qualitative studies within health services, where users may feel pressurised to participate because of dependency of the service. The first author conducted information rounds in open meetings at the centres during the autumn of 2004. Written information was put up on information boards and the staff informed new users about the project. All those interviewed gave their informed written consent beforehand. Names are fictional and informants' ages are not included in the article to secure anonymity.

Procedure and participants

Individual interviews with service-users were conducted as a process during a 7-month period of fieldwork; aiming to facilitate the participation of persons who wished to share their experiences but who might not otherwise have come forwards as informants. The criteria for participation were (i) to be a user of one of the centres and (ii) to have an interest in sharing this experience. We also aimed to illuminate different aspects of user participation by exploring variations in experiences (31, 32). Based on preliminary analysis, the first eight interviews contained varied descriptions of user participation. However, in order to obtain a gender balance as well as to have all three centres represented, two more interviews were included. A total of five women and five men (40–60 years), all regular users of one of the three centres, were included in the study. Reading through all the 10 interviews, we identified detailed descriptions of a wide range of experiences illuminating the theme of user participation from the perspective of service-users.

At these centres no medical records are kept, as the aim is to support the users in their life situations. Both due to the research context and the purpose of the study we did not ask about diagnoses or treatment. However, during the interviews all users volunteered information about earlier treatment from mental health services. The interviews with service-users were not tape recorded, both for ethical and methodological reasons. Some informants said that this would make them feel uncomfortable, and we wanted to avoid using disturbing interview techniques as well as to have a transparent research process (33, 34). We also had the background knowledge that many who have been patients in psychiatric hospitals have experienced being written about without having a say about the content of their medical journals (35). Notes taken were summoned up for the informants during the interview (34, 36). Seven informants also read and commented upon their interview text. This procedure, described as member-checking, adds to the transparency of the research process and can be considered as a validity-measure (36). Three informants were not available for re-interviews.

The selection criteria for the group interviews with professionals were to have worked at one of the centres for 1 year or more and to have previously worked in an institution. Our intention was to interview experienced professionals with a variety of work experiences. We also wished to include professionals from all the three centres. Five women and one man (40–60 years), two from each centre, volunteered to participate. This mirrored the gender difference among professionals within these services. The professions of occupational therapy, nursing and social education were represented, either on the upper secondary or university college level. All had an additional year of specialised mental health education. Their work

experiences at the centres averaged 7 years and work experiences from institutions ranged from 8 to 18 years. Both group interviews were tape recorded and lasted for 1½ to 2 hours. The interviews were conducted by the first author. The second author was an observer in the first interview to aid in our discussions during data analysis.

Data analysis

The general perspective behind the analysis is inspired by principles of grounded theorising applied to ethnographic studies as described by Hammersley and Atkinson (31: 158). This study was developed during preliminary analysis of data from a field study (31). User participation was described in documents about the service and it was also a regular topic during meetings and field conversations. Different views and understandings expressed awoke our interest in exploring this theme further in interviews. In order to illuminate different experiences, user participation was analysed thematically across all the interviews (36, 37). The full text from the 10 individual interviews with service-users was read several times. Next, all the text on user participation was identified and marked in each interview. The data from both group interviews with professionals was analysed similarly, but with an additional focus on discussions within the group (32). Finally, sub-themes identified were developed into three main themes across all interviews with users and professionals and the whole text was re-read to ensure that these themes represented the responses of the informants. Some early analyses were presented during meetings attended to by both users and professionals at each centre. No disagreement with our general understandings of the data material was voiced.

Findings

In this study, we asked users and professionals within three community mental health centres to describe their experiences of user participation. Three main themes were developed during the data analysis: (i) user participation – experiences and preferences, (ii) an environment that promotes user participation and (iii) professional help, responsibility and user participation.

User participation – experiences and preferences

To participate in decision-making about activities at the centre was important for most users. This included planning and deciding which activities that should be available. Jenny said: 'For me it is important that we plan activities together (...) that these are activities that we as users have decided on ourselves'. Grete underlined the importance of individuals' personal choice about which activities to participate in: 'The professionals are important as motivators.

But it is good that they do not make decisions for us ... that we decide for ourselves and can fall down on something that feels right for us'. Some users who described themselves as not very active for the time being also appreciated knowing that there were possibilities for user participation. David put it this way: 'I am not very active in that area, but it is good that it is possible for those who want to, to participate in decisions about activities'.

All users who responded to the following question: 'Do you have user-participation here at the centre?' gave positive answers. Some did, however, underline the importance of understanding that having mental health problems means that people can sometimes feel too anxious to take active part in activities and discussions. Jenny, for example, explained the following about the possibilities for user participation:

Yes, we have participation from users here, for example through the house meetings. We also choose user representatives who have meetings with the leaders of the centres. But it is often difficult to get people to participate as representatives. I think social anxiety may be what stops many (...) many users do not want to participate, and say 'Not another house meeting again'. Sometimes it seems as if it is more important for the staff that the users participate, than it is for the users themselves.

Maria explained the importance of having user representatives by pointing out that, although participation at the centre can strengthen people in their daily life situation, people who are users at the centres have different backgrounds and that 'contributing to making psychiatry better' demands more energy than what many people have. When asked about the possibilities for user participation at the centre, she said:

(...) we have a meeting for all once a week, which we call the house meeting. There we can raise different issues. But it is sometimes difficult to feel well enough to manage to take up things at these meetings, so we also have the possibility of leaving a written note in a box beforehand.

One question in the individual interviews was what it meant to be able to choose when and how to participate at the centres. Andreas said: '(...) it means that you do not have to account for what you do to anybody'. Some users contrasted this self-determination with experiences from previous psychiatric treatment. Hans, for example, described psychiatric hospitals as '(...) places where you can be administered all day and night', and both Grete and Jenny described experiences of feeling ignored as patients in psychiatric hospital wards.

According to the professionals, some users felt the need to use the centres for a very long time and mainly for maintaining their own quality of life, while others welcomed training and challenges: '(...) we shall motivate for that, too, but each person has to do this their own way'. As

one group participant put it: 'The most important question is how they manage to have an influence on their own life situation.' What users want to decide was described as 'very individual'. There were great variations in users' wishes to take part in decision-making and this could also vary over time for individual users. One group participant put it like this: '(...) but user participation can also be little things, like deciding what to have on the menu, or where this year's summer trip shall go to'. To take on a more formal role was understood as difficult because many users did not have much training in this area. However, a reluctance to take on the role as a representative for a group was also pointed out as normal in all organisations. One group participant gave this example: '(...) maybe, if you say something, then you are pointed at and told to take the responsibility. We know ourselves that this is not always easy. I certainly do not always dare to do these things'.

An environment that promotes user participation

The importance of keeping the centres safe and free from conflict was underlined by all the users in this study. Feeling secure was very important for Karin, who said this about her situation: 'I need a very long time to connect to people. I feel proud that I am able to come here and take part in some things. This gives me more confidence'. Other users also valued that the centres gave them possibilities for new challenges. All users interviewed said that the professionals were very important in creating an environment where everybody could be heard. Ivar welcomed increased user participation, but he also underlined the importance of the professionals' role: '(...) sometimes there can be too many bosses, so someone with authority has to cut through all this. But back to user participation: there's a big difference between shaving and cutting your head off'. Hans also emphasised the importance of keeping the environment safe and to have competent leaders, however: 'It is not so important for me whether they are users or professionals, because the important thing is that someone takes responsibility and ensures that the centre functions'.

The professionals said that an important part of their job was to create a social environment which would promote positive relationships and where all users could be heard. Sometimes users could have great difficulties in demanding their rights or even raising their voice. User participation was therefore not only an individual issue:

Someone has to see the whole group at the same time, what it is that benefits the whole group ... this sometimes disappears in discussions about user participation (...) We have to organise so that most users shall be able to have an influence. This is part of enhancing the users' social competence, and this is the

reason for us being here, - helping them to feel competent to participate in the world.

The group of professionals described user participation as important training for the users, in order to achieve confidence and to cope with everyday life. However, they also described how they sometimes experienced a dilemma when trying to motivate users to become user representatives or to be active during meetings at the centres. The group discussed this as a dilemma between, on the one hand promoting user participation and on the other hand allowing users to choose how to use the centres. Some users would at times and for different reasons prefer just to receive services and not to take an active part in decision-making. One group member put it this way:

(...) on the one hand we tell the users that this is a service free from obligations and you do not have to be actively engaged if you do not wish to. You can be here and observe for instance for half a year if you wish ... and take your own time. But on the other hand we want active participation and we spend a lot of time every day motivating and putting pressure on people ... And there is an antagonism here: the users have the possibility to participate (...) But it has also been pointed out that this is voluntary ... and that participation in decision-making is a possibility.

