

Service user involvement in in-patient mental health services

by
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To Kenny and my three children Madeleine,
Benjamin and Sebastian

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SUMMARY

The main objective with this thesis is to improve the understanding of user involvement in inpatient mental health services. This thesis conceptualizes and operationalizes service user involvement into variables that can be empirically measured. This thesis also assesses the implications of conducting the intervention program “Service user involvement in practice.” The program was implemented in order to increase attention to user involvement and to develop current user involvement practices in inpatient departments in two community mental health centers (CMHCs).

In paper 1, multiple items to measure user involvement were developed, validated, and empirically tested with service providers in one CMHC. In paper 2, we used cross-sectional data from service providers in inpatient departments in five CMHCs. The study investigates if providers’ reports of user involvement vary between organizational contexts and ascertains if a provider’s characteristics affect the reports. In the intervention stage, both qualitative and quantitative data were collected. The qualitative data were used in paper 3 and provided insight into both inpatients’ and providers’ experiences with user involvement. In paper 4, we used quantitative survey data from providers and inpatients to study the possible effect of the intervention program “Service user involvement in practice” on reports of user involvement. The study design was quasi-experimental, involving inpatient departments in five CMHCs. Two CMHC took part in the intervention program while three CMHCs participated as comparisons.

In paper 1, the Service User Involvement in Mental Health (SUIM) Scale was developed with 30 items and four subscales: “Democratic patient involvement,” “Assisted patient involvement,” “Carer involvement,” and “Management support.” The cross-sectional data in paper 2 showed that user involvement at the departmental and individual level could be measured with three subscales or variables: “assisted patient involvement,” “patient collaboration,” and

“organizational user involvement.” The first two variables were derived from the Service User Involvement in Mental Health (SUIIMH) Scale, while “organizational user involvement” is a selection of items from the Consumer Participation Questionnaire (CPQ) (Kent & Read, 1998). The data also revealed that reports of user involvement at the departmental level were low, but there were differences among CMHCs. Providers reported more often user involvement at the individual level, and providers’ work shifts arrangements impacted on these reports. The qualitative data in paper 3 revealed that user involvement is a complex matter in inpatient mental health care. Providers and patients hold different perspectives on several issues related to user involvement and involvement in treatment and care. In paper 4, the quantitative survey data from providers showed that there were significant changes in three of the user involvement variables: “organizational user involvement,” “patient collaboration,” and “carer involvement.” There were no significant differences between patients in the intervention and comparison groups with regard to their experiences with treatment and care.

The results in this thesis shows that service user involvement from providers’ perspective can be measured with the following variables: “patient collaboration,” “assisted patient involvement,” “carer involvement,” “management support,” and “organizational user involvement.” Attention should be paid to the relatively few reports of “organizational user involvement” and that there are variations among institutions with regard to implementation user involvement. The study results suggest that an intervention program can turn attention to and increase competence about user involvement among providers and inpatients but that more work is needed to increase patients’ self-advocacy.

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.....**Part I**

1 Introduction

1.1 Study background

Service user involvement is a principle of health policy in many countries and health service systems around the world. In Norway, service user involvement was introduced in several political documents pertaining to health care in the 1990s (Norwegian Ministry of Health and Care Services, 1996, 1997, 1999). Today, user involvement is recognized in supra national strategies to improve mental health (European Commission, 2005; WHO, 2005). User involvement intended to increase the actual and “real” influence of patients on decisions about treatment, to ensure that services are provided in accordance with their needs and to enhance patients’ control over their health care. The attention to service user involvement paralleled deinstitutionalization and the new focus on community mental health models to support independent living for people with mental disorders. In Norway the Norwegian Action Plan for Mental Health (1999-2006) contained the following approaches to improving mental health services: 1) developing community mental health care, 2) restructuring and development of services, 3) enhancing providers’ competencies and stimulating research, 4) stimulating service user involvement and participation and 5) stimulating initiatives to increase employment of people with mental illnesses.

There are several challenges to user involvement in inpatient mental health care in particular. Patients admitted to inpatient care experience troublesome mental health symptoms and a difficult life situation, which they to varying degrees are able to handle. User involvement provides patients with opportunities to influence their own situation and service provision. Some patients might want to be very involved in treatment decisions. Others may not have the wish, the capacity or the energy to make choices for themselves and to participate actively in their care planning (Taylor, et al., 2009). It is not only the mental health condition that affects and can slow down the patient’s active role in treatment and care decision-making. Service providers play an

important role in facilitating or impeding service user involvement. They are professional care takers using their expertise for the best of their patients. Patients' and providers' perspectives on important treatment and care issues can be divergent. In everyday practices, care providers may get into a position where they make the treatment decisions on behalf of their patients based on an assumption that these decisions are in the patient's best interests. Providers may lack competence in the area of user involvement. For example, a study by Rutter et al. (2004) showed that while nurses reported that they were expected to involve patients in their everyday nursing practices, they had not received any training in implementing involvement strategies.

The literature mentions various terms such as service user, user and patient. In its most general term, a service user is a person using public services (Olsen, 2005). In relation to inpatient mental health care, a *service user* is a patient with a mental disorder who is receiving inpatient care. The patient's carers are included in this understanding of service users. Carers can be the patient's family, relatives, partner or caretakers appointed by the patient (Storm, Hausken, & Mikkelsen, 2010). The term *service user* can also refer to people who continue to use mental health services after discharge, or people who have used and therefore have experiences with mental health services (Diamond, Parkin, Morris, Bettinis, & Bettsworth, 2003). It is common to make a distinction between user involvement for individual patients, and user involvement in service development and service provision (Norwegian Ministry of Health and Care Services, 1996). The first concerns a patient's right to influence and participate in decision-making about planning and implementation of his/her individual treatment and service provision. The second understanding involves various approaches and methods for involving people with experience from mental health services and background from user organizations in service development, for example, as members of service user advisory boards (Andreassen, 2008; Crawford & Rutter, 2004; Happell & Roper, 2006a), in research (Beresford, 2005; Lammers & Happell, 2004; Smith, et al., 2008), and in education and training of mental health professionals (Repper & Breeze, 2007). This broad understanding of service user involvement can complicate the implementation of user

involvement in inpatient mental health care. Research in the area user involvement in mental health services in Norway has identified a variety of understandings of user involvement among providers (Steinsbekk & Solbjør, 2008). In accordance with the Norwegian Ministry of Health and Care Services (1996) this thesis applies the following understanding of service user involvement: 1) a patient or service user and his/her carers participate in and influence his/her service planning and service provision, and 2) service users influence on mental health service provision in general.

There are few measurement scales available for service providers covering the topic of service user involvement.¹ The Consumer Participation Questionnaire (CPQ) developed by Kent and Read (1998) has been most extensively used to survey service providers' attitudes toward consumer involvement in the planning, management and evaluation of mental health service delivery (Kent & Read, 1998; Richter, Halliday, Grømer, & Dybdahl, 2009; Soffe, Read, & Frude, 2004; Steinsbekk & Solbjør, 2008). Diamond et al. (2003) used structured interviews with staff comprising 11 questions that examined the level of service user involvement, focusing on: staff recruitment, self assessment, evaluation of services, staff training, and organization and planning of services. The study indicated three levels of implementation of user involvement: successful, established, and limited.

¹ Literature searches in CINAHL, Medline, and Psych Info via EBSCO and ISI using the terms "user involvement," "service user involvement," "patient participation," and "consumer participation". These terms were chosen because user involvement is related to concepts such as patient participation and patient involvement (Cahill, 1996; Elwyn, et al., 2001; Hickey & Kipping, 1998; Latvala, 2002; Latvala, Saranto, & Pekkala, 2004), consumer involvement and consumer participation (Happell & Roper, 2006b; Lammers & Happell, 2003). The search words were used individually and in combination with "mental health" and "psychiatric care" as well as in combination with "instrument," "measurement," and "scale."

1.2 The focus of the thesis

The widespread use of the concept *service user involvement* and the limited research in the area of user involvement in inpatient mental health care justifies conducting an empirical study of current user involvement practices. The core aspects of this thesis are to develop a measurement scale for service providers to collect data on implementation of user involvement in their daily work. To be a valid measurement scale, the concept must be grounded in a theoretical framework (Netemeyer, Sharma, & Bearden, 2003). The theoretical part of this thesis presents theories that are considered important to the understanding of and conceptualization of user involvement in mental health services. Based on current literature and research in the field of user involvement, the following key concepts are identified and elaborated on: 1) individual user involvement, 2) carer involvement, and 3) user involvement in services. In addition, assumed influencing factors on implementation of user involvement (e.g. the mental disorder, the provider/patient relationship, power, organizational culture and leadership) are presented and discussed.

In the empirical papers in this thesis, we developed a set of related empirical concepts or variables which can be used to measure user involvement from a provider's perspective. In paper 1, user involvement is conceptualized and operationalized. We elaborate on item generation, content validity, and the exploration of the dimensionality of the items in the Service User Involvement in Mental Health (SUIM) Scale. In paper 2, we test a simple theoretical model with three key variables: "patient collaboration" and "assisted patient involvement" representing user involvement at the individual level and "organizational user involvement" representing user involvement at the departmental level of services. In paper 4, we argue that user involvement is a multidimensional concept which can be measured with the following variables: "patient collaboration," "assisted patient involvement," "carer involvement," "management support," and "organizational user involvement." The four first variables were derived from the SUIM scale while organizational user involvement was derived from the CPQ (Kent & Read, 1998). Several aspects

related to measurement validity and reliability are addressed in the papers in this thesis. These issues are emphasized because the usefulness and scientific value of a measure depend on the scale's psychometric properties, the standardization of the measure, and the measurement's ability to perform reliably and to be replicated under similar testing conditions (Netemeyer, et al., 2003).

The studies in this thesis were conducted in Norwegian Community Mental Health Centers (CMHCs). Establishment of CMHCs has been an important focus during the Mental Health Action plan period. Despite the political attention, the development of CMHCs in Norway has varied among geographical areas. There are some indications that user involvement practices may vary among organizations. In a report by Sletnes, Hansen, Winther and Magnussen (2008), only about one-third of the CMHCs had established a service user advisory board in their organization. The factors that influence service providers' support for user involvement has been addressed only to a limited extent. Kent and Read (1998) explored the possibility that professionals holding a medical orientation towards mental disorders are less likely to support effective user involvement than professionals with a psychosocial orientation. One important purpose in paper 2 is to examine factors that affect providers' reports of service user involvement. Providers' reports may be influenced by individual characteristics such as gender, age, profession or work shift arrangement, or they may be shaped by the organizational culture in which the provider is employed.

Successful implementation of service user involvement initiatives seems to be influenced by service providers' attention to user involvement, training and competence, and supporting organizational cultures (Rutter, Manley, Weaver, Crawford, & Fulop, 2004). Some intervention studies have changed providers' attitudes and improved their competencies regarding person-centered care and recovery (Taylor, et al., 2009; Young, et al., 2005). However, we have found no intervention studies that focus specifically on strengthening user involvement in inpatient mental health care. As part of this thesis, we have developed an intervention program "Service user involvement in practice," to increase attention to and facilitate changes in user

involvement practices in inpatient mental health departments. The program is developed in light of the literature on organizational culture and organizational learning, and in research on organizational interventions (Argyris & Schön, 1996; Mikkelsen, Saksvik, & Landsbergis, 2000; Schein, 2000). Providers' and inpatients' experiences with participation and involvement in treatment and care are a cornerstone of the intervention program, as are five educational sessions to enhance providers' and inpatients' competences about service user involvement. The third and fourth papers in this thesis address the implications of an intervention program implemented in two CMHCs in the western health region of Norway. Paper 3 reports on the qualitative data from the intervention program focusing on both inpatients' and providers' perspectives on user involvement. Paper 4 test the assumption that an intervention program can affect providers' reports on key user involvement variables and inpatients' experiences with care.