The main focus for the professionals was on user participation as a democratic right and collaboration between them and the users as essential in achieving this. They also described how users participate in decisions about all activities and the social milieu at the centres. However, neither they as employees on the 'ground level' nor the users had an influence on the budget. This limited decision-making about the range and type of activities. Having to discuss and make priorities was, however, also described as part of 'normalisation'.

Professional help, responsibility and user participation

Most users emphasised their needs for support as well as the right to have influence. The importance of available professional help was underlined by all. For David, this was very important in order to cope with everyday life. Both Karin and Linda emphasised very strongly that people have different needs and that many need help from professionals in addition to activities together with others. Maria said the following: 'When one is ill, one wants the staff to have good professional knowledge, so that they are able to understand what is wrong and to take care of my interests and to care for me when I need it.'

A few users discussed the focus on user participation in mental health in political terms and were critical in case this policy would turn out to be about cutbacks and the reduction of resources within mental health services. Erik, for example said the following:

One can be suspicious and think that this is really about money. It may be about participation and the responsibility that we have to take ourselves, but it may also mean that the professionals disappear and the users shall run these centres themselves. It is very nice to hear that I shall be heard, but how much valued is this really when decisions are taken in society? It may be that they ask us in order to make it all look better and that my opinions do not have any influence when real decisions are to be made. (...) Which way is this moving? Is there some kind of control over this process?

The professionals underlined the importance of clarifying what user participation means in practice. All had experienced that some users were worried in case the focus on user participation might lead to reduced support and more responsibility than what they felt able to handle. Some group participants described the concept of user participation as too vague: 'I want us to be able to define what user participation means in practice here at these centres. If we cannot do that, then I think we should stop using the word'. In a discussion, the focus on user participation was described as a positive change towards more democratic services. As one experienced group participant illustrated: 'For me it is enough to think back to the time when patients did not even have an influence on what to have on their sandwiches'. Another group participant did, however, question whether user participation could become 'just another concept made up by us professionals'.

Discussion

The aim of this study was to add to our understanding of the development of user participation in community mental health, based on the experiences of users and professionals. The research context was three community mental health centres with aims of enhancing user participation, which is also a central policy aim for contemporary community mental health services in many countries (5, 6). We therefore believe that the findings from the study may have relevance outside of the local research context (38). The study includes users who were observed not to be active during meetings or conversations at the centres. This information, based on the first authors' field notes, indicates that the recruitment of informants as a process over several months might have contributed to the inclusion of persons with mental health problems who are seldom interviewed.

The present study does, however, also have some methodological limitations. First of all, the findings can not be generalised to all persons with mental health problems living in the community. The informants in the individual interviews participate as regular users of community mental health centres. Persons who for example participate in user-led organisations may have different views. Another

important question is whether further interviews might have added substantially to our understanding of the theme of user participation. This explorative study had a focus on the experiences of regular users of community mental health centres. A different approach, including more 'peripheral' users, might have provided a broader perspective. Thirdly, users were interviewed about their individual experiences, whilst the professionals were interviewed as a group, focusing on their work experiences. The aim was to explore user participation from both these perspectives. It is, however important to bear in mind that the different interview methods used means that responses from the two groups cannot be directly compared.

All users and professionals interviewed valued user participation at the centres and also highlighted the importance of maintaining an atmosphere that promotes the participation of all users. Exploring the experiences of both these groups of informants did, however, also highlight some different perspectives of user participation. To have an influence on activities at the centres, as well as being able to use the community services according to their own felt needs was valued by all the users interviewed. Most users also emphasised that their needs for available professional help must not be overlooked when discussing user participation. Recurring themes in the professionals' discussions were user participation as collaboration between themselves and the users, as a democratic right for the users and as training to cope with everyday life in the community.

Both users and professionals underlined that some users did participate in decisions about activities and the social milieu of the centres. However, both groups of informants also described that many users were reluctant to participate in decision-making during meetings and on the organisational level. Variation in users' desire for participation in decision-making is in line with some previous findings (8, 18). In this study, the professionals described how they sometimes experienced a dilemma between motivating users to participate in decision-making while also respecting individual users' right to control their own degree of involvement. Could 'demands' for user participation on the service level exclude persons who do not feel able to be actively involved in decision-making? Or, on the other hand, could a focus on individual self-determination within services reduce user participation on the systems level? Such questions highlight some important challenges for policy-makers as well as for users and professionals who are expected to collaborate and further develop user participation as practice within community mental health services.

All informants among the users highlighted the importance of self-determination in how to use the service. This provides possibilities to define one's own needs and to receive support without being subjected to control or surveillance, as some users underlined. Research on people's experiences of recovery from mental health problems

has highlighted the importance of being regarded as persons who are worth listening to and who are able to express their own goals (39). Experiences of having an influence on one's life situation can enhance feelings of self-respect, self-confidence and a positive identity; factors which contribute to positive mental health (11, 20, 33). Such issues, which were important for the informants in this study, relates to individuals' experiences from participation in situated activity and social interaction on the 'micro-level' (14). However, some users in this study were also concerned that the focus on user participation might imply reduced services and some professionals were concerned that unless user participation is properly defined, it might become an empty phrase. These findings also illustrate the importance of clarifying what user participation may mean both on the individual and organisational level, as well as the degrees of users' involvement that are possible within particular services.

User participation can be viewed as one single process, ranging from the level of individual service-users through to user control over services (13). This model is useful for planning and research into the organisation of mental health services. However, degrees of user participation and influence on the individual level should not be viewed as at the bottom of a hierarchy in general. As this and other studies have found, processes on the 'ground level' of services, like face-to-face interaction and participation in activities, can be of central importance for users of mental health services in their life-situations in the community. Processes on the micro- and macro-level can be viewed as both separate and intertwined (14) and an important question is how services can be responsive to users' rights on both levels. There is a need for greater clarity about what user participation means in practice, for example what competencies and contexts that are necessary to facilitate it (27). These are important areas for further research.

Conclusions and implications for services

Flexible community mental health services which are responsive to users' experiences may enhance the participation of persons with different needs for support and challenges. Users' experiences should have an influence on community mental health work on the ground level as well as on service development. These levels of user participation are equally important to develop within community mental health services. Hopefully, such processes may also support the social inclusion of people with mental health problems as a group in society.

Acknowledgements

We wish to thank all the informants for sharing their experiences.

Author contributions

Toril Anne Elstad designed the study, carried out the data collection and main data analysis and drafted the manuscript. Arne Henning Eide and Toril Anne Elstad discussed the analysis and findings and both provided critical revisions of the manuscript for important intellectual content.

Funding

The study was carried out as part of the first author's PhD-project, which is financed by the Faculty of Nursing, Sør-Trøndelag University College.

References

- 1 Pilgrim D, Rogers A. *A Sociology of Mental Health and Illness*, 3rd edn. 2005, Open University Press, Buckingham & Philadelphia, PA.
- 2 Sayce L. *From Psychiatric Patient to Citizen. Overcoming Discrimination and Social Exclusion*. 2000, Palgrave MacMillan, Houndmills, Basingstoke, Hampshire & New York.
- 3 Huxley P, Thornicroft G. Social inclusion, social quality and mental illness. *Br J Psychiatry* 2003; 182: 289–90.
- 4 Pilgrim D, Rogers A. *Mental Health and Inequality*. 2003, Palgrave MacMillan, Houndmills, Basingstoke, Hampshire & New York.
- 5 World Health Organisation. *Mental Health: New Understanding, New Hope. World Health Report*. 2001, World Health Organization, Geneva.
- 6 Sosial-og helsedepartementet. *Åpenhet og Helhet. Om Psykiske Lidelser og Tjenestetilbudene (Openness and Comprehension. Mental Illness and Mental Health Services)*. St. meld. nr. 25 (Norwegian Government White Paper). 1996–1997, Sosial-og helsedepartementet, Oslo.
- 7 Sosial-og helsedepartementet. *Om Opptrappingsplanen for Psykisk Helse (Norwegian Government's Plan for Mental Health Services)*. St. prp. nr. 63. 1997–1998, Sosial-og helsedepartementet, Oslo.
- 8 Lammers J, Happell B. Consumer participation in mental health services: looking from a consumer perspective. *J Psychiatr Mental Health Nurs* 2003; 10: 385–92.
- 9 Sosial-og helsedepartementet. *Brukermedvirkning – Psykisk Helsefeltet. Mål, Anbefalinger og Tiltak i Opptrappingsplan for Psykisk Helse (User Participation in Mental Health. Aims, Recommendations and Initiatives in the National Plan for Mental Health)*. Rapport IS-1315. 2006, Sosial-og helsedirektoratet, Oslo.
- 10 Davidson L. Recovery, self-management and the expert patient – changing the culture of mental health from a UK perspective. *J Mental Health* 2005; 14(1): 25–35.
- 11 Antonovsky A. *Unraveling the Mystery of Health*. 1987, Jossey-Bass, San Francisco, CA.
- 12 Masterton S, Owen S. Mental health service user's social and individual empowerment: using theories of power to elucidate far-reaching strategies. *J Mental Health* 2006; 15(1): 19–34.
- 13 Hickey G, Kippings C. Exploring the concept of user involvement in mental health through a participation continuum. *J Clin Nurs* 1998; 7(1): 83–88.

- 14 Layder D. *Sociological Practice. Linking Theory and Social Research*. 1998, Sage Publications, London, Thousand Oaks, New Delhi.
- 15 Crawford MJ, Aldridge T, Bhui K, Rutter D, Manley C, Weaver T, Tyrer P, Fulop N. User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. *Acta Psychiatr Scand* 2003; 107(6): 410–4.
- 16 Rutter D, Manley C, Weaver T, Crawford M, Fulop N. Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Soc Sci Med* 2004; 58(10): 1973–84.
- 17 Sverdrup S, Kristoffersen LB, Myrvold TM. *Brukermedvirkning og Psykisk Helse (User Participation and Mental Health)*. NIBR-Rapport nr. 6 (Norwegian Institute for Urban and Regional Research, Report no. 6). 2005, NIBR, Oslo.
- 18 Hill SA, Laugharne R. Decision making and information seeking preferences among psychiatric patients. *J Mental Health* 2006; 15(1): 75–84.
- 19 Nelson G, Lomotey J. Quantity and quality of participation and outcomes of participation in mental health consumer run organizations. *J Mental Health* 2006; 15(1): 63–74.
- 20 Truman C, Raine P. Experience and meaning of user involvement: some explorations from a community mental health project. *Health Soc Care Community* 2002; 10(3): 136–43.
- 21 Connor SL, Wilson R. It's important that they learn from us for mental health to progress. *J Mental Health* 2006; 15(4): 461–74.
- 22 Saeterstrand TM. Interaction and user participation in the field of district psychiatry. *Vård i Norden (Nurs Sci Res Nord Ctries)* 2004; 24(3): 26–30.
- 23 Minett R. User participation in mental health care: a literature review. *Br J Ther Rehabil* 2002; 9(2): 52–55.
- 24 Hodge S. Participation, discourse and power: a case study in service user involvement. *Crit Soc Policy* 2005; 25(2): 164–79.
- 25 Stickley T. Should service user involvement be consigned to history? A critical realist perspective *J Psychiatr Mental Health Nurs* 2006; 13: 570–7.
- 26 Hofseth C. *Brukermedvirkning i Psykiatrien – Fra Politikk til Praksis (User Participation in Psychiatry – from Policy to Practice)*. 2000, SINTEF Unimed Helse og rehabilitering (SINTEF Living Conditions and Service Delivery Research), Oslo.
- 27 Mental Health Commission New Zealand. *Service User Participation in Mental Health Services. A Discussion Document*. 2002, Mental Health Commission, Wellington.
- 28 Prior L. *The Social Worlds of Psychiatric and Ex-Psychiatric Patients in Belfast*. 1991, The Queen's University of Belfast Health and Health Care Research Unit, Belfast.
- 29 Prior L. *The Social Organization of Mental Illness*. 1993, SAGE Publications, London, Newbury Park & New Delhi.
- 30 Guillemin M, Gillam L. Ethics, reflexivity and 'ethically important moments' in research. *Qual Inq* 2004; 10(2): 261–80.
- 31 Hammersley M, Atkinson P. *Ethnography. Principles in Practice*, 3rd edn. 2007, Routledge, London.
- 32 Holloway I (ed.). *Qualitative Research in Health Care*. 2005, Open University Press, Berkshire & New York.
- 33 Bergem R, Ekeland TJ. Identitet og integrasjon Menneske med psykiske lidinger i små samfunn (Identity and integration. Persons with mental illness in small communities). *Tidsskr Velferdsforskning* 2004; 7(2): 64–77.
- 34 Holstein JA, Gubrium JF. *The Active Interview*. 1995, Sage Publications, Thousand Oaks, CA.
- 35 Kristiansen K. Owners of chemistry, hope and evidence. In *Resistance, Reflection and Change. Nordic Disability Research* (Gustavsson A, Sandvin J, Traustadottir R, Tøssebro J, eds), 2005, Studentlitteratur, Lund, 89–103.
- 36 Kvale S. *InterViews. An Introduction to Qualitative Research Interviewing*. 1996, Sage Publications, Thousand Oaks, CA.
- 37 Weiss R. *Learning From Strangers. The Art and Method of Qualitative Interview Studies*. 1994, The Free Press, New York.
- 38 Kristiansen S. Det kvalitative kontinuum – om data og teoriutvikling i kvalitativ sosiologi (The qualitative continuum – on data and theory development in qualitative sociology). In *Liv, Fortælling, Tekst. Strejftog i Kvalitativ Sosiologi (Life, Narrative, Text. Incursions in Qualitative Sociology)*, 2nd edn (Jacobsen MH, Kristiansen S, Prieur A eds), 2005, Aalborg Universitetsforlag, Aalborg DK.
- 39 Borg M. *The Nature of Recovery as Lived in Everyday Life: Perspectives of Individuals Recovering from Severe Mental Health Problems*. (PhD thesis). 2007, Norwegian University of Science and Technology, Trondheim.

Paper 4

FEATURE ARTICLE

Community mental health centres: A qualitative study of professionals' experiences

Toril Anne Elstad^{1,2} and Ove Hellzén^{3,4}

¹Faculty of Nursing, Sør-Trøndelag University College, Trondheim, ²Institute of Social Work and Health Science, Norwegian University of Science and Technology, Trondheim, ³Faculty of Health Science, Nord-Trøndelag University College, Namsos, and ⁴Centre for Care Research Mid-Norway, Steinkjer, Norway

ABSTRACT: This article presents findings from a qualitative study of mental health work in community mental health centres with a multiprofessional workforce and aims of active user participation in the service. User participation implies collaborative relationships and different roles than that of expert professionals and dependent patients. How do professionals working in these services experience their work and professional role? This question was explored in order to highlight important aspects of community mental health work. A group of six experienced professionals from three community mental health centres in a Norwegian city were interviewed twice. The informants highlighted the complexity of community mental health work and the need to be flexible when working to support people with mental health problems in their everyday life situation. To see the service users as people and to facilitate social interaction was important. Their work was described as 'liberating' compared to working in institutions. However, although in their experience they found that professional knowledge and skills were important in their work situation, all had experienced that this was not always acknowledged by professionals in other services.

KEY WORDS: community mental health centres, professionals' experiences, work role.

INTRODUCTION

The encouragement for active user participation in the development of mental health policy has seen an increased focus on collaboration and the development of partnerships between service users and professionals within community mental health services (Dowling *et al.* 2004; Jubb-Shanley & Shanley 2007; Roper & Happell 2007; Rose 2003; Shanley *et al.* 2003; Sharkey 2002). According to Davidson (2005), help, such as treatment or medication, is only one part of maintaining wellness and recovery. Supporting people with mental health problems

in their daily lives requires a broad perspective, including psychosocial rehabilitation, user involvement, and a person-centred approach (Anthony *et al.* 2002; Corrigan *et al.* 2008; Davidson 2005; Hellzén & Asplund 2006; Lauder *et al.* 2006; Spaniol *et al.* 1997). Discussing 'empowerment', Masterton and Owen (2006) highlight the necessity to develop collaborative partnerships between professionals and service users, allowing users of mental health services to define their own situations and set the agenda for their care and treatment.