1.3 Thesis objective and aims

The main objective of this thesis is to improve the understanding of user involvement in inpatient mental health services. This thesis operationalizes and transforms the concept of service user involvement into a set of related variables that can be empirically measured. This will also allow for the testing of hypotheses and assessing causality among the user involvement variables and variables such as individual and organizational characteristics. This thesis also assesses the implications of the intervention program "Service user involvement in practice," which was implemented to develop user involvement in inpatient care. Qualitative methods and data are used to explore how patients experience their participation in treatment and care and to assess how providers experience their efforts to strengthen user involvement during the intervention process. We also measure the possible effects of the intervention on reports of user involvement.

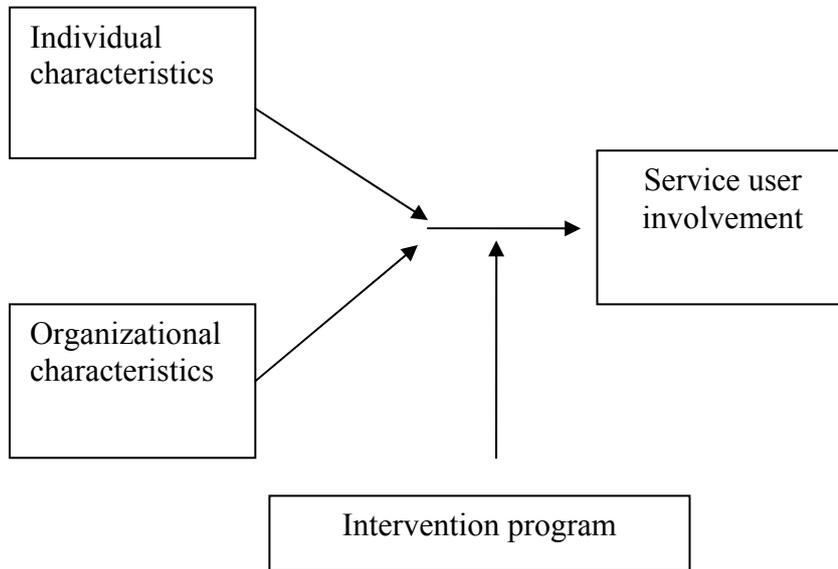


Figure 1. Illustration of the issues and associations explored in this thesis.

The conceptualization and operationalization of user involvement is represented by the box on the right. The two boxes on the left represent individual and organizational characteristics that can affect reports of user involvement; the last box depicts the intervention program implemented to increase attention to and develop current user involvement practices. The arrows point to the statistical associations studied in this thesis.

Based on these considerations, the aims of the four empirical papers are as follows:

Aim of paper I: To develop, empirically test, and validate a scale measuring service user involvement in in-patient mental health from the mental health providers' perspective.

Aim of paper II: To examine service providers' reports of service user involvement at the individual and departmental levels in different organizational contexts.

Aim of paper III: To qualitative explore inpatients' perspectives on what it means to be involved in own care, and service providers' experiences with encouraging user involvement in care planning and service provision during the intervention program.

Aim of paper IV: To study the possible effects of an intervention program to 1) increase attention to user involvement and 2) increase user involvement at the inpatient departmental level on providers' reports of service user involvement and inpatients' satisfaction with care.

1.4 Structure of the thesis

The thesis consists of two parts. Part I presents the purpose of the study and the aims of the four empirical papers. The theoretical section outlines the theories relevant to service user involvement in health services. Section 3 describes the methodology and section 4 reviews the findings from the four papers. Section 5 discusses the results, elaborates on study limitations and the implications of the results for future research. The four papers are presented in part II.

2 Theory

In this section, theories considered important to the understanding and conceptualization of user involvement in health services are outlined. It will begin with a short history of psychiatric treatment, followed by presentation of theories of service user involvement, and a conceptual clarification of service user involvement in inpatient mental health. The section ends with a presentation of factors influencing on service user involvement in inpatient mental health services.

2.1 *The history of psychiatric treatment*

The history of treatment practices for people with mental disorders and the characteristic of mental health institutions is an important framework for understanding contemporary mental health services and the strong emphasis on service user involvement.

Asylums were the main psychiatric institutions in the western world during the 19th and first part of the 20th century. These institutions were originally built on an ideology of moral treatment with a humanistic perspective, and the idea that separating the mentally disturbed patients from the society, their family, and friends was beneficial to both the patients and to society. The staff of the asylums were to show kindness and benevolence, exercise authority, and act as role models for good behaviors (Hollander, 1981; Norvoll, 2007; Osborn, 2009). In the asylums, the patients' days were regimented. There were routines for rest, meals, work, and activities, all in order to encourage the establishment of calmer and regular habits, obedience, orderliness, and self-control. Isolation and restraint were only to be used as a last resort (Hollander, 1981; Osborn, 2009). Although the therapeutic goal was to treat mental health disorders, the mental hospitals and asylums ended up overcrowded. They became total institutions characterized by the controlling and demoralization of the patients, long-term stays, and lack

of skilled and qualified staff to provide treatment (Goffman, 1961; Løchen, 1970).

In the 1950s and 1960s, attention turned to abuse of patients in the mental hospitals and the negative and antitherapeutic aspects of prolonged institutionalization. A new emphasis on the treatment and supervision of people with mental disorders in the community followed (Rose, 2001). In the institutions, new treatment ideologies such as “milieu therapy” and “therapeutic communities” stressed the democratization of authority structures in the institutions, patient participation, tolerance, communalism, and group discussions (Hollander, 1981; Løchen, 1970; Norvoll, 2007). Humanistic psychiatric nursing and client-centered counseling evolved (Horsfall, 1997). Peplau’s *Interpersonal relations in nursing*, originally published in 1952 (1988), claimed that relations between nurses and patients had a qualitative impact on patients’ outcome.

A new era in the treatment of people with mental disorders followed, as psychiatry moved into the community. In the US and Europe, asylums were closed during in the 1970s and 1980s, and mental health services were reoriented towards community-based care. In the US, the closing of these large mental hospitals was not followed by sufficient care for people with mental disorders in the communities. Many of these people became homeless (Osborn, 2009). The Norwegian Parliament’s White Paper no. 25 (1996) criticized the country’s mental health services for making little progress in developing community mental health care. Focus was turned to issues like patient rights, empowerment, and the need for a general awareness of user involvement for individual patients and of user influence on mental health services.

2.2 Citizenship and patient rights

The democratic development of the public sector and welfare state is important for understanding service user involvement in health services and has led to making user involvement and patient participation important values in current mental health services. Democracy is a

form of government that includes rights and legal guarantees for individuals and groups, and for forms of citizen participation (Norwegian Ministry of Government Administration, Reform & Church Affairs, 2003). As a citizen in a democracy, one has a right to vote and take part in elections. People are not only to be governed but also to take part in governing. People have opportunities to participate in public debates and to influence political decision-making. Marshall (1965) in Eriksen and Weigård (1993) describes a system of rights. Civil rights ensure that the law applies equally to all members of the community, and protects the individual and communities from abuse of power. Political rights ensure universal and equal voting rights for women and men, and social rights ensuring equal access to health and welfare, which is an important principle of the welfare state (Eriksen & Weigård, 1993). During the last two decades, there has been a greater focus on peoples' social rights, and special attention to people with weak legal protection (Norwegian Ministry of Government Administration, Reform & Church Affairs, 2003). In Norway, several laws have been passed ensuring people equal access to health and social services.

In Norway, user involvement in mental health services is regulated by law and is a political goal and priority (Norwegian Directorate of Health, 2005; Norwegian Mental Health Act, 1999; Norwegian Ministry of Health and Care Services, 1996; Norwegian Patient Rights Act, 2001). The Patient Rights Act (2001) ensures the right to access health care, to receive information, to consent to or to decline treatment, and to participate in treatment decisions. Information is necessary to access and benefit from treatment, and is a prerequisite for the patient to make informed choices about treatment and to consent to treatment and health care (Kjellefold, 2005). Patients are entitled to information about rights, duties and practices, and to professional advice that is adapted to their individual needs. The right to participate in the implementation of health care is stated in the Patient Rights Act § 3-1. Participation shall be adapted to the individual's capacity to participate. The patient's right to participation requires an interaction between the patient and service provider for which the service provider is obliged to accommodate and prepare (Kjellefold, 2005). The Patients

Rights Act also entitles patients with chronic and long-term diseases to an individual care plan. The Mental Health Act in § 4-1 stipulates that the institution has a responsibility to formulate an individual care plan if the patient consents. In addition to coordinate and tailor services to a patient, the individual care plan is to consider the patient's resources, goals and need for services (Norwegian Directorate of Health, 2010). If the patient's rights to, for example, to information, participation or individual care plan are not fulfilled, the patient can file a complaint with the regional health authorities. Although the law ensures patients' equal rights, there may be variations in the extent to which patients assert their rights. For the patient, involvement and participation involve their own efforts, and the patient can choose not to participate (Kjellevold, 2005).

2.3 Empowerment

In extension of citizenship and the rights model, self-advocacy and empowerment are important to the understanding of current service user involvement. This "democratic approach" to user involvement is considered to have originated with service users' expression of their views and fight for their rights. Empowerment has its ideological roots in the civil rights movement in the U.S. in 1960s and the fight for women's and black people's rights. The slogan "Power to the People" is descriptive. A primary goal of these social movements was to ensure civil rights and equal opportunity for all people in society (Croft & Beresford, 1996)². Important to empowerment is the idea of influencing policy making and reforming power structures in the society, in response to the marginalization and oppression of individuals and groups. According to Rappaport (1981), empowerment enhances people's control over their own lives, and increases community participation. It challenges existing models and standardized

² The empowerment literature has different positions. Here the discussion centers on empowerment in relation to self-advocacy and suppressing social and structural aspects in society. Askheim (2007) discuss empowerment as a market-oriented approach and empowerment as a therapeutic position.

approaches to health and social problems. An important step is for professionals to redefine their roles as experts holding all of the solutions and to become collaborators who consider people's experiences and knowledge about their lives and situations (Starrin, 1997). Although empowerment can be useful for the understanding of user involvement, and involvement is necessary to empowerment, user involvement and participation do not necessarily imply empowerment (Rifkin, 2003). Empowerment refers to a redistribution of power, enhanced awareness of one's own rights and self-advocacy, all in order to increase one's control over his/her life and health. User involvement for inpatients does not necessarily reflect these aspects. User involvement may be limited to participation in certain situations, be based on providers' professional judgments, and not be derived from the users themselves.

2.4 Consumerism

New concepts and issues such as service users, individual choices, consumerism, and service quality have entered the public sector over the last two decades. These are reflected in New Public Management (NPM), an ideology that emerged as a critique of bureaucracy and inefficiency in the public sector (Stamsø, 2005). A core goal of NPM has been to increase the public sector's ability to deliver economically efficient services, by adapting market models, and principles and ideas from management and administration of the private sector (Busch, Johnsen, & Vanebo, 2003). Although the applicability of market models to social institutions and health services has been debated (Arrow, 1963), consumerism and NPM have had a major impact on the development of public welfare services in many European countries.³ In relation to user involvement, NPM and consumerism emphasize that

³ A more complete elaboration on NPM and the implications of NPM reforms in Norway is provided by Stamsø (2005).

citizens ought to be viewed as consumers of public services, free to choose among different services, and to participate in planning public services (Busch, et al., 2003). This approach represents a shift in focus from viewing users of public services as passive and dependent recipients to viewing them as active and competent consumers with demands for medical and health services. For example, people in Norway choose their general practitioner. The information service “Free hospital choice Norway”⁴ supports patients’ right to choose where to receive treatment (Norwegian Patient Rights Act, 2001). Service users have the power to choose the services that best fit their needs, preferences and that are of the highest quality (Storm, Rennesund, & Jensen, 2009).