Mental health policy, the organization of services and the prevailing ideology are all part of the framework that surrounds and influences community mental health work and the relationships between service users and professionals (see Prior 1993). The roles of service users and professionals are developed through interaction within practical contexts. Lipsky (1980), for example, developed the concept of 'street level bureaucrats' when describing

Correspondence: Toril Anne Elstad, Faculty of Nursing, Sør-Trøndelag University College, Postmottak, 7004 Trondheim, Norway. Email: toril.elstad@hist.no

Toril Anne Elstad, RGN, RPN, MSc.

Ove Hellzén, RN, PhD.

Accepted July 2009.

professionals' important role as gatekeepers in their face-to-face encounters with clients, arguing that their roles must be examined in order to understand the implementation of public policy. Changing relationships from traditional roles as experts versus passive recipients of care towards collaborating partners imply less control and power for mental health professionals and more control and responsibility for service users. According to Manning *et al.* (2000, p. 134), the most important lesson learnt from a resource centre based on empowerment theory has been that the professionals have to 'learn to let go of power gracefully', while 'consumers must learn to handle power'. Roper and Happell (2007, p. 85) highlight the important role of psychiatric nurses in ensuring opportunities for genuine user participation; however, 'the literature suggests that this role is not always realized in practice'. Wilson *et al.* (2006; 2007) ask whether some health professionals might feel their sense of professional responsibility and accountability threatened when dealing with increasingly active patients.

Following the deinstitutionalization of mental health services, an important question is whether community mental health work is developing a new knowledge base and new roles or if traditions based on treatment within institutions still prevails. In a study of staff involved in the transition from a psychiatric hospital to community-based services, Carpenter *et al.* (2000, p. 211) found 'very significant changes' towards more community-oriented practices reported after 1 year of working in the new services. Community mental health nurses have identified the concept of 'quality of life' (Clark 2004), as well as the principle of patients' rights to self-determination (Høgberg *et al.* 2006) as central to their practice. It has also been identified that nurses working in community mental health services and rehabilitation settings (Bertram & Stickley 2005; Hellzén 2004; Hellzén & Asplund 2006) display paternalism and a lack of person orientation. Lilja and Hellzén (2008, p. 284) interpreted former inpatients' experiences from psychiatric care as 'a struggle for dignity in the face of discrimination and rejection'. Based on a study of 'rehabilitation relationships', Finaret and Shor (2006) identified a need for flexibility and professional knowledge in psychiatric rehabilitation services, concluding that, as the field of mental health is in a process of change, psychiatric rehabilitation needs to be studied as a unique area of practice. Research based on mental health service users' experiences have identified professionals' interpersonal skills, experience, person orientation (Adam *et al.* 2003; Scanlon 2006), and 'recovery orientation' (Borg & Kristiansen 2004) to be helpful. Happell (2008a,b) identified

support from staff and peers as influential factors for recovery, and isolation and lack of safety and security as barriers. To receive professional help without being subjected to control was appreciated by the service users interviewed in another part of the present research project (Elstad & Kristiansen 2009).

The development of community mental health work on the ground level, including the competencies and skills that are necessary to support user participation, needs to be clarified (Mental Health Commission New Zealand 2002). Changes that have occurred in mental health policy and organization demand a shift in mental health professionals' work roles towards more collaborative relationships with service users. How do professionals working in community mental health services with aims of increased user participation describe their work and professional role? The aim of this study is to explore such questions, based on the experiences of professionals working in multiprofessional community mental health centres called 'meeting places'.

METHOD

The aim of this study was to explore professionals' experiences of their work and professional role, in order to highlight important aspects of contemporary community mental health work. Group interviews, inspired by focus group methodology (Kitzinger 2005) and a 'multistage focus group' approach (Granerud & Severinsson 2007; Hummelvoll 2008), were chosen as the data collection method. Collecting data through focus groups is considered to be a fruitful research method when aiming to illuminate experiences and attitudes. A research topic is explored through interaction between people purposively selected for their experiences with the research topic (Kitzinger 2005; Krueger & Casey 2000). In this study, focus group methodology was considered to be a useful approach in order to explore different aspects of community mental health work based on the experiences of professionals. According to Kitzinger (2005), attention to group interaction should be part of focus group methodology, but the relative weight given to the text and observations vary between different analytic perspectives. Although the main focus in this study is on the content of the informants' discussions and responses, issues of consensus and variation within the group are included in the findings. The study is part of a research project based on fieldwork, including participant observation and individual interviews with service users, which were conducted within three community mental health centres in a Norwegian city. Field notes based on the first author's

observations and reflections about the professional role in these settings provided background knowledge for the development of the present study (see Hammersley & Atkinson 2007).

Ethical issues

The research project was approved by the Regional Committee for Medical Research Ethics in Mid-Norway and the Norwegian Social Science Data Services. The medical officer in charge of the service permitted access to the setting. Information rounds for service users and staff were conducted as a process during fieldwork at all three centres, and written information about the research project was handed out and put up on information boards. The informants gave their written informed consent beforehand and are referred to by letters (A–F) in order to be both anonymous and sex neutral. For the same reason, only the age range within the group is presented. The professionals interviewed in this study represent more than one-third of the employees in this particular service. To preserve anonymity, the number of informants representing each profession is not included in this paper.

Study context

The study was conducted within three centres, which are part of the municipal community mental health services in a Norwegian city of approximately 150 000 citizens. The centres are located in residential or business areas within or close to the city centre, and are called 'meeting places' for people with mental illness living in the community. According to the municipal mental health service plan, central aims for the centres are to support service users in their everyday life situation and to enhance their personal growth, confidence, and feelings of safety in their social environment. Some visit the centres most days, while others drop in occasionally, and although participation in activities is encouraged, it is not a prerequisite for using the service. There are no intake procedures and no medical records are kept at the centres. The centres have a multi-professional workforce that aim to provide a variety of professional knowledge in order to support people with mental health problems in their daily life situations. The professionals do similar work, but also aim to employ their particular professional knowledge and skills according to the situation and individual service users' needs. Service users' social inclusion in their community, as well as user participation in shaping the service, is a central aim. Such aims are in line with contemporary community mental health services in many countries (WHO 2001). The findings from this study should, therefore, have relevance outside of its local context.

Participants and procedure

In order to recruit people experienced in mental health work to reflect upon their own practice, the selection criteria for this study were: (i) to have worked at one of the centres for 1 year or more; and (ii) to have previous experience from working in an institution. Five women and one man, aged 40–60 years, volunteered to be interviewed. The group of informants represented the disciplines of occupational therapy, nursing, and social education, either on the upper secondary or university college level. All six had an additional 1 year or more of specialized education, most in mental health work. Their work experience at the centres ranged from 4 to 10 years, with an average of 7 years. Previous work experiences included psychiatric hospitals, nursing homes, and institutions for people with learning disabilities, ranging from 8 to 18 years, with an average of 14 years.

The same group was interviewed twice in the spring of 2006. Both interviews took place at one of the centres and were conducted by the first author. A colleague participated as an observer during the first interview and in the preliminary analysis and preparations for the second interview. Each interview lasted for 1.5–2 hours. An open topic guide was used in order to facilitate group discussions, as well as keep focus on the main research question: Could you describe your work at the centres? Both interviews were taperecorded and transcribed by the first author. The informants read the interview transcripts after they had been translated from an oral to a more verbatim language. This was to ensure that the participants' meanings had not been altered during this process and to safeguard anonymity within the research context. In addition, this procedure facilitated a relatively open research process.

Data analysis

During the interviews, the first author asked clarifying questions to determine that the informants' meanings were fully understood. According to Kvale (1996), this is an early analytic step. The interview responses were transcribed and then modified for correct grammar, while ensuring the meaning was unaltered (Kvale 1996). The full text from the first interview was read several times and notes were written down, in order to obtain an overview and early understanding. Second, the whole text was read line by line, identifying and marking out preliminary themes. These themes were summarized and presented orally to the participants at the start of the second group interview. The second interview was conducted and analyzed similarly. Following this, both interviews were first read through and then the full text was searched for

themes that illuminated the informants' experiences from their work and of their professional role. These themes were then categorized and developed into higher-order themes, which serve as headings in the presentation of the results from the study. Finally, the full text from both interviews was read, checking that the identified themes covered the main issues from the informants' discussions and individual responses.