Despite service users’ increasing self-advocacy, there is a concern over the extent to which patients are able to fulfill the consumer role and to make informed choices when sick and in need of professional assistance (Bradshaw, 2008). Taylor-Gooby’s (1994) critique of the post-modern welfare argues that market liberalism’s emphasis on individual responsibility, individual rights, and choices may obscure the increased risk of the marginalization of groups with fewer economic and social resources. Although the consumerist approach allows the individual to become the judge of services, this does not necessarily allow the consumer to influence the underlying service ideology (Hickey & Kipping, 1998). Croft and Beresford (1996) claim that participatory initiatives in a consumerist approach has tended to come from service providers to address the concerns and needs of services.

Regardless of perspective and theoretical basis, service users’ involvement in health services entails a redistribution of power between providers and recipients of care. User involvement is relevant as people have more knowledge about their health, treatment, and care, which had earlier been reserved to experts or professionals, and people are important in managing their own health. The extent to which providers

⁴ <http://www.frittisyekehusvalg.no/english>

and patients are prepared for these changes in their roles and relationships has not fully been explored (Anderson & Funnell, 2005).

2.5 Individual user involvement

The terminology describing patients' role in planning and implementing their own treatment includes concepts such as participation, involvement, shared-decision making, and partnership (Cahill, 1996; Elwyn, Edwards, Kinnersley, & Grol, 2000; Hickey & Kipping, 1998). These concepts are often used interchangeably (Thompson, 2007).

Arnstein's (1969) eight-rung ladder of citizen participation is an early model derived to describe the levels of citizen participation and citizen power in community development. Manipulation and therapy are the lowest rungs of the ladder and are considered non-participation; informing, consultation and placation are in the middle and are referred to as degrees of tokenism; while partnership delegated power and citizen control is placed at the top of the ladder, reflecting degrees of citizen power. Although the model was not developed to conceptualize the patient-professional relationship, it has been an important frame of reference for the development of frameworks relevant to that relationship (Eklund, 1999; Thompson, 2007). Charles and DeMaio (1993), influenced by Arnstein's model, proposed an analytical framework describing different aspects of lay participation in health care decision-making. They include the following three variables in their model: 1) decision making domains referring to treatment, service delivery and broad macro-or system-level decision-making, 2) role perspectives, including the user perspective and the public policy perspective, and 3) level of participation and to the extent to which individuals have control over the decision-making process using the terms informing, partnership and lay control.

Cahill (1996) made an important conceptual clarification when distinguishing patient participation from patient involvement and patient collaboration. According to Cahill, patient involvement are the

basic often-delegated tasks and do not extend to more complex intellectual activities. Patient collaboration is a matter of intellectual cooperation between provider and patient for the purpose of decision-making. Both are precursors to patient participation, and are at the bottom of the hierarchy. Patient participation is in the middle of the hierarchy and involves sharing of information, power transfer from nurse to patient, intellectual, and/or physical activities, and the positive benefits of these activities. Partnership is at top of the hierarchy and demands a working association between two people in a joint venture; it is contract-based and includes risks and benefits. In a partnership model, both the patient and provider hold expert knowledge which needs to be shared, and combined for the patient to manage the illness and achieve a beneficial outcome (Cahill, 1996). The sharing of information and joint decision making are the key components in making patients partners in managing a chronic disease (Coulter, 1999).

In a mental health hospital context Hickey and Kipping (1998) argue that service user involvement can be described on a participation continuum, with four positions: information/explanation, consultation, partnerships, and user control. The first two are fundamental to user involvement, but do not guarantee the inclusion of user involvement in the final decision-making process. Providers can make the final treatment decision on behalf of patients based on their own professional discretions. For partnerships, more power is distributed to patients, as patients and service providers jointly participate in decision-making. For user control, power is redistributed to service users as patients can make their own decisions, which can be independent of service providers. The participation continuum can be useful to illustrate service user involvement as a process, where patients can be passive or active participants in their treatment and care, depending on mental health symptoms, motivation, and interests for participation. In inpatient mental health care, patient involvement may be limited to participation in certain situations, be based on providers' professional judgments and models of care, and not be derived from the users themselves.

Participation, involvement, and shared-decision making can pose challenges. When a patient's and provider's perspectives are both taken into account in decisions about treatment and care, differences in perspectives on the course of the disorder and recovery might occur. Deegan and Drake (2006) illustrate such a clash of perspectives when it comes to medication. Can a provider know when a medication is working well? The patient might feel that he or she is being controlled by the medication, and experience a feeling of losing him/herself. Deegan and Drake (2006) wonder who should be the one to decide if a medication is working. A shared decision-making model acknowledges both perspectives, strives for consensus on the patient's problem, and sets treatment goals and a course of evaluation. There will be situations in which shared-decision making is not fully applicable, such as when a patient is temporarily incapacitated. Paternalistic treatment practices in which a patient's autonomy is disregarded are still a part of psychiatric treatment practices in Norway (Norwegian Mental Health Act, 1999) however, providers must be responsive to individual patients' preferences, needs, and values in the decision-making.

2.6 Carer involvement

The importance of family when a person experiences longstanding mental health problems, especially schizophrenia, has long been acknowledged in psychological treatment (Pilling, et al., 2002). From the early 1960s there has been interest in the effect of family environment and level of expressed emotions on the maintenance of major mental disorders (Brown, Birley, & Wing, 1972). The importance of family involvement in the therapeutic ward milieu was also emphasized by Laing et al. (1977). Providers were to facilitate family involvement by having patients set goals for increased family involvement, inviting family members to the department, and having nurses spend time with patients and family for purposes of assessment and intervention (Laing, et al., 1977).

The effects of family therapy programs for treatment of schizophrenia have been extensively investigated (Leff, Kuipers, Berkowitz, Eberlein-

Vries, & Sturgeon, 1982; Pfammatter, Junghan, & Brenner, 2006). Today there is evidence that psycho-educational programs with families, especially single-family therapy, has clear positive effects on individual outcomes: there are fewer psychotic relapses and readmissions, in addition to benefits related to adherence to medication (Pfammatter, et al., 2006; Pilling, et al., 2002). Common elements in family programs are social support, education about the disorder and its treatment, guidance and resources during crisis, communication training, and training in problem solving (Chien & Chan, 2004; Falloon, Boyd, & McGill, 1984).

Including family in the understanding of user involvement is important as it focuses on how families are to be viewed and met when it comes to inpatient treatment and care. In Norway, the Patient Rights Act (2001) gives family members or caregivers a right to receive information about regulations, common practices and procedures, and to receive advice about the mental disorder. But information about specific treatment interventions and services that the patient receives is still protected by confidentiality, when the patient does not agree to that information being disclosed.

Despite the beneficial effects of family therapy programs, and the importance of family for people with longstanding mental health disorders, studies from Norway show that carers are not always satisfied with mental health services (Engemark, Alfstadsæter, & Holte, 2006; Sverdrup, Kristofersen, & Myrvold, 2005). Carers report that they lack influence on decision-making, and that they receive little information about their relative's mental health disorder, treatment, and recovery. One common complaint is that providers are too strict about confidentiality (Engemark, et al., 2006). International studies also report that carers would like more information, more time, and support from the mental health services in addition to greater involvement in the planning and implementation of services (Goodwin & Happell, 2006; Lakeman, 2008; Walker & Dewar, 2001). Challenges perceived by providers were that patients and carers disagree on treatment and care. Providers expressed a genuine desire to involve carers, but there were conflicts with the wishes of the patient. Sometimes the rights of

carers to information and participation were viewed as secondary to the patient's right to confidentiality (Goodwin & Happell, 2006).

2.7 User involvement in services

A precondition to offering high-quality health services is to acknowledge the perspectives of service users, their experiences from and knowledge of service provision (Andreassen, 2005). This implies that user involvement involves more than the individual patient's influence on his or her own treatment and care. User involvement also intends to ensure that people with experiences of mental health services and background from user organizations are involved in the development and delivery of health care services (Andreassen, 2005; Crawford, et al., 2003). Crawford et al. (2003) list numerous methods used by mental health trusts in London for enhancing service users' influence on development of services: users are involved in staff appointments, users contribute to planning training programs for staff, users are involved in assessing the quality of services provided, and users attend trust board meetings. Service users are often active partners in health research in order to achieve better quality research which might lead to better quality health services (Beresford, 2005; Smith, et al., 2008). A suggested area for development in Norway has been employment of service users to work as providers in health services (Poverud, 2008). In the US the term "consumer providers" is frequently used. A consumer provider is a person with a serious mental illness, along in recovery and therefore in a position to act as a provider of health services (Chinman, Young, Hassell, & Davidson, 2006).

These methods for stimulating user involvement ensure that people's experiences and perspectives on service provision are heard and taken into account in decision-making and in service development (Andreassen, 2005). These methods can moderate the power and knowledge base possessed by the health professions (Andreassen, 2005), and are an important step in the development of user-oriented and high-quality services. Still, there are challenges. Carr (2007) suggested that views and insights of service users may challenge

rationales for current practices among service providers and that conflicts and resistance will result. There are also practical concerns such as lack of competence of user involvement among providers; difficulties in recruiting service users; lack of adequate training; little support and guidance; questions about whether service users' views are representative of the user group they represent; and concerns about financial resources to support service users and their organizations (Chinman, et al., 2006; Crawford, et al., 2003; Crawford & Rutter, 2004; Rutter, et al., 2004).

2.8 *Influencing factors on service user involvement*

2.8.1 *The mental disorder*

Common experiences following living with a long-standing mental disorder such as schizophrenia are: “deficits in social skills and judgments, thought disorder, attention, concentration, and communication difficulties, hypersensitivity towards negative affect and interpersonal conflict and loss of self” (Davidson, et al., 2001, p. 276). People also describe obstacles that do not relate to the disorder itself, such as loss of interpersonal relationships, loneliness and social isolation, stigma, poverty, unemployment and lack of opportunities for establishing meaningful social relationships with people outside of the mental health system (Davidson, et al., 2001; Davidson & Stayner, 1997). Most people diagnosed with schizophrenia take antipsychotic medication. There is increased evidence that treatment with medications may not be sufficient in removing the most troubling symptoms in schizophrenia (Pilling, et al., 2002). Good information, self-determination and participation in making important choices, and developing competence about coping, self-care and social skills are some aspects associated with recovery and capability of establishing meaningful lives (Wilken, 2007).

2.8.2 *The provider and patient relationship*

Providers who are therapeutically involved with their patients are the foundation of the therapeutic environment (Laing, et al., 1977). In psychotherapy, the quality of the therapeutic alliance, defined broadly as the collaborative and emotional bond between the patient and the therapist, has a significant influence on the therapeutic outcome (Martin, Garske, & Davis, 2000). It is associated with satisfaction with care, retention in treatment, and adherence to treatment recommendation both in inpatients and in outpatients (Eisen, Dickey, & Sederer, 2000). Most theoretical definitions of the alliance have three themes: “the collaborative nature of the relationship, the affective bond between patient and therapist and the patient’s and therapist’s ability to agree on treatment goals and tasks” (Martin, et al., 2000, p. 438). These elements can be considered important for user involvement.

There are several aspects of user involvement and the patient-provider relationship. People living with a mental disorder have a range of needs and interests when it comes to participation and involvement in care planning (Anthony & Crawford, 2000; Lammers & Happell, 2003). Service users’ and providers’ perspectives on treatment and care are not necessarily the same (Thompson, 2007). Studies have found differences in patients’ and providers’ views on the patient’s need for monitoring and follow-up from mental health services (Hansen, Hatling, Lidal, & Ruud, 2002, 2004; Thornicroft & Slade, 2002). Service users and providers also differ in their perception of the barriers to collaborative treatment planning (Chinman, et al., 1999). In a study by Chinman et al. (1999), providers regarded patients’ disabilities, non-compliance with treatment, and lack of interest as the three greatest barriers. Patients reported being resigned to being excluded from the planning of their own care because they perceived their providers as too busy or as insufficiently trained in collaborative care. They were also uncertain as to whether or not care planning or care in general would make a significant difference.

A review of service users’ expectancies with UK mental health nurses (Bee, et al., 2008), reported few studies with evidence of user

collaboration. In the inpatient mental health setting, patients reported inadequate provision of information, poor communication among professionals, inaccessible nurses, and lack of opportunities for collaborative care. The information that service users desired related to the mental disorder, social and legal aspects, information about the environment in which they were receiving care and organizations that were able to help. When such information was not provided, patients were found to be more likely to perceive providers as impersonal or paternalistic. Inpatient staff showing empathy, compassion, respect and understanding was also emphasized as important (Bee, et al., 2008).

2.8.3 Power

Enabling patients' involvement and participation in inpatient mental health care requires a closer focus on power. Weber (1971) argues the direct power perspective: power is related to individuals' ability to assert their own will, despite the resistance of stakeholders. Dahl (1961) contributed to the direct power perspective in *Who governs?* His analysis assumes that power is exercised directly in decision-making processes, involving observable conflicts of interest, depending on power resources and influence from involved stakeholders. Power is manifested when a decision is made after alternatives proposed by involved stakeholders have been rejected. Lukes (2005, p. 37) define the concept of power as follows: "A exercises power over B when A affect B in a manner contrary to B's interests." These power perspectives have implications for inpatient mental health treatment and care. Providers have a therapeutic and legal responsibility for the patients' treatment and for the coordination of services. If a person with a serious mental disorder refuses to consent to treatment, the Norwegian Mental Health Act (1999), § 3-3 allows compulsory psychiatric treatment in order to prevent that the person a) from having reduced prospects to cure or recovery, or b) from constituting an obvious danger to his or her own or other people's lives and health. The patient has a right to be heard, to file a complaint about the decision to the commission, and to receive information about his or her illness,

treatment and rights (Norwegian Mental Health Act, 1999; Norwegian Patient Rights Act, 2001).

Lukes (2005) is concerned that power also can be hidden. Hidden power is exercised when problems or conflicts are prevented from coming to the surface; they have been excluded from debate and decision-making (Lukes as cited in Croft & Beeresford, 1996). Hidden power is sustained in daily life and institutions through rules, norms and routines (Vik, 2007). Ward rules may be examples of hidden power. Rules and routines are important as they keep order and ensure predictability (Norvoll, 2007), but they are only rarely being challenged or questioned by staff or patients.

Croft and Beresford (1996) emphasize that user involvement does not necessarily mean that power is taken from providers and given to the service users. Involvement is concerned with changing the relationship among involved stakeholders. Providers have professional competence and knowledge of mental disorders. The patients live with their disorder. Croft and Beresford (1996) argue that participatory initiatives can be the most important route for redistributing power and altering current relationships. They also emphasize that stakeholders need to be clear on objectives and expectations of involvement and participation, what the opportunities are, and where control lies.

2.8.4 *Organizational culture and leadership*

Despite enhanced focus on service user involvement, studies from the UK and the US show that mental health services do not necessarily adapt quickly to user-oriented practices, even when these practices have been documented to be useful (Carr, 2007; Chinman, et al., 2006; Nelson & Steele, 2007). Implementation may be influenced by organizational culture, service providers' awareness and attention, training and competence about user involvement (Hodges & Hardiman, 2006; Rutter, et al., 2004; Steinsbekk & Solbjør, 2008). It is not yet known how such factors might affect the implementation or lack of implementation of service user involvement in inpatient settings.

Organizational culture is a characteristic, that can be changed, improved, or managed (Davise, Nutley & Mannion, 2000). Schein (1992, 2004) is one of the most important contributors to this perspective on organizational culture. A common understanding of organizational culture is that it is learned and built from its members' shared experiences. Organizational culture cannot be avoided, and has the potential to reinforce desirable behaviors and sanction undesirable ones (Schein, 1990). Characteristic of an organizational culture are norms specifying how things should be done, values and assumptions of preferable or desirable organizational behaviors, as well as organizational goals and structures (Scott, 2001). Organizational culture influences leadership practices, interactions of leaders and followers, leaders and followers' foci of attention and their decision-making. Croft and Beresford (1996) express a concern that people's rights to participation and involvement can be undermined or remain unused because they are not part of the dominant culture or tradition.

Differences in organizational culture among health care institutions have been explored. Glisson et al. (2008) identify organizational culture profiles, which influence providers' use of evidence-based practices. The authors found that reports on key culture constructs were often tied to the clinic in which the provider worked. There has in literature been a discussion concerning how deeply seated the culture is in organizations and if this has implications to change processes. A distinction is made between culture as open and conscious to organizational members, as distinct to culture as covert and unconscious (Davies, Nutley, & Mannion, 2000). Schein (1990) and Argyris and Schön (1996) use the term *espoused values* when referring to values, rules and norms made explicit in organizations, for example in strategic documents. These are easiest to change. Opposed to *espoused values* are *theories in use*. These are implicit and unconscious assumptions, beliefs, and values that organizational members take for granted. These aspects of organizational culture affect perceptions, feelings and behaviors of leaders and followers, they can be inconsistent with espoused values, and might be hard to uncover and change.

Some theorists have focused on how to change or improve organizational culture. According to Schein (1992), leaders can influence organizational culture in several ways. Schein emphasizes the leader's focus of attention, the leader's reaction to crisis and pressure, the leader as a role model and the leader's ability to influence organizational routines, systems, or organizational design. Successful organizations continually adapt to changing social expectations. A basic assumption in theories of organizational learning is that in organizations learning takes place beyond its members' knowledge and experience (Senge, 2006). Argyris and Schön's (1974, 1996) model describes organizational learning as single- and double-loop learning. In single-loop learning, the individual, group or organization changes behavior to achieve results according to the organization's norms and values. Existing methods are refined in order to avoid mistakes. When the behaviour of the individual, group or organization is changed as a result of questioning fundamental values and the usefulness of procedures and norms, one can talk about double-loop learning.

Central to Argyris's writings has been descriptions of difficulties to achieve double-loop learning, resistance to change in organizations, and the difficulties people have with being open and in dialogue. This is also about the relationship between what the organizational members claim to do and what they actually do. Yukl (2006) states that cultural change may be difficult as history and traditions justify current organizational practices, and can create resistance to change among organizational members. Resistance to change can follow from beliefs that changes are unrealistic, not achievable, will have personal and organizational costs. It might also be caused by fear of losing power and authority.

The intervention program "Service user involvement in practice" was developed and implemented as part of this thesis as an initiative to facilitate change. The program was based on literature on organizational culture and organizational learning, and research on organizational interventions emphasizing employee learning, dialogue, and participation (Argyris & Schön, 1996; Mikkelsen, et al., 2000; Schein, 2000, 2004). A core aspect was that change cannot take place

without the participation and experiences of those most directly affected (Le Blanc, Hox, Schaufeli, Taris, & Peeters, 2007; Mikkelsen & Gundersen, 2003). Providers' and inpatients' experiences with participation and involvement in treatment and care are a cornerstone in the intervention. In addition there is an educational program to enhance providers' and inpatients' competence about service user involvement.

2.8.5 Research questions

The literature presented above is essential to conceptualize user involvement. It is an important basis for the research questions in this thesis. The following research questions are examined in the four empirical papers:

- 1) How can service user involvement in inpatient mental health care be conceptualized and empirically measured from providers' perspective? (Paper I, Paper II, Paper IV)
- 2) Do individual and organizational characteristics influence providers' reports of service user involvement? (Paper II)
- 3) What are the experiences of inpatients' and providers' with user involvement in inpatient mental care? (Paper III)
- 4) Can an intervention program designed to turn attention to and develop user involvement practices in inpatient mental health care influence on service providers' user involvement practices and inpatients' experiences with care? (Paper IV)

3 Methods

3.1 Methodological considerations

A fundamental issue in social science research is the relationship between data and social reality and the extent to which the researcher can represent the social reality he or she claims to be studying. These issues are related to what is believed to constitute reality (ontological assumptions) and claims about how to gain knowledge about social reality (epistemological assumptions) (Blaikie, 2000). For example, do different research approaches or paradigms such as positivism and constructivism entail contradictory viewpoints with regard to what constitutes reality and how to study it. From a positivist view, the world is singular and objective, paying strong attention to validity and/or generalizability in the research process. In the constructivist view, the world is multiple, and individually or culturally constructed (Crotty, 1998; Sandelowski, 2000). The researcher's own experiences, discipline-based knowledge, culture, and expectations from the research community will influence the research approaches that are adopted (Blaikie, 2000).

There is disagreement over the extent to which a researcher can study a phenomenon within the frame of two different world views or paradigms (Blaikie, 2000; Crotty, 1998; Sandelowski, 2000). This does not contradict the combination of research methods and the use of both quantitative and qualitative data in the same research project. According to Blaikie (2000), different methods can be used to explore the same assumed objective reality, and data from different sources can be translated from one form to the other (e.g. from qualitative to quantitative). In a critical realist perspective, the ultimate goal of research and combining quantitative and qualitative method is to deepen the understanding and arrive at an explanation of the phenomenon under study (McEvoy & Richards, 2006). This thesis uses both quantitative and qualitative research methods to explore different

aspects of user involvement in order to obtain a complete picture of user involvement in inpatient mental health. The quantitative methods attempts, in an objective and standardized manner, to measure certain aspects of service user involvement, to identify statistical associations and to test potential causal associations. The qualitative methods and data are used to explore and describe user involvement from the perspectives of both inpatients and providers. The qualitative methods allow for themes to emerge during the inquiry and can illuminate the complexity of the phenomenon being studied (McEvoy & Richards, 2006).

3.2 Research context

Norway is a Scandinavian country of 4.8 million in Northern Europe. Norway maintains a Scandinavian welfare model with advanced and universal public social and health care services. Universal welfare systems are based on principles of equity and equal access to high-quality health services regardless of income and place of living (Stamsø & Hjelmtveit, 2005). The mental health service system comprises primary community care and specialist health care. The latter is provided by psychiatric hospital care and Community Mental Health Centers (CMHCs) (Norwegian Directorate of Health, 2006). CMHCs in Norway are independent units, most often affiliated with a mental hospital. A standard CMHC has an outpatient clinic, an ambulant team, and one or more inpatient departments, and is responsible for providing specialized, easily accessible, and coordinated inpatient and outpatient mental health services to people between 18-70 years within a designated geographical area (Norwegian Directorate of Health, 2006; Norwegian Ministry of Health and Care Services, 1996). The most common diagnoses among inpatients are schizophrenia and bipolar disorder (Lilleeng, Ose, Bremnes, Pedersen, & Hatling, 2009). Nurses, nurses specialized in mental health care and auxiliary nurses are the main professional groups at the CMHCs and the inpatient departments. Regarding psychiatrists these are often not distributed to the underlying organizational units, for example inpatient departments (Sletnes, et al., 2008).

3.3 Research design

The research design has two phases. Phase 1 focuses on the conceptualization of user involvement, development, and on the testing of items to empirically measure service user involvement in inpatient mental health services from providers' perspective. These measurement building efforts comprise the basis of paper 1. Paper 2 is a cross-sectional study, using data from inpatient providers in five CMHCs in Norway to investigate user involvement at the individual and departmental levels of service. We also examine factors that influence providers' reports of service user involvement.

In phase 2, the focus is on the intervention program "Service user involvement in practice" implemented to 1) increase attention to user involvement and 2) increase user involvement at the inpatient departmental level. Paper 3 uses qualitative data collected as part of the intervention program to explore inpatients' and providers' experiences with user involvement in inpatient care. In paper 4, we study the impact of the intervention program using a quasi-experimental design with non-equivalent comparisons. Two CMHCs were assigned to participate in the intervention program. Three CMHCs participated for the purpose of comparison. Survey data to assess the impact of the intervention was gathered from providers before implementation of the program (T1) and when the intervention program ended (T2). Data from inpatients was gathered only when the program ended (T2).