RESULTS

To explore the informants' own descriptions and discussions based on their experiences, the interviews started with the following, broad research question: Could you describe your work at the centres? Other topics related to how they experienced their professional role. The main themes developed in the analysis were: (i) to be consultants, supporters, and carers in daily life; (ii) to really see the person and facilitate social contact; (iii) a liberating role; and (iv) expectations from and attitudes of other health-care professionals. The first two themes present the group of informants' descriptions of their work, while the next two relate to the professional role. The findings are illustrated by extracts from the group's discussions and some individual responses.

To be consultants, supporters, and carers in daily life

An important theme in the informants' discussion was the varied nature of the job. Being ready to respond and give support at the spur of the moment and according to different people's needs was highlighted as an important part of their work. This meant that they had to be flexible and use non-bureaucratic solutions in order to help sustain an independent life situation in the community for service users. 'Support' was described as practical help, as well as problem solving related to social relationships and more emotional day-to-day experiences. Responding to the main research question: Could you describe your work at the centres? One informant (A) spontaneously answered: 'Everything! We are a kind of consultants for most things in everyday life'. This theme was further explored in the interview, as illustrated by this extract from the discussion:

D: I agree . . . we deal with everything that goes on in people's daily lives . . . there are not many who come to us with the things that go well. It is very much about problem solving of some kind.

A: Yes, and I think that it is often about things that are experienced as very big problems in the user's life there

and then, but once we sit down and relax, and you tell the person that it is really just to make a phone call and then you can get this sorted out quite easily . . . It may feel like a big problem when they come here in the morning, saying that they should have paid their bill yesterday, but we can calm down the situation by helping them to make a call, asking if it is ok to pay the next day, and then it is all ok.

E: These can be things that we may think of as small, but they are not small matters for those who are not able to do them. We need to understand what it is that sometimes make things so difficult to handle.

During the field study, the first author observed how professionals participated in 'daily talk' at the centres as ordinary conversation partners, but also often seemed to consciously focus on subjects that enabled users to show their resources. In the interview, the informants described how ordinary conversations often would contain therapeutic support. Although they felt that their work contained elements of both rehabilitation and milieu therapy, the group agreed that mental health work at the centres lacked a clear definition.

To really see the person and facilitate social contact

A further central theme in the focus group discussion was about seeing individual users as people and making sure that they felt welcome. According to one participant (F), this could be as simple as 'showing that you really see the person who comes in through the door'. Others underlined and elaborated upon this:

B: I am conscious of greeting people by their name, so that each person feels especially welcome.

E: Yes, this is essential. It is what we teach all students that come here, too . . . to stop for a few seconds and to look at the person . . . not to just say 'hello' and walk away.

In addition to being conscious about seeing and greeting each person, the informants all agreed that to enhance service users' self-esteem by focusing upon their resources was a very important part of their work. As B put it:

To facilitate situations where people can experience that they cope with things, so they can grow through the challenges that they get . . . and that this may strengthen their self-esteem . . . I think that this is a very important part of what we do. We have very many examples of this through the years: people have been strengthened by participating at the centre and getting challenges that are appropriate.

It was important that the professionals were present in the social environment, as it was their responsibility to facilitate active participation and social inclusion for all users. An important part of this work was described as knowing when to intervene in a social situation and when to withdraw from it. A statement from one informant, which was followed by agreement from the rest of the group and a lively discussion, serves as an illustration:

B: I think that the centre first and foremost is a social meeting-place, where a primary aim is that people shall get contact with one another and us that work there . . . I often think that the service users may become too interested in us, as if all conversation should go through us. Then it is important to try to help include others, so that the conversation can go more across . . . not just back and forwards between us and the users, and when the talking flows easily and people have good contact . . . then we can be conscious about withdrawing a little from the situation because there and then there is no need for us.

A liberating role

One question posed to the group was how they experienced working at the centres compared to their previous experiences of working in institutions. One informant told the following story about starting to work at the centre after working for a number of years in psychiatric hospitals and being accustomed to reading medical journals and attending treatment meetings:

B: It was about 'getting under people's skin': knowing almost all about their lives before you met them. Here, we do not read any journals or documents. We do not have access to these. So to have to meet the users without knowing anything about them was an unusual situation and a great challenge for me, but this has been a very good experience . . . the person has become much more visible for me. Before they were in a way patients, but here things became different; you saw the person and not the symptoms or a diagnosis. . . . When you are not seen as a 'case', your resources are more visible, but I can still use my professional knowledge to understand the person without necessarily reading any journal and this has been a very valuable experience for me. (*Exclamations of agreement from the rest of the group.*)

D: I agree. It is very liberating not to know anything about the users before they come here.

B: I think this can be about learned helplessness, as well as having low expectations towards the person. You become a bit blind when you work in an institution. We see this clearly when people come to us, who are connected to a psychiatric institution. For example, one user is obviously not permitted to have control over his money.

If he is going to pay for something, he gives us an envelope with the money inside. This is stigmatizing. It is important to have a purse and be able to handle one's own money.

This discussion then focussed on the relationship between service users and professionals in an institutional setting compared to a community mental health setting. Although their previous work experiences from psychiatric institutions varied, there was a consensus in the group that working outside of institutions provided opportunities for more egalitarian and person-oriented relationships between service users and professionals. Informant E described experiencing a gradual process of learning to let go of control and to let service users take more responsibility this way:

I am not sure if I would have been able to work at this centre if I had not had work experience from the local psychiatric institution beforehand. I came there from working in a locked ward where you had learned to behave in a certain way . . . a very special environment within psychiatry, where you took all responsibility.

Expectations from and attitudes of other professionals

A topic by the researcher was introduced to examine what professionals in other mental health services expected from them. This question was followed by a discussion where the informants gave examples of high and low expectations from other professionals in institutions, as well as in primary care: high expectations that they should solve problems there and then, but sometimes low expectations towards and views about their professional knowledge and experience. All the informants described situations where they were met by great expectations, as the following example illustrates:

C: It is often like this at our centre now . . . that we are expected to solve everything. Even if service users are very ill, it is expected that we shall handle the situation . . . then you make a lot of phone calls, and you can't get help. . . .

B: . . . They drive someone to the centre, a person who is unwell . . . for example, on a Friday at 2.00 PM.

Researcher: Are these tasks defined as the responsibility of the centres?

B: No, no it's not. It probably has more to do with the fact that primary care sometimes is in a pressurized situation . . . and then they pass the problem on.

However, when contacting other services on behalf of users who needed more help, they sometimes felt that

they were not taken seriously as professionals, an attitude exemplified this way by A: 'You who work at a community mental health centre, you don't know anything about this'.

This experience of not always being recognized as a knowledgeable mental health worker was shared. Such attitudes could come from professionals working in psychiatric hospitals, as well as in other parts of primary care. As participant B put it:

Many have a one-dimensional view of the centres, but this is a very exciting workplace, which gives us great opportunities to get to know people and to do something positive in their everyday lives.

The interviewer asked if they felt that there was a difference in status between specialist psychiatric services and community care. This was confirmed by all the informants. One (A) commented: 'Yes, low threshold services and low status, you know'. However, when meeting professionals from other services face-to-face together with a service user, some found that they were taken more seriously. When asked whether working to enhance user participation could imply a work role that others viewed as less 'professional', A said:

Yes, and this is a very important issue. This is what we experience daily from some professionals who work within treatment or rehabilitation, which we are not supposed to be doing and that may be the reason for this view of our work. We have a different role. We are more on the same level as the users and this is the way we work. Our professional knowledge is still with us, but we do not show it all the time in our work-role. . . . This may be the reason why some others who work in institutions or with individual treatment sometimes don't see what we are doing and why some don't think that we have any professional knowledge.

F: Yes, we don't show our knowledge in the same way, that's what lies behind these attitudes . . . and we don't document what we do . . . so there is nothing written left behind by us.

Following this discussion, the informants appeared thoughtful. D said: 'By stating so clearly that we do not do treatment, I think maybe we have reduced our status'.

B: But I think this has to do with the fact that we decided that these centres should be places where the users could come without feeling that they were being observed . . . which is important because they are observed in all other parts of the system.

Researcher: If you were to start documenting in the same way, as it is done in other parts of mental health services, what would happen?

F: Many of the service users would then stop coming.

This remark was followed by E, who made a comment that some service users recently had complained about being 'observed' by students visiting one of the centres.

DISCUSSION

This study's aim was to add to a knowledge base about community mental health work and the professional role in community mental health centres, based on the experiences of professionals within a service with a flexible organization and aims of active user participation. The two main themes explored were how professionals in community mental health centres described their work and their professional role. The informants actively discussed and openly shared their experiences, giving several examples from their work situations.