3.4 Samples

The study participants in this thesis are from six CMHCs in Norway. Figure 2 shows the time of measurement, sample sizes, response rates, and populations in the four papers.

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Paper 1:	Paper 2:	Paper 3:	Paper 4:
<p>Population: Service providers in one CMHC</p> <p>2006: N=121</p> <p>Response N=98 (81%)</p>	<p>Population: Service providers in inpatient departments in five CMHCs</p> <p>2007: N=224</p> <p>Response N=186 (83%)</p>	<p>Population: Inpatients and service providers in the intervention departments in two CMHC</p> <p>2007: 20 individual interviews with inpatients</p> <p>2007/2008: 16 recordings of minutes from staff meetings and 14 log reports from providers</p>	<p>Population: Service providers and inpatients in inpatient departments in five CMHCs</p> <p>Providers: 2007: N=224 (Time1) Response: N=186 (83%) 2008: N=186 (Time2) Response: N=123(66%)</p> <p>Inpatients 2008: N=110 (Time2) Response: N= 47 (43%)</p>

Figure 2. Populations, samples and response rates for the four papers.

In paper 1, the sample consisted of 121 mental health providers employed at both an inpatient and outpatient clinic at a CMHC in the western health region of Norway. The main inclusion criteria were contact with patients and at least a 50% employment position. A total of 98 providers filled out and returned the questionnaire, yielding a response rate of 81 %. Nurses, auxiliary nurses, and social educators constituted 67 % of the respondents, while psychiatrists, doctors, psychologists, and social workers constituted 24 % of the respondents. The largest percentage of the respondents worked day and evening shifts (46 %).

Study sample in paper 2 was inpatient mental health providers from five CMHCs, three CMHCs in the western health region and two

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CHMCs in the south-east health region. A questionnaire was administered to 224 service providers employed in the inpatient departments in August 2007. In total, 186 providers filled out and returned the questionnaire, yielding a response rate of 83 %. The largest occupational group was nurses, followed by auxiliary nurses and social workers. A few psychiatrists completed the questionnaire, and were included in the category “other occupational group.” Most service providers (63 %) had a two-shift work arrangement, working day and evening shifts.

The study sample in paper 3 consisted of inpatients and service providers in the two CMHCs that participated in the intervention program “Service user involvement in practice.” Twenty inpatients took part in individual interviews. They were between 18-70 years of age, and had been diagnosed with Schizophrenia, Schizoaffective, or Bipolar disorder. The majority of the interview participants were voluntarily admitted. Two interview participants reported that they were admitted to inpatient care for the first time, while the rest of the interview participants had histories of multiple and long term admissions to mental hospitals. Service providers in the study were nurses, mental health nurses, auxiliary nurses, social workers, department leaders and therapists employed at the inpatient departments in two CMHCs. Data were log reports written by providers, and meeting minutes from staff meeting.

Paper 4 included the same sample of providers as paper 2. The 186 providers who responded to the survey in August 2007 (T1) were given a second questionnaire in May, 2008 (T2). At T2 there were 123 respondents, which gave a response rate of 66 %: 51 respondents from the intervention departments and 72 respondents from comparison departments. Some reasons for non-response to the second questionnaire were retirement, maternity leave, long-term sick leave, moving, and changing jobs.

In paper 4, a sample of inpatients and providers from the same departments was included. One hundred and ten questionnaires were administered to inpatients during a two week period in May, 2008 (T2).

Forty-seven inpatients filled out and returned the questionnaire, which gave a response rate of 43 %. There were twenty-seven men and nineteen women. Seventeen respondents were involuntarily admitted. There were seventeen respondents from the intervention site and thirty respondents were from the comparison site.

3.5 Scale development

Measuring psychological and social phenomena, most often by the use of self-reports in questionnaires, is an important aspect of research in the behavioral and social sciences (Netemeyer, et al., 2003). There are constructs that are relatively easy to measure by self-reports, for example, sex or age. To measure more complex social-psychological constructs (or latent variables) believed to exist, there is a need for a deeper theoretical understanding, multi-item measurement scales to reveal varying levels of the underlying construct, and statistical methodology (DeVellis, 2003). Current literature on scale development note that it is time-consuming and demanding to develop solid and relevant measurement scales. Special attention during the development process should be placed on the instrument's psychometric properties: dimensionality, reliability and validity (DeVellis, 2003; Netemeyer, et al., 2003).

A requirement of a valid measurement scale is that the construct and its domain be clearly defined. Theory plays an important role and attention should be paid to what is to be included and excluded from the domain of the construct. The constructs content domain can be either one-dimensional or multidimensional. In a one-dimensional measurement scale, the items represent a single construct or latent variable. In a multidimensional measure, the scale items tap more than one dimension, and more than one construct is needed to reduce the partial correlation to zero. Each dimension represents a latent variable, and the items operationalize their dimension (Netemeyer, et al., 2003).

Scale reliability represents the proportion of the measurement that reflects the scale's permanent effects: the proportion of variance

attributable to the true score of the latent variable. Reliability is concerned with the internal consistency and homogeneity of the items within the scale (DeVellis, 2003; Pedhazur & Schmelkin, 1991). Internal consistency is influenced by the scale items' inter-correlations, the number of items in the scale, and is typically assessed with Cronbach's coefficient alpha. Cronbach's alpha can range from 0.0 to 1.0. A low alpha score is usually considered to be below .06, while acceptable values lie between .70 and .90 (DeVellis, 2003; Netemeyer, et al., 2003; Pett, Lackey, & Sullivan, 2003).

Although a measurement scale turns out to be reliable, this does not guarantee that the latent variable is of interest. A measurement scale's validity is inferred from the process of constructing the scale, the scale's ability to predict specific events, or its relationship with other constructs (DeVellis, 2003; Netemeyer, et al., 2003). The degree to which the measure actually measures the latent construct it is intended to measure is a key issue (Netemeyer, et al., 2003). Content validity is the ability of the items on the scale to tap the entire constructs content domain and the meaning of the latent constructs (Imle & Atwood 1988). There are various recommendations and ways of ensuring a measurement's content validity. Interviews with participants for whom the measure is intended can be one useful method of capturing the concept domain, identifying domain dimensions, and providing item wordings (Morgan, 1997; Pett, et al., 2003). Items can also be generated by the use of statements from research involving the construct or be based on the researcher's knowledge and understanding of the construct domain and its underlying theory (Netemeyer, et al., 2003). The initial item pool should be comprehensive in coverage and include a large number of potential items across the defined theoretical dimensions. A large number of items increases the likelihood that all dimensions of the construct will be adequately represented. During the item generating and judging process, attention should be paid to item writing and response format. A useful approach is to use a panel of lay people and experts to judge both content and face validity of items in the initial item pool, and follow-up with a pilot test of the items on a larger relevant population ($n > 100$). This latter procedure will allow testing of the scale's psychometric properties and explorative factor

analysis to establish an initial factor structure, and retain a set of final items (Netemeyer, et al., 2003). Exploratory factor analysis is generally used in instrument development when the researcher is uncertain about the number of factors that are necessary to explain the interrelationship among the items (Pett, et al., 2003).

To secure a measurement's psychometric properties, confirmatory factor analysis (CFA) is recommended. CFA confirms the scale's hypothesized structure by testing the relationship between the measurement items and their dimensions (also referred to as factors or subscales). It is commonly used when the researcher has some knowledge about the underlying structure of the construct (Pett, et al., 2003). Goodness of fit measures is important in CFA. Fit measures are used to test the degree to which a hypothesized model fits the sample data. The following fit indices are common and applied in papers 2 and 4 in this thesis: root mean square error of approximation (RMSEA), comparative fit index (CFI), and incremental fit index (IFI). With reference to applied rules for acceptable fit reported in Byrne (1998) for RMSEA, $RMSEA < .08$ considered moderate fit, values $< .05$ are considered as close fit. RMSEA values greater than .10 indicate poor fit. For CFI and IFI, values greater than .90 are considered as acceptable model fit (Byrne, 1998). It is common to use the statistical software package SPSS when conducting EFA. CFA require statistical software such as LISREL that can undertake SEM (structure equation modeling) and extensive analysis of covariance structures (Pett, et al., 2003). Further usefulness of the measurement scale will depend on repeatability and stability of the measure over time (Netemeyer, et al., 2003).

3.6 *Measuring service user involvement*

In paper 1 we describe the process of generating items, ensuring the items' face and content validity before empirically testing items with a sample of inpatient mental health service providers. Thirty items and four relatively distinct dimensions or subscales: "democratic patient involvement," "carer involvement," "assisted patient involvement," and

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“management support” were established, and named the Service User Involvement in Mental Health (SUIMH) Scale. All items were measured on a 5-point Likert scale, from 1=“completely disagree” to 5=“completely agree.”

Following the empirical test, some revisions were made to the items in the subscales. These were based on feed-back from service providers who took part in the testing, and from consulting literature on user involvement. The most important modifications were altering the items response format from a 5- to a 7- point Likert scale, and changing the labeling from agreement, to measuring frequency of behavior using the labeling 1=“never” to 7=“always.” Three items in “democratic patient involvement” were modified and named “patient collaboration” assessing the provider-patient relationship. All modifications were made to emphasize providers’ behaviors in their daily work.

The questionnaires administered to providers at T1 and T2 contained the following definition to clarify the meaning of *service user involvement*: 1) A patient or service user and his/her carers is to participate and have influence on his/her service planning and delivery, and 2) service users are to have influence on mental health service provision in general. The study participants were also asked: “In your opinion, how important is service user involvement in mental health services?” This question assesses a general opinion about user involvement. It was rated on a unipolar scale from 1=“not important” to 10=“very important.” This rating was included as an independent variable in the regression analyses in paper 2.

In paper 2, two subscales, “patient collaboration” and “assisted patient involvement” were used to measure user involvement at the individual level. “Patient collaboration” is measured by three items, and is the extent to which service providers view themselves as encouraging, discussing, and collaborating with their patients when planning and implementing treatment. “Assisted patient involvement” is measured with five items, and is the extent to which service providers perceive their patients as involved in their own treatment in the department. All items were measured on a Likert scale from 1=“never” to 7=“always.”

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To survey service user involvement at departmental level, four items from the CPQ (Kent & Read, 1998) were adapted and used. These represent the 5-item subscale “organizational user involvement.” The subscale’s items cover service user involvement in terms of soliciting service user representatives at the department level or at the community mental health center, involving service users in teaching and training sessions, and in the hiring decisions of providers in the departments. All items were measured on a 5-point Likert scale from 1=“never” to 5=“very often.”

In paper 4, the impact of the intervention on providers’ reports of user involvement was assessed with the following five subscales: “patient collaboration,” “assisted patient involvement,” “carer involvement,” “management support,” and “organizational user involvement.” The first four subscales are derived from the (SUIMH) Scale. The items were measured on a Likert scale from 1=“never” to 7=“always.” “Carer involvement” is measured with five items. The subscale assesses the extent providers’ share information, and involves carers in treatment planning and decisions about discharge. “Management support” is measured with five items and represents providers’ perception of encouragement and support for patient involvement. “Organizational user involvement”, “patient collaboration,” and “assisted patient involvement” was the same selection of items as in paper 2.

In paper 4, inpatients’ experiences with their involvement in the decisions about treatment and care were measured with the Psychiatric In-Patient Experiences Questionnaire (PIPEQ) (Bjertnæs, Garratt, & Johannessen, 2006; Garratt, Danielsen, Bjertnæs, & Ruud, 2006). The questionnaire contains 15 questions covering relationship with therapist, benefit of inpatient stay, information, and influence on treatment. As the questionnaire was designed to be administered to patients after discharge, some minor grammatical corrections were made before administering it to inpatients (e.g. Did you get to spend enough time with your therapist? was changed to: Do you get to spend enough time with your therapist?). Two items were also removed, as these concerned experiences with discharge. Instead the following two questions were added with yes or no response categories: Do you have

a treatment plan? Did you receive information about your right to access your medical records?

3.7 Intervention program

The aims of the intervention program were to increase awareness of user involvement practices and to stimulate development of service user involvement in the departments that took part in the intervention program. If successful, the intervention was expected to improve providers' reports of user involvement and increase inpatients' satisfaction with their treatment and care.

The program started with a 6-hour dialogue seminar in which providers, inpatients, family members, and service user representatives discussed service user involvement and its implications for the individual participants, their department, and the CMHC. Through a combination of individual work, group work activity, and plenary sessions, an action plan was established on the most important areas for work with service user involvement during the intervention period. Following the dialogue seminar, providers used monthly staff meetings with a facilitator to share and discuss current user involvement practices and their attempts to strengthen user involvement in their departments. A steering committee with a facilitator, researcher, department and organizational leader, a representative from service providers and service user representatives kept track of the intervention process through log reports from providers and written minutes from staff meetings.

During the program period, eight staff meetings were held with the facilitator. Between these staff meetings, providers concentrated on practical work to promote service user involvement in their departments, also documenting their work in log reports. In the staff meetings the log reports were presented and were followed by discussions about current work with user involvement. In the fifth session a summary of the results from the survey conducted at T1 was presented to the participants. The theme was on experiences so far, implemented activities, and need for change of course or new foci. In

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the final session, the participants formulated suggestions on how the focus on service user involvement could be sustained after the intervention period. In addition to the staff meetings, the intervention program had an educational component to enhance providers' and inpatients' knowledge about service user involvement, the benefits of involvement, and challenges. During the educational part, five sessions were held on service user involvement and its content domain, legal aspects of user involvement, user experiences with mental health services, and family involvement. Each session lasted for about one hour. The complete manual for the intervention program is available in Storm et al. (2009). Figure 3 presents the design and content of the intervention program. The program had a parallel implementation in the two CMHCs.

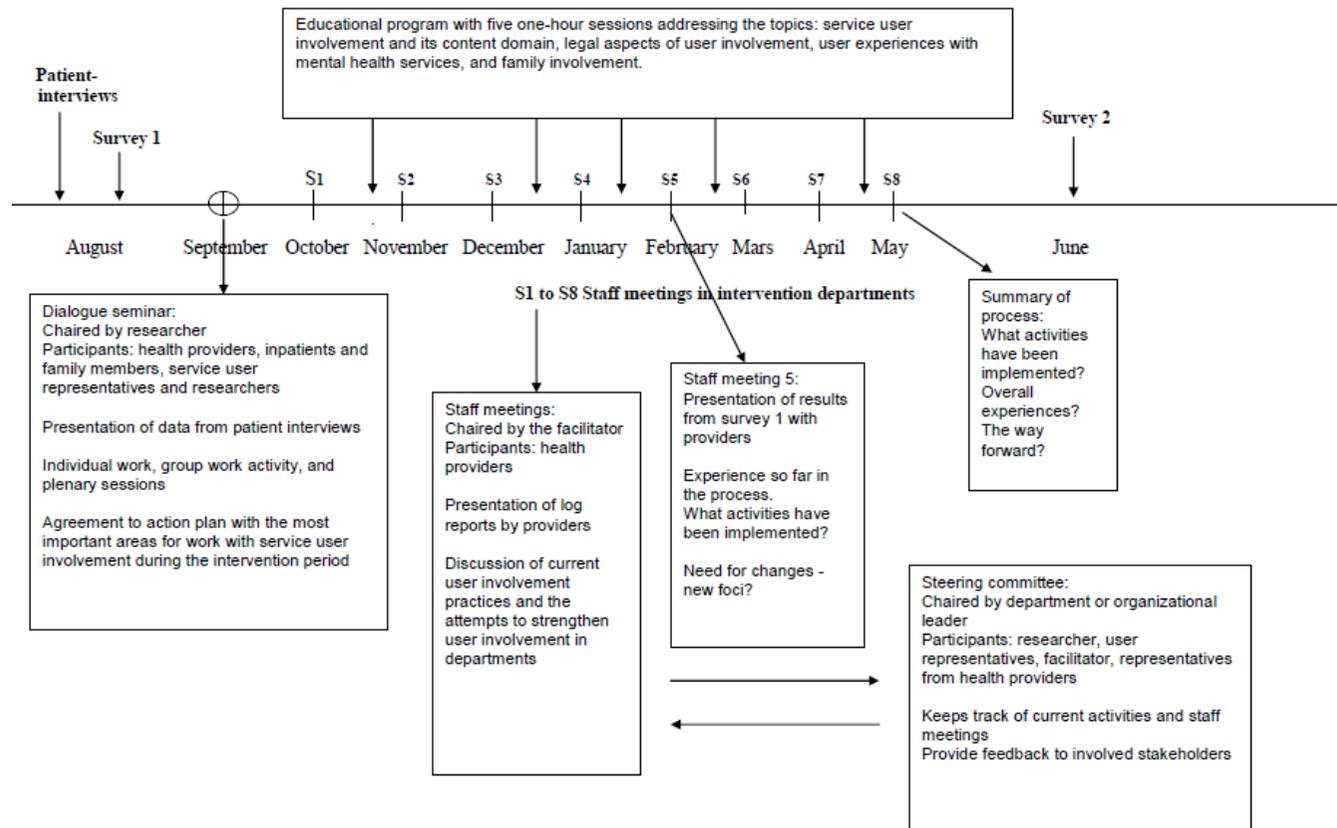


Figure 3. The design and content of the intervention program.

3.8 Qualitative data and analysis

The qualitative data gathered as part of this thesis is reported in paper 3 and includes interviews with inpatients, reports from two dialogue-seminars, log reports written by providers, and minutes from the staff meetings with the facilitator during the intervention period.

According to Kvale and Brinkman (2009, p. 1), “The qualitative research interview attempts to understand the world from the subjects’ point of view, to unfold the meaning of their experiences, to uncover the lived world prior to scientific explanations.” Research interviews with inpatients were conducted to gain insight into and to explore experiences with involvement in treatment and care while admitted to a CMHC. A semi-structured interview guide was used in each interview. Interview questions pertained to the patient’s experiences with involvement in his or her own treatment and care. The questions covered participation in the following areas: 1) discussions about medication and activities to attend in the department, 2) meetings about treatment, being provided with training and skills to cope with mental health problems, 3) filling out individual care plans and 4) relationship with service providers. An extraction of the data from the interviews was presented at the dialogue-seminar to ensure that patients’ voices and perspectives on involvement in treatment and care were heard and heeded by providers during the intervention period.

Reports from dialogue-seminar, log reports written by service providers, and minutes from staff meetings constitute the material from providers. The reports from the dialogue-seminars contained an overview of the activities to be implemented during the intervention period along with the guiding principle for user involvement in the departments. The log reports were structured and providers were to describe their efforts to promote user involvement, including their own experiences and the challenges they faced in their work. Minutes from staff meetings provided a summary of the themes discussed, questions, raised and foci during the intervention period.

According to Hsieh and Shannon (2005) and Holsti (1969) content analysis has a long history in research, and has been used both as a quantitative and qualitative approach. In qualitative content analysis, text data from, for example, open-ended survey questions, transcripts from individual interviews or from focus groups, or other printed text is analyzed. Qualitative content analysis goes beyond merely counting words to probing the meaning of the text represented either in explicit or inferred communication. The primary goal is to gain knowledge and understanding of the phenomenon under study. Hsieh and Shannon (2005, p. 1278) define qualitative content analysis as “a research method for the subjective interpretation of the content of text through the systematic classification process of coding and identifying themes or patterns.”

Qualitative content analysis was used as the analytical approach in paper 3. Empirical research on providers’ and patients’ differences in perspectives on involvement in treatment and care served as background for the analysis of the data. This is reflected in the two main themes: inpatients’ experiences with being involved and service providers’ perspective of user involvement. Since the qualitative data were collected as part of the intervention program, the guiding principles for user involvement defined by the participants at the dialogue-seminar served as the framework for organizing the findings. Interview transcripts, log reports, and meeting minutes were read several times by the researchers, to identify meaning units and sub-themes representing providers’ and inpatients’ perspectives on user involvement in inpatient mental health care. These steps were important to ensure validity in the analytical process.

3.9 Quantitative data and statistical analysis

We used quantitative survey data and performed statistical data analysis in papers 1, 2, and 4.

In paper 1, exploratory factor analysis with both varimax and oblique rotation was performed to establish a simple factor structure with a reasonable number of items to measure user involvement from the

providers' perspective. The internal consistencies of the instrument's subscales (components) were assessed using Cronbach's alpha, unstandardized mean score for each subscale were established in addition to a total score for the SUIM scale (DeVellis, 2003).

In paper 2, the statistical analyses included descriptive statistics, factor analyses, reliability testing, product moment correlation, and multiple linear regression analyses using SPSS 15.0. Confirmatory factor analysis conducted with LISREL 8.80 and maximum likelihood estimations assessed the stability and fit of the data in the subscales: "patient collaboration," "assisted patient involvement," and "organizational user involvement" to a proposed 3- and 2-factor solution that measured user involvement. Unstandardized factor-based subscales were computed, and the internal consistency of subscales was estimated using Cronbach's alpha coefficients. We were interested in assessing how individual and organizational characteristics influenced providers' reports of user involvement. Separate 4-step hierarchical regression analyses were performed for the three subscales (dependent variables), using a fixed effect or dummy variable approach allowing the detection of possible differences among CMHCs while taking individual characteristics of providers into account.

In paper 4, CFA conducted with LISREL 8.80 using maximum likelihood was performed separately on the data from providers at T1 and T2. This was done to assess the stability and fit of the data to a proposed 5-factor solution measuring providers' perceptions of service user involvement. Further statistical analysis was conducted using SPSS 15.0. Tests of reliability and computation of unstandardized mean scores for each subscale were performed before multivariate analysis of variance (MANOVA) to assess an overall effect of the intervention over time. A significant intervention effect from T1 to T2 also justified further analysis of variance by repeated measures for each of the five dependent variables. A difference in difference estimation was performed with separate regression analyses for each dependent variable to assess an intervention effect. The procedure separately tested the effect of time, the effect of treatment, and the effect of time interacting with treatment. Last, a paired sample t-test was estimated

for each subscale to assess if the changes were significant from T1 to T2, separately for the intervention and comparison group. Data from inpatients were analyzed using independent t-test and chi-square analyses to test the differences between the intervention and comparison groups on each of the items in the PIPEQ.

3.10 Ethics

The Regional Ethical Committee (no. 014.07) (Appendix A) and The Norwegian Social Science Data Services, the Privacy Ombudsman for Research (no. 16179) (Appendix B) approved the studies and the storage of data in the project.

Written information about who was conducting the research project, how the results were to be used, and that participation was voluntary was provided to all of the study participants, together with the questionnaires. Providers administered the questionnaires to inpatients, while department leaders administered the questionnaires to providers in their departments. Completed questionnaires were returned anonymously using a stamped addressed envelope. Consent was implied by returning the questionnaire. To ensure that the questionnaires were administered to the same respondents at T2, each questionnaire to providers had an identification number. The researcher kept a list of employee names and identification numbers, separate from the electronic data file and in accordance with guidelines from the Norwegian Social Science Data Services.

Before each patient interview, service providers provided written and oral information about the research project and how the data were to be used. A declaration of consent was provided to those who agreed to participate in the interview. The declaration of consent stated that participation was voluntary, that there would not be any consequences for not participating, and that it would be possible to withdraw at any time from the interview and the study.