Methodological considerations

As with other qualitative research, the findings from this study cannot be generalized in a traditional sense. The study was conducted in a context with relatively few employees, and only one group of professionals was interviewed, both for pragmatic and for methodological reasons. In our experience, the two-stage interview procedure combined with background knowledge from participant observation facilitated an in-depth exploration of important aspects of community mental health work. This study was conducted in an urban area. Professionals working in community mental health services in rural areas may have different work experiences. Findings from this study cannot be directly compared to professionals' experiences from community mental health centres in general, as the organization of these services vary between countries. As illustrated in the introduction to this article, user participation and collaboration between service users and professionals are central aims for the mental health policy of many countries. Along with studies from other countries with similar aims, and with both similar and different ways of organizing services, this study could add to a knowledge base about the professional role in community mental health services.

Discussion of the findings

These centres or 'meeting-places' differ from more traditional services in that they have a 'low threshold' organization with aims of supporting people with mental health problems in their daily life, as well as increasing users' influence and participation in the service itself. This implied a varied and sometimes unpredictable work

situation, which one group participant described as being 'consultants in everyday living'. The work role was described as 'liberating', allowing for a more person-centred approach, as well as more egalitarian relationships between professionals and users than in their previous experiences from working in institutions. In line with findings from a study examining 'rehabilitation relationships' (Finaret & Shor 2006), the informants in this study highlighted the complexity of their work, concluding that flexibility, experience, and professional knowledge was important. Professionals' experience and interpersonal skills along with a person orientation have also been reported as helpful by mental health service users (Adam *et al.* 2003; Scanlon 2006). Schön (1991) argued that professionals need to pay attention to the contextual circumstances of people's lives and to 'reflect in action' based on their experience when interacting face to face with clients. This is in line with other authors' claims about the importance of expert skills, 'tacit knowledge', and improvisation (Alterhaug 2004; Benner 1984; Dreyfus & Dreyfus 2005; Polanyi 1967).

A further main focus in the informants' discussions was their responsibility as professionals to develop and maintain a milieu that felt safe and welcoming, so that each service user has a voice and participates socially. This included knowing when to intervene and when to withdraw from social situations in order to allow users to take the lead. A main observation during the field study was that, in these services, there seemed to be more interaction between users and professionals compared to more traditional services. The informants also described their work as different from work in institutional settings. Informants B and E, for example, described changes in their work roles when leaving the framework of the institution to work in the community mental health centres. Both described experiences of having to let go of control, which seemed stressful at first and later liberating. This shift, from an 'expert role' towards more egalitarian relationships meant that service users became more visible as persons, as opposed to 'cases'. This supports findings from a study by Carpenter *et al.* (2000), showing changes towards 'community-oriented practices' among staff who had previously worked in psychiatric hospitals.

As pointed out in the introduction to this article, collaboration between service users and professionals are central aims in the mental health policy of many countries (Dowling *et al.* 2004; Jubb-Shanley & Shanley 2007; Roper & Happell 2007; Rose 2003; Shanley *et al.* 2003; Sharkey 2002). Despite this, the informants in this study found that they were not always acknowledged as professionals by colleagues in other services. They discussed this

as a possible consequence of not entering an expert role, which included not observing and writing about the service users. According to informant B, service users should be able to use these centres without feeling that they were being observed, and informant F believed that many users would stop coming if they started documenting the way this is done in other services. These findings suggest that attempts to create collaborative relationships by not entering an 'expert role' versus service users can contribute to being seen as less professional by colleagues in other services. This is a surprising finding, considering that increased user participation has long been an aim in the mental health policy of several countries.

CONCLUSION

Creating more collaborative relationships between users and professionals can be a step towards developing mental health services that support community integration, participation, and social inclusion for persons with long-term mental health problems. It is important to further develop a knowledge base about the skills and experience needed to fill professional roles within such services. Findings from this study highlight some aspects of this work, like the need for flexibility, a person-centred approach, and the ability to create a social milieu that encourage user participation. The findings also suggest that professionals in other parts of health and social services should gain more knowledge about mental health work in community mental health centres, which has been reported as important by persons with mental health problems living in the community. This study was conducted in an urban area and did not focus on interprofessional issues. Future studies should explore community mental health work in rural areas, as well as the professional role in multiprofessional environments.

ACKNOWLEDGEMENTS

The authors would like to thank the mental health professionals who made this study possible by sharing their experiences, and Dr Arne Henning Eide for participating as an observer in the first interview and in discussions during the preliminary data analysis. The project was funded by a PhD grant from Sør-Trøndelag University College, Norway.

REFERENCES

- Adam, R., Tilley, S. & Pollock, L. (2003). Person first: What people with enduring mental disorders value about psychi-

- atric nursing and CPN services. *Journal of Psychiatric and Mental Health Nursing*, 10, 203–212.
- Alterhaug, B. (2004). Improvisation on a triple theme: Creativity, jazz improvisation and communication. *Studia Musicologica Norvegica*, 30, 97–118.
- Anthony, W., Cohen, M., Farkas, M. & Gagne, C. (2002). *Psychiatric Rehabilitation*, 2nd edn. Boston MA: Boston University, Centre for Psychiatric Rehabilitation.
- Benner, P. (1984). *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*. Menlo Park CA: Addison-Wesley.
- Bertram, G. & Stickle, T. (2005). Mental health nurses, promoters of inclusion or perpetrators of exclusion? *Journal of Psychiatric and Mental Health Nursing*, 12, 387–395.
- Borg, M. & Kristiansen, K. (2004). Recovery-oriented professionals: Helping relationships in mental health services. *Journal of Mental Health*, 13 (5), 493–505.
- Carpenter, J., Ring, C., Sangster, A., Cambridge, P. & Hatzidimitriadou, E. (2000). From the asylum to the community: A longitudinal study of staff involved in the transition from Tone Vale Hospital to community based services. *Journal of Mental Health*, 9 (2), 211–230.
- Clark, E. H. (2004). Quality of life: A basis for clinical decision-making in community psychiatric care. *Journal of Psychiatric and Mental Health Nursing*, 11, 725–730.
- Corrigan, P. W., Mueser, K. T., Bond, G. R. & Solomon, P. (2008). *Principles and Practice of Psychiatric Rehabilitation. An Empirical Approach*. New York: The Guilford Press.
- Davidson, L. (2005). Recovery, self-management and the expert patient – changing the culture of mental health from a UK perspective. *Journal of Mental Health*, 14 (1), 25–35.
- Dowling, B., Powell, M. & Glendinning, C. (2004). Conceptualising successful partnerships. *Health and Social Care in the Community*, 12 (4), 309–317.
- Dreyfus, H. L. & Dreyfus, S. E. (2005). Expertise in real world contexts. *Organization Studies*, 26 (5), 779–792.
- Elstad, T. A. & Kristiansen, K. (2009). Mental health centres as ‘meeting-places’ in the community: Exploring experiences of being service users and participants. *Scandinavian Journal of Disability Research* [Cited 10 July 2009]. Available from: URL: [http://www.informaworld.com/smpp/content~db=all~content=a911011751]
- Finaret, A. E. & Shor, R. (2006). Perceptions of professionals about the nature of rehabilitation relationships with persons with mental illness and the dilemmas and conflicts that characterize these relationships. *Qualitative Social Work*, 5 (2), 151–166.
- Granerud, A. & Severinsson, E. (2007). Knowledge about social networks and integration: A co-operative research project. *Journal of Advanced Nursing*, 58 (4), 348–357.
- Hammersley, A. & Atkinson, P. (2007). *Ethnography. Principles in practice*, 3rd edn. London & New York: Routledge.
- Happell, B. (2008a). Determining the effectiveness of mental health services from a consumer perspective: Part 1: Enhancing recovery. *International Journal of Mental Health Nursing*, 17, 116–122.
- Happell, B. (2008b). Determining the effectiveness of mental health services from a consumer perspective: Part 2: Barriers to recovery and principles for evaluation. *International Journal of Mental Health Nursing*, 17, 123–130.
- Hellzén, O. (2004). Nurses’ personal statements about factors that influence their decisions about the time they spend with residents with long-term mental illness living in psychiatric group dwellings. *Scandinavian Journal of Caring Science*, 18, 257–263.
- Hellzén, O. & Asplund, K. (2006). Nurses’ narratives about their residents when caring for people with long-term mental illness in municipal group dwellings. *International Journal of Mental Health Nursing*, 15, 60–69.
- Hummelvoll, J. K. (2008). The multistage focus group interview: A relevant and fruitful method in action research based on a co-operative inquiry perspective. *Norsk tidsskrift for sykepleieforskning (Norwegian Journal of Nursing Research)*, 10 (1), 3–14.
- Høgberg, T., Magnusson, A. & Lutzén, K. (2006). Living by themselves? Psychiatric nurses’ views on supported housing for persons with severe and persistent mental illness. *Journal of Psychiatric and Mental Health Nursing*, 13, 735–741.
- Jubb-Shanley, M. & Shanley, E. (2007). Trialling of the partnership in coping system. *Journal of Psychiatric and Mental Health Nursing*, 14, 226–232.
- Kitzinger, J. (2005). Focus group research: Using group dynamics to explore perceptions, experiences and understandings. In: I. Holloway (Ed.). *Qualitative Research in Health Care*. (pp. 56–70). Berkshire, UK & New York: Open University Press.
- Krueger, R. A. & Casey, M. A. (2000). *Focus Groups. A Practical Guide for Applied Research*, 3rd edn. Thousand Oaks – London – New Delhi: Sage Publications.
- Kvale, S. (1996). *InterViews. An Introduction to Qualitative Research Interviewing*. Thousand Oaks, California: Sage Publications.
- Lauder, W., Forrest, S. & Masters, H. (2006). The national review of mental health nursing in Scotland: Implications for the profession. *Journal of Psychiatric and Mental Health Nursing*, 13, 634–635.
- Lilja, L. & Hellzén, O. (2008). Former patients’ experience of psychiatric care: A qualitative investigation. *International Journal of Mental Health Nursing*, 17, 279–286.
- Lipsky, M. (1980). *Street-Level Bureaucracy. Dilemmas of the Individual in Public Services*. New York: Russel Sage Foundation.
- Manning, S. S., Brinkman, E., Burgess, D. D. et al. (2000). The CHARG experience with consumer–professional partnership. *Psychiatric Rehabilitation Journal*, 24 (2), 125–134.