Research involving people affects the participants in a variety of ways. A person admitted to inpatient mental health care may be in a situation, in which participating in a research project is an extra burden. This situation might also complicate a person's ability to consent to participation. The researcher has a responsibility to consider the ethical implications of the research project for the patients and other participants (Den nasjonale forskningsetiske komite for samfunnsvitenskap og humaniora [NESH], 2005). Interpretation of ethical accountability is always a question of taking care of or inflicts harm on the person. All patients admitted in the period when interviews and the dialogue-seminar were carried out were informed about the project. Providers invited patients to participate in interviews and in the dialogue-seminar. Those patients who agreed to an interview met with the researcher.

Conducting an intervention program in inpatient mental health departments and including inpatients at a seminar with health providers who are providing care to the same patients have ethical implications. Some patients might have believed that taking part at a dialogue-seminar with providers would restrict them in their openness about their care experiences. Interviews were therefore made by a researcher before the dialogue-seminar to ensure that patients' voices and perspectives on involvement in treatment and care were elaborated. This was also a way of ensuring that the voices of those patients who did not participate in the seminar were heard.

4 Results

4.1 Results in paper 1

A 30-items instrument called the Service User Involvement in Mental Health Scale (SUIMH) was developed to measure service providers' perceptions of user involvement. The exploratory factoranalytical procedures established a scale with four components/subscales "democratic patient involvement," "carer involvement," "assisted patient involvement," and "management support" showing adequate internal consistency. Cronbach's alphas for the four subscales were 0.81, 0.82, 0.78, and 0.75, respectively. The total mean score for the scale was 3.88, Cronbach's alpha 0.88. These results indicate a reliable and valid measurement.

4.2 Results in paper 2

Confirmatory factor analysis revealed that the data showed adequate fit to a three factor model with the three subscales: "organizational user involvement," "patient collaboration," and "assisted patient involvement."⁵ These could be used to measure user involvement at the departmental/ward level and the individual level. Little user involvement was reported at the departmental level, but there were institutional differences. Providers in two CMHCs reported significantly more organizational user involvement. Providers more often reported user involvement at the individual level, although evening/night shift workers reported a lesser degree of individual user

⁵ The following fit indices were obtained: root mean square error of approximation (RMSEA) = .058, p value for test of close fit (RMSEA < 0.05) = .026, comparative fit index (CFI) = .97 and incremental fit index (IFI) = .97.

involvement. Providers' rating of importance of user involvement was a significant predictor of patient collaboration.

4.3 Results in paper 3

The following two issues, which were agreed to at the dialogue-seminar as central to service user involvement in inpatient settings, served as a framework for the analysis. Service user involvement requires: 1) offering inpatients opportunities to participate in decision-making about their treatment and their life situation; and 2) acknowledging a person's right to be seen, heard and understood. The first issue was later divided into two related but distinct themes: decision-making and participation. The results were presented first for inpatients and second for providers.

Several differences between inpatients' and providers' perspectives on user involvement were described. From the inpatients' perspective, taking part in decision-making about their own treatment, or attending daily activities provided in the departments, were not prominent aspects of their inpatient stay. Exhausting mental health symptoms, but also unpleasant experiences as participants in meetings, were cited as reasons why people did not attend more meetings or activities in the departments. There also appeared to be confusion about the meaning of involvement in treatment and individual care planning. Providers were described as being nice, understanding, and supportive, but this did not always translate into participants believing that they were being seen or heard as individuals. The data suggest that service providers often perceive inpatients as unmotivated and unwilling to take part in their own care. Providers also appear to struggle with engaging patients in dialogue about their care, getting treatment be goal-directed, involving inpatients in developing individual care plans or in meetings about treatment, and developing user involvement at the departmental level.

4.4 Results in paper 4

The study assessed the impact of the intervention program “Service user involvement in practice.” Study results showed that the intervention led to improvements in providers’ reports on the three dependent variables: “organizational user involvement,” “patient collaboration,” and “carer involvement,” which are core aspects of user involvement practices in inpatient mental health departments. Despite the improvement in providers’ reports, the intervention program was not associated with inpatients in the intervention sites reporting more satisfaction with care than inpatients in the comparison group. The results demonstrated that an intervention program can be useful in increasing attention to service user involvement in inpatient mental health services.

Confirmatory factor analyses were performed with data from the five involvement variables: “patient collaboration,” “assisted patient involvement,” “carer involvement,” “management support,” and “organizational user involvement” at T1 and T2. Generally, the results indicate satisfactory fit of the sample data at T1, and close to satisfactory fit at T2. The two lowest loading items at T2 were “Are service users involved in the hiring decisions of mental health providers to your department?” and “Department management are not encouraging involvement of patients in own treatment.” These were also the lowest-loading items at T1. Assessment of the internal consistency at T2 revealed a reduction in Cronbach’s alphas but the values were still acceptable, implying five reliable and valid subscales applicable for assessing inpatient providers’ perceptions of service user involvement.

5 Discussion

This thesis contributes to the understanding of service user involvement in inpatient mental health services. Four papers empirically investigating user involvement have been published. Paper 1 operationalizes, validates, and empirically tests several items of what we refer to as the “SUIM scale.” The paper demonstrates that user involvement is a concept with several dimensions which can be useful to take into account when measuring service user involvement from the provider’s perspective. In the second paper, a theoretical model representing user involvement at individual and department levels of services is empirically tested. We also assess the influence of individual or organizational characteristics on providers’ reports of user involvement. The analyses demonstrate the importance of taking both individual and organizational characteristics into account when assessing current user involvement practices in inpatient care. In the third paper, we explore both the providers’ and inpatients’ perspectives on being involved in treatment and care. The qualitative data illustrate the complexities associated with user involvement in the context of inpatient mental health care. The diversity in patients’ and providers’ perspectives on user involvement is important to address in future efforts to increase user involvement. The last and fourth paper describes the possible effects of conducting an intervention program to focus attention on user involvement and to develop user involvement practices in inpatient mental health departments. Study results illustrate that an intervention program can be a useful first step in promoting user involvement among providers. But more work is needed in order to strengthen patients’ self-advocacy.

This discussion addresses the following overarching issues relating to the four empirical studies: 1) conceptualization and measurement of service user involvement, 2) characteristics influencing providers’ reports of user involvement, and 3) impact of an intervention program to enhance service user involvement in inpatient mental health care.

5.1 Conceptualization and measuring service user involvement

User involvement in inpatient mental health services is a complex matter. Few empirical studies have examined the way in which mental health providers attend to service user involvement. A central aim of this thesis has been to conceptualize, develop, and ensure a valid measure to survey current user involvement practices in inpatient mental health services. Valid and reliable measurements are a necessity to guide, monitor, and evaluate mental health services and to assess if services are changing and strengthening user involvement.

The CPQ developed by Kent and Read (1998) has been used in several studies covering the area service user involvement in mental health services (Richter, et al., 2009; Soffe, et al., 2004; Steinsbekk & Solbjør, 2008). The CPQ was designed in close collaboration with people with extensive experience as users of mental health services. Items in the CPQ represent aspects of user involvement at both the individual and system level of services covering the areas: treatment, evaluation, planning, and management.⁶ Richter et al. (2009) comment, based on their results, that the CPQ should be critically evaluated because of high interrelatedness among items from the various topics. They also question if the items are valid indicators of the construct consumer involvement.

Transforming theoretical language into empirical concepts requires operationalization, which is the process of turning concepts into variables that can be measured (Blaikie, 2000). It is questioned in literature to what extent the development of a scale to measure “patient or user involvement” should be guided by the perspectives and experiences of the service users or patients, or by those of the

⁶ The CPQ consisted of 20 items, of which 14 items had *yes, no or do not know* responses (e.g. “Are service users involved in the hiring decisions of your service?”). Four items had Likert scale responses (e.g. “In most cases where does the responsibility for deciding the goals of treatment usually lie?”) and two items had 6-8 specific response options.

professionals, or perhaps both (Elwyn, et al., 2001). Elwyn et al. (2001) suggest that no standard exists. The most important task is to focus on construct validity.

Netemeyer et al. (2003) argue that establishing construct validity involves at least four steps: 1) specifying a set of theoretical constructs and related theory; 2) developing methods to measure the construct of the theory; 3) empirically testing the fit of the observable indicators/items to the proposed theory; and 4) testing the hypothesized relations among the constructs of theory. Conceptualization of user involvement in this thesis has been a stepwise process, involving both literature review and empirical work described in papers 1, 2, and 4. Qualitative focus group interviews with providers, the item validation process, and identification of the domain dimensions/subscales through exploratory factor analysis in paper 1 resulted in a four factor solution with four dimensions/subscales: “democratic patient involvement,” “carer involvement,” “assisted patient involvement,” and “management support.” We consider these subscales to represent important dimensions of user involvement from the provider’s perspective in inpatient mental health care.

In paper 2 we analyzed user involvement at the individual and departmental levels of mental health services. This issue was briefly mentioned in paper 1. This focus was of interest, as providers do not always seem to differentiate between the initiatives said to be user involvement for individual patients, and user involvement in service development and service provision in inpatient mental health services (Steinsbekk & Solbjør, 2008). A theoretical model with the three key variables: “patient collaboration” and “assisted patient involvement” derived from the SUIM scale in paper 1, and “organizational user involvement” derived from the CPQ (Kent & Read, 1998) was empirically tested. The statistical analysis showed that the items fit a three-factor model, with “patient collaboration” and “assisted patient involvement” as separate variables representing individual user involvement and “organizational user involvement” representing user involvement at the departmental level of services. The study results indicate that the variables/subscales are valid and reliable, and can be

useful to turn providers' attention to the core aspects of service user involvement in inpatient mental health care.

In paper 4 we argue that service user involvement in inpatient mental health care is a multidimensional concept which can be measured with the following key variables: "patient collaboration," "assisted patient involvement," "carer involvement," "management support," and "organizational user involvement." The advantage of using these variables or subscales is that we were able to replicate the factor model in CFA at T1 and T2. These results support the contention that the subscales contain valid items representing user involvement practices in providers' daily work in the departments. These variables can be useful in characterizing a group of providers as low, medium, or high with regard to their reports of user involvement, also allowing comparisons of results across institutions. O'Connell, Tondora, Croog, Evans and Davidson (2005) have argued for such a use of the Recovery Self Assessment (RSA) questionnaire, with 36 items reflecting objective practices associated with the conceptual domain of recovery. The RSA contains five dimensions, one of which parallels "organizational user involvement." This dimension is named "involvement" and reflects the extent to which people in recovery are involved in the development and provision of programs/services, staff training, and advisory boards/management meetings. The authors argue that the RSA can be used to assess providers', persons' in recovery, family/user advocates', and service directors' perceptions of the degree their mental health agencies have implemented recovery-oriented practices. Such assessments can be used to generate recovery profiles for individual institutions/agencies allowing for comparing different institutions.

In order to finalize the Service User in Mental Health (SUIM) scale, determining the extent to which the different variables fits into a network of relationships using structural equation modeling (SEM) (DeVellis, 2003) will be a useful procedure. Another issue will be to assess the need for adapting the items in the subscales/variables to inpatients' or services users' perspectives. This procedure can permit

the gathering of information from multiple perspectives in the conceptual domain of user involvement in mental health services.

5.2 Characteristics influencing providers' reports of user involvement

Studies have begun to explore providers' reports of user involvement, but it is not yet known to what extent service providers' reports of user involvement are related to a provider's or an organization's characteristics. Kent and Read (1998) suggest that professionals who have a medical orientation toward mental disorders may be less supportive of user involvement than are providers who hold a more psychosocial orientation.⁷ The authors found a smaller likelihood for consumers to be accorded responsibility for assessing their own difficulties and deciding the goals of treatment when interacting with a medical oriented provider. They also found a smaller likelihood for consumers to be encouraged to contribute to writing their notes and in their records. Their study, however, was limited by a low response rate. Although not focusing explicitly on service user involvement, Glisson et al. (2008) found that providers' reports on key culture constructs often were tied to the clinic in which the respondents worked. They provided statistical evidence for differences among clinics with regard to implementation of evidence-based practices. Although the study does not focus on user involvement practices, differences in organizational cultures can have implications for user involvement.