- Masterton, S. & Owen, S. (2006). Mental health service users' social and individual empowerment: Using theories of power to elucidate far-reaching strategies. *Journal of Mental Health, 15* (1), 19–34.
- Mental Health Commission New Zealand (2002). *Service User Participation in Mental Health Services. A Discussion Document*. Wellington, New Zealand: Mental Health Commission New Zealand.
- Polanyi, M. (1967). *The Tacit Dimension*. London: Routledge & Kegan Paul.
- Prior, L. (1993). *The Social Organization of Mental Illness*. London, Newbury Park & New Delhi: Sage Publications.
- Roper, C. & Happell, B. (2007). Reflection without shame – reflection without blame: Towards a more collaborative understanding between mental health consumers and nurses. *Journal of Psychiatric and Mental Health Nursing, 14*, 85–91.
- Rose, D. (2003). Partnership, co-ordination of care and the place of user involvement. *Journal of Mental Health, 12* (1), 59–70.
- Scanlon, A. (2006). Psychiatric nurses' perception of the constituents of the therapeutic relationship: A grounded theory study. *Journal of Psychiatric and Mental Health Nursing, 13*, 319–329.
- Schön, D. A. (1991). *The Reflexive Practitioner*. New York: Basic Books.
- Shanley, E., Jubb, M. & Latetr, P. (2003). Partnership in coping: An Australian system of mental health nursing. *Journal of Psychiatric and Mental Health Nursing, 10*, 431–441.
- Sharkey, V. B. (2002). Perspectives of collaboration/non-collaboration in a mental health inpatient setting. *Journal of Psychiatric and Mental Health Nursing, 9*, 49–55.
- Spaniol, L. R., Gagne, C. & Kohler, M. (Eds) (1997). *Psychological and Social Aspects of Psychiatric Disability*. Boston MA: Boston University, Center for Psychiatric Rehabilitation.
- WHO (2001). *Mental Health: New Understanding, New Hope. World Health Report*. Geneva: World Health Organization.
- Wilson, P. M., Kendall, S. & Brooks, F. (2006). Nurses' responses to expert patients: The rhetoric and reality of self-management in long-term conditions: A grounded theory study. *International Journal of Nursing Studies, 43*, 803–818.
- Wilson, P. M., Kendall, S. & Brooks, F. (2007). The Expert Patients Programme: A paradox of patient empowerment and medical dominance. *Health and Social Care in the Community, 15* (5), 426–438.

Cr r gpf kz



Stipendiat Toril Anne Elstad

Saksbehandler:
Rådgiver Arild Hals
Telefon 73 86 7152
Fax 73 86 72 89
E-post: arild.hals@medisin.ntnu.no
rek-4@medisin.ntnu.no
Adresse: Det medisinske fakultet
Kreftbygget 5. etg, St. Olavs Hospital
7006 Trondheim

Vår dato.:
05.05.04

Vår ref.:
073-04

Deres dato:

Deres ref.

Medbestemmelse og sosial tilhørighet for mennesker med alvorlige og langvarige psykiske lidelser som utfordring innen psykisk helsearbeid.

Komiteen vurderte prosjektet i sitt møte 23. april 2004 med følgende merknader og tilråding:

Formålet med prosjektet er å få mere kunnskap om den sosiale livssituasjonen for hjemmeboende mennesker med alvorlige psykiske lidelser, der fokus vil særlig være på betydningen av medbestemmelse og sosial tilhørighet, og videre å se på hvilke utfordringer målsettinger om selvbestemmelse og sosial integrasjon stiller brukere og ansatte overfor. Studien vil bli gjennomført ved feltarbeid med deltagende observasjon som forskningsmetode. Det er ikke spesifisert hvor mange som vil bli inkludert i studien. Informantene vil være brukere og ansatte innenfor tjenestetilbudet i Trondheim kommune.

Komiteen har følgende merknader til prosjektet:

- Komiteen viser til prosjektprotokollen og til at det ikke skal være noen form for intervensjon i utgangspunktet, kun observasjon, men at det ute i prosessen vil bli aktuelt med å foreta dybdeintervju med noen av klientene. Problemet med et slikt opplegg vil være informasjons- og samtykkeområdet. Komiteen mener at det, selv om det her ikke er mulig å innhente informert samtykke på tradisjonelt vis, må kunne gjennomføres slik det er foreslått. Det er sikkert viktig med en "run-in"-periode, dvs en periode hvor prosjektleder gjør seg kjent i blant klientene, og at det da blir gitt informasjon som skissert ved oppslag o.l.
- Komiteen viser til informasjonsskrivet og ber om at det anføres at det er frivillig å delta, og at ingen er forpliktet til å delta i den observasjonen som gjøres eller å snakke med prosjektleder. Komiteen viser til vedlagte mal for informasjonsskriv og ber om at dette legges til grunn ved en gjennomgang av skrivet. Skrivet vil bli mere lesbart ved at en deler det inn i kortere avsnitt, gjerne med overskrift. Det må skilles klart mellom observasjon og intervju.
- Selve samtykkeformularet forenkles, og de opplysninger som står der flyttes over til informasjonsskrivet.

Komiteen ber om å få tilsendt artikkel/rapport når studien er fullført.

Tilråding:

”Komiteen godkjenner at prosjektet blir gjennomført med de merknader som er gitt.”

Vi viser til dette og ønsker lykke til med prosjektet.

Med hilsen


Arne Sandvik
Professor
Leder i komiteen


Arild Hals
Rådgiver
Sekretær i komiteen



Hans Holmboes gate 22
N-5007 Bergen
Norway
Tel: +47/ 55 58 21 17
Fax: +47/ 55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Toril Elstad
Avdeling for sykepleie
Høgskolen i Sør-Trøndelag

Ranheimsveien 10
7004 TRONDHEIM

Vår dato: 03.12.2004

Vår ref: 200401524 LT /RH

Deres dato:

Deres ref:

MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 22.11.2004. Meldingen gjelder prosjektet:

11816

Medbestemmelse og sosial tilhørighet for mennesker med alvorlige og langvarige psykiske lidelser som utfordring innen psykisk helsearbeid

Behandlingsansvarlig
Daglig ansvarlig

*Høgskolen i Sør-Trøndelag, ved institusjonens overste leder
Toril Elstad*

Meldingen er behandlet av Norsk samfunnsvitenskapelig datatjeneste AS (NSD). Etter gjennomgang av opplysninger gitt i meldeskjemaet og dokumentasjon, finner vi at prosjektet ikke medfører behandling av personopplysninger i henhold til personopplysningsloven §§ 1 til 3, og følgelig ikke utløser meldeplikt eller konsesjonsplikt etter personopplysningslovens §§ 31 og 33.

Vedlagt følger vår vurdering. Prosjektet kan settes igang.

Dersom prosjektopplegget endres i forhold til de punktene som ligger til grunn for vår vurdering, skal prosjektet meldes på nytt.

Vennlig hilsen


Bjørn Henrichsen


Lis Tenold

Kontaktperson: Lis Tenold tlf: 55583377

Vedlegg: Prosjektbeskrivelse

Avdelingskontorer / District Offices:

OSLO: NSD, Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47/ 22 85 52 11. nsd@uio.no

TRONDHEIM: NSD, Norges teknisk-naturvitenskapelige universitet, 7491 Trondheim. Tel: +47/ 73 59 19 07. kyrr.svarva@svt.ntnu.no

TROMSØ: NSD, SVF, Universitetet i Tromsø, 9037 Tromsø. Tel: +47/ 77 64 43 36. nsdmaa@sv.uit.no

Prosjektbeskrivelse

Daglig ansvarlig

Toril Elstad
Avdeling for sykepleie
Høgskolen i Sør-Trøndelag

Ranheimsveien 10
7004 TRONDHEIM

11816 Medbestemmelse og sosial tilhørighet for mennesker med alvorlige og langvarige psykiske lidelser som utfordring innen psykisk helsearbeid

FORMÅL

Formålet med prosjektet er å frembringe kunnskap om den sosiale livssituasjonen for hjemmeboende mennesker med psykiske lidelser. Fokus vil særlig være på betydningen av medbestemmelse og sosial tilhørighet.

UTVALG

Utvalget vil bestå av ca. 200-300 voksne mennesker av begge kjønn som velger å oppsøke tre åpne treffsteder for mennesker med psykiske lidelser, organisert som en del av hjelpe tilbudet i Trondheim kommune.

REKRUTTERING - INFORMASJON

Rekrutteringen foregår ved hjelp av informasjonsrunder med muntlig og skriftlig informasjon.

Det informeres om frivillig kontakt med forsker og ingen konsekvenser for den som ikke vil delta eller som trekker seg. Eventuelt dybdeintervju med enkeltpersoner underveis i studien vil være basert på initiativ fra informant og forskers vurdering av temaets relevans for studiens formål.

Informasjonsrundene gjennomføres først av enhetsleder Stig Antonsen i Trondheim kommune, deretter av Toril Elstad. Lederne ved de tre treffstedene gjør evt. nye brukere oppmerksomme på informasjonsskriv som oppslag, og deler i tillegg ut kopi dersom brukere ønsker det. Lederne kontakter Toril Elstad, som vil gjennomføre ekstra informasjonsmøter dersom bruker(e) etterspør mer informasjon for studien settes igang.

Samtykke er ensbetydende med aktiv deltakelse.

Ved eventuelle dybdeintervju underveis i studien vil det innhentes skriftlig samtykkeerklæring. Personvernombudet forutsetter at registrering av navn, adresse og/eller telefonnummer skjer manuelt og at det ikke er kopling til opplysninger som samles inn fra intervjuet.

METODE FOR DATAINNSAMLING - REGISTRERING AV OPPLYSNINGER

Undersøkelsen vil gjennomføres som et feltarbeid, med deltagende observasjon ved tre treffsteder for mennesker med psykiske lidelser i Trondheim kommune.

Datagrunnlaget vil være feltnotater med beskrivelser basert på hendelser, samhandling og samtaler som foregår som en naturlig del av aktiviteten på stedet.

Det registreres ikke opplysninger som direkte eller indirekte kan identifisere enkeltpersoner.

Datamaterialet vil inneholde informasjon som gir kunnskap om hverdagslivet til hjemmeboende mennesker med psykiske lidelser. Observasjonene skrives ned i form av håndskrevne notater i feltdagbok.

Innsamlede opplysninger registreres manuelt og på pc. Både håndskrevne notater og notater på datamaskin slettes når prosjektet er avsluttet.

Forespørsel om å delta i en vitenskapelig undersøkelse

Navnet mitt er Toril Elstad. Jeg er ansatt på sykepleierutdanningen ved Høgskolen i Sør-Trøndelag, og har tidligere arbeidet som psykiatrisk sykepleier. For tiden er jeg stipendiat, noe som innebærer at jeg arbeider med et forskningsprosjekt i samarbeid med NTNU. Jeg har kalt prosjektet: *"Medbestemmelse og sosial tilhørighet som utfordring i psykisk helsearbeid."*

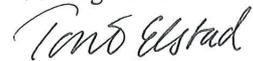
Formålet med prosjektet er at det skal bidra til økt kunnskap om hvordan det er å leve med psykiske helseplager i hverdagen, og at denne kunnskapen skal være til nytte i den videre utviklingen av hjelpetilbudet. Jeg er spesielt opptatt av spørsmål om betydningen av sosial kontakt, og om betydningen av å ha innflytelse på sin egen livssituasjon og på hjelpetilbudet. Mange av dere har helt sikkert synspunkter og erfaringer som kan bidra til viktig kunnskap på dette området. Jeg ønsker derfor å ta del i noen av deres erfaringer gjennom å være sammen med dere på treffstedene i perioder fra januar til desember 2005. Hensikten er å være tilstede for å lære om det dere gjør, og jeg vil verken være ansatt eller bruker.

Forskningsmetoden kalles *deltagende observasjon*. Det innebærer blant annet at jeg vil skrive notater i en bok som oppbevares nedlåst på arbeidsplassen min. Disse notatene vil bli brukt til å skrive artikler, som jeg vil søke å få publisert i fagtidsskrifter. Å delta i forskningsprosjektet er helt frivillig, - det betyr at ingen er forpliktet til å gi meg informasjon. Alle opplysninger vil bli behandlet anonymt, og det skal ikke være mulig å finne tilbake til bestemte personer gjennom å lese det jeg senere skriver. Selve doktorgradsprosjektet som denne studien vil være en del av, forventes å være ferdig i 2008. Artikler jeg får publisert vil være tilgjengelige, og jeg vil informere om hovedresultatene på treffstedene hvis dere ønsker det.

Prosjektet er vurdert og godkjent av Etisk komité for medisinsk forskning, Midt-Norge, og av Personvernombudet for forskning ved Norsk samfunnsvitenskapelig datatjeneste AS. Jeg har taushetsplikt etter Forvaltningslovens § 13 og Lov om Helsepersonells § 21. Dette gjelder også for mine veiledere, som er Kristjana Kristiansen, førsteamanuensis ved NTNU og Arné Eide, forskningssjef ved SINTEF og professor 2 ved Høgskolen i Sør-Trøndelag.

Dersom noen av dere ønsker det, kan jeg gjennomføre et eget intervju om noe dere er opptatt av, når det gjelder psykisk helse og betydningen av sosial kontakt og medbestemmelse. Et slikt intervju vil vare i ca. en time, og tid og sted vil bli avtalt med den enkelte. Skjema for *informert samtykke* vil bli underskrevet på forhånd. Den som avtaler å bli intervjuet vil ha betenkningstid, og kan trekke seg fra intervjuet når som helst uten å oppgi noen grunn. Dette vil ikke få noen konsekvenser for vedkommende. Hvis et slikt intervju blir gjennomført, vil det bli tatt opp på bånd som vil bli slettet straks prosjektet er gjennomført.

Vennlig hilsen



Toril Elstad

Doktorgradskandidat

Jeg kan treffes ved Høgskolen i Sør-Trøndelag, Avd. for sykepleie, tlf. 73559150 / 73559244

Eksempel på samtykkeerklæring som vil bli benyttet dersom vi avtaler intervju:

Informert samtykke

Jeg har mottatt skriftlig og muntlig informasjon, og er villig til å bli intervjuet som en del av Toril Elstads forskningsprosjekt. Intervjuet vil bli tatt opp på bånd, som vil bli slettet straks studien er ferdig.

Jeg er klar over at min deltagelse i prosjektet er helt frivillig, og at jeg når som helst kan trekke meg fra intervjuet uten at det får noen konsekvenser for meg.

All informasjon jeg gir vil bli behandlet anonymt.

Jeg vil ha tilgang til resultatene fra prosjektet dersom jeg ønsker det.

Trondheim.....

Underskrift, informant