⁷ The mental health questionnaire was used to measure attitudes towards mental disorder on a continuum from "psychosocial" to "medical." The medical orientation contains the following four factors: 1) biogen that is views on biological and genetic aetiology and psychopathology, 2) ideological issues, 3) diagnostic issues and importance of diagnosis for treatment, and 4) attitudes towards medical and drug oriented treatments. The psychosocial orientation is represented with two factors: 5) psychosocial emphasizing on psychotherapy and client autonomy, and 6) aspects representing an egalitarian practitioner role and importance of life experiences.

In paper 2, a 4-step multiple hierarchical regression model was set up to assess the extent to which service providers' reports of user involvement are shaped by individual characteristics and/or are tied to characteristics to the CMHC. User involvement at the individual level was measured with the variables: "patient collaboration" and "assisted patient involvement" and user involvement at departmental level was measured with the variable "organizational user involvement." The model had the following logic: the basic organizational characteristic, CMHC, was placed in the first step. In the second step, individual characteristics such as gender and age were included, followed by management position, job tenure, profession, and work-shift arrangement in the third step. Finally, in the last step providers' rating of importance of user involvement was included. The following interesting observations were noted: a) reports of user involvement at the departmental level were relatively low but there were institutional differences; b) individual user involvement was reported more often than departmental user involvement; c) work-shift arrangements had an impact on reports of patient collaboration; and d) providers' rating of importance of user involvement had a significant impact on patient collaboration.

The analyses in paper 2 indicated that organizational user involvement was not well developed in the five Norwegian CMHCs. Corresponding findings have been made in the US, New Zealand, and from Norway (Kent & Read, 1998; O'Connell, et al., 2005; Richter, et al., 2009). Some possible interpretations of this result may be a lack of attention to and/or competence in user involvement among organizational leaders and providers; staff resistance to power sharing with service users; and lack of financial resources to support service user representatives and their organizations (Crawford *et al.*, 2003; Crawford & Rutter, 2004; Rutter *et al.*, 2004). The statistical analyses showed variations across the CMHCs with regard to reports of organizational user involvement. This could indicate stronger awareness among providers and a more established organizational culture for this aspect of user involvement in some institutions. As will be discussed later, our study is limited because we did not include any other variables than dummy variables

in the regression analyses representing organizational characteristics that could explain these results.

It was not unexpected that providers more often reported user involvement at the individual than at the departmental level of services. Although these results cannot be compared directly because of the different Likert scales (patient level items are scaled 1-7 and organisational level items 1-5), they suggest variations in current user involvement practices. Richter et al. (2009) argue that some aspects of user involvement at the individual level appear to be perceived as implicit elements in providers' daily interactions with patients. An interesting result was that providers' rating of importance of user involvement had a significant impact only on the reports of "patient collaboration." The lack of impact on "assisted patient involvement" was more unexpected, especially with reference to some of the items in the subscale; for example: "the patient takes part in filling out the individual care plan," "the patient participates in assessing his or her level of functioning," and "the patient has input into what follow-up care he or she will receive from mental health services." These represent important user involvement practices that providers need to accommodate. Results in paper 3, in relation to individual care planning, may shed some light on this result. In several log reports, providers described challenges in relation to individual care plans. Providers described some patients as "not understanding the meaning content, or the usefulness, of a plan and therefore having little interest in participating" (Storm & Davidson, 2010).

One significant predictor of the reports of individual user involvement in the regression analysis was providers' work shift arrangement. Those providers who worked only the evening/night shifts reported less "patient collaboration" and "assisted patient involvement" than providers with other shift arrangements. There were also comments in the questionnaire that these providers perceived user involvement to be less relevant. This finding may seem obvious. Working only evening or night shifts are common work arrangements among inpatient providers in mental health services in Norway. The extent to which evening and night shift workers are sufficiently included in ongoing therapeutic

work with patients has not been well explored. The results from providers are also in contrast to an inpatient's perspective. One woman told in an interview of her experiences when providers held rigidly to unit routines instead of responding to her individual needs:

At first when I was here I could not sleep...anxiety. I did not get to talk to night staff. It is horrible to spend much time in the room. I understand that I must not turn night into day, but it is important to make exceptions when you cannot sleep (Storm & Davidson, 2010).

As a whole, the statistical analyses were useful to identify characteristics influencing providers' reports of user involvement. The qualitative interview data from paper 3 helped to round out the discussion of these results.

5.3 *Impact of an intervention program on reports of service user involvement*

An important theme in this thesis is the extent to which is it possible to develop or strengthen user involvement practices in inpatient mental health departments. Paper 3 uses qualitative data to explore inpatients' experiences of being involved in their own treatment and care, and providers' attempts to develop and strengthen user involvement in the departments during the intervention program. In paper 4 we reported on the quantitative survey data. We hypothesized that participation in the intervention program "Service user involvement in practice" would have a positive influence on service providers' reports of user involvement represented by the variables: "patient collaboration," "assisted patient involvement," "carer involvement," "management support," and "organizational user involvement."

The results of the multivariate analysis of variance (MANOVA) in paper 4 revealed no overall change, but a significant intervention effect. The extensive statistical analysis showed that the intervention led to significant changes in providers' reports on the dependent variable:

“organizational user involvement.” The results were significant but weaker for “patient collaboration” and “carer involvement.” One possible interpretation is that the intervention program made providers and the departments more aware of user involvement, causing the stability of or increase in providers’ reports. Despite the positive changes in providers’ reports in the intervention group, the intervention program was not associated with inpatients reporting more satisfaction with care than inpatients in the comparison group.

Several initiatives described in paper 4 were made by providers in order to increase inpatients’ involvement and participation during the intervention period. The study data in paper 3 illustrate the complexities and differences in patients’ and providers’ perspectives associated with user involvement in inpatient services in Norwegian CMHCs. In paper 3, providers referred to inpatients as unmotivated, as not wanting to participate in daily activities or in meetings about treatment and follow-up, and as failing to see the usefulness of an individual care plan. Inpatients told in interviews that they were reluctant to participate because of exhausting mental health symptoms or because they did not find participation useful. These findings do illustrate the differences in perspective that providers and patients can have on being involved. Similar differences have been described by Chinman et al. (1999). Our results reflect some of the ambiguity in current mental health service provision in Norway. These are important issues that must be addressed in order to establish user-oriented mental health services.

In this thesis, involving family members in treatment and care is advocated as an important aspect of service user involvement. Family members and patients sometimes have different perspectives on treatment and follow-up, and involvement of family members will depend on the patient’s own desires. This issue is reflected in two of the items in the subscale, e.g., “If the patient wants, carers are involved in planning the patient’s treatment.” Our results suggest that there was more awareness among providers of this aspect of user involvement following participation in the intervention program. A limitation is that

we did not gather any data from carers to assess their views on participating in the treatment planning of their family members.

Based on the literature on leadership, we argue that organizational leaders can play an important role in stimulating user involvement practices in inpatient mental health departments. In paper 4, there was no positive development in perceived management support. The high mean values initially could have made it difficult for the intervention program to have additional positive impact on this dimension. Another possible explanation for this development could be that the expectations for leadership support were not fulfilled during the intervention. Therefore it could have been useful to include some evaluative questions concerning the participants' appraisal of the intervention program in the questionnaire administered at T2.

According to Øvretveit (1998), an intervention is an action that is intended to result in a change. The main objective with the intervention program was to increase providers' attention towards user involvement and to develop user involvement practices. The intervention program would ideally be associated with inpatients reporting more involvement in treatment and care. Service providers' assessment of the intervention program and its impact are one side of program evaluation. Just as important is the inpatient's perspective, and his or her experiences with being involved and participating in his or her own treatment and care. In paper 4, the hypothesis that the intervention program would be associated with inpatients reporting more satisfaction with care was not supported. These results should be interpreted with some caution due to the small sample size, especially in the intervention group, increasing the risk of type 2 errors and not detecting a significant difference between the groups. In addition, there was no pre-measurement with inpatients, so there was no opportunity to assess a potential positive development in the reports.

The implementation of the intervention program was made in close collaboration with organizational leaders and service providers. Croft and Beresford (1996) distinguish initiatives for increased user involvement and participation that are state or provider-led schemes,

from user-led initiatives initiated by service users and their organizations in order for them to have more of a say. State- or provider-led initiatives are important to secure people's access and support for involvement. The intervention program was a professional initiative with several activities: the dialogue-seminar; inclusion of service user representatives in steering committees; and the educational program in which user representatives told their stories, providing increased opportunities for user participation and involvement. Hearing what service users and inpatients have to say about care and service provision are necessary first steps in order to make services more user oriented. These initiatives also ensured that providers experienced working with mental health service users in different roles or positions than solely as inpatients, which might have influenced providers' reports of organizational user involvement at T2.

5.4 Limitations

Important issues in social research relate to study sample and sample size. Nurses and auxiliary nurses were the main professional groups in the studies in this thesis. This can reflect the workforce in inpatient departments at Norwegian CMHCs, in which the majority of service providers employed are nurses or auxiliary nurses (Sletnes, et al., 2008). The study samples are relatively small and must be considered purposive since selection of study sites was based on the researcher's knowledge of the study population, and providers' and organizational leaders' willingness to participate in the surveys and intervention program. Purposive sampling limits the ability to generalize the results to a broader group of providers and CMHCs.

Some issues related to sample size have already been discussed. The study samples of providers in paper 2 are relatively small $n=224$, although the response rate is rather high (83%). In general, a small sample size increases the risk of Type 2 errors and accepting the null hypothesis when it is not true. This is in contrast to Type 1 errors, where the null hypothesis is rejected even though it is true (Polit & Hungler, 1999). However, it is a strength that the providers were

recruited from five CMHCs. A larger study sample would have provided a better opportunity for a general understanding of implementation of service user involvement in Norwegian CMHCs. Another issue relevant to sample size is that the regression analysis in paper 2 controlled for a number of individual characteristics (e.g. age, gender, profession, work-shift arrangement etc.). We have chosen a strict significance level $p < .05$ and $p < .01$ in order to avoid type 1 error, but we did comment on values almost significant, that is $p < 0.10$ in table 5-7 in paper 2. These associations are worth pointing out, since this is among the first studies to examine influencing factors on providers' reports of service user involvement.

We employed a cross-sectional study design in paper 2. Cross-sectional designs are frequently used to describe a phenomenon and have been used in several studies with the CPQ (Kent & Read, 1998; Richter *et al.*, 2009; Soffe, Read, & Frude, 2004). A limitation of the design is that the data is gathered at one point in time and therefore cannot capture variations in the respondents' reports over time. Cross-sectional data is also limited since they cannot actually demonstrate causal connections between variables, rather they show statistical associations. Despite these limitations, cross-sectional studies designs are useful, practical and require limited economic resources. A future cross-sectional study of providers' reports of user involvement would benefit from increasing the number of participating CMHCs, by including outpatient clinics and perhaps by applying a probability sampling procedure. According to Polit and Hungler (1999), probability sampling is considered the only viable method of obtaining a representative sample and of avoiding sampling bias. This would allow a broader comparative analysis of service user involvement in Norway. Larger study samples can allow for the comparison of user involvement across multiple professional groups. Some measures representing organizational characteristics such as organizational size, patient population, treatment offered at the center and user involvement initiatives could be included in the statistical analyses. It could also be useful to assess aspects such as providers' commitment to the organization or leadership characteristics. This would enable data

analyses to consider both measures characterizing service providers and the service organization.

To assess the impact of the intervention program in paper 4 we used a quasi-experimental design, with an intervention group and a comparison group. Like “true experiments,” quasi experiments involve a manipulation of the independent variable, but lack at least one of the two characteristics found in “true experiments,” such as randomization or a control group. This makes the quasi-experimental design weaker and it is more difficult to draw causal inferences when interpreting the results. The researcher constantly has to rule out competing causes and explanations that may otherwise account for the observed effect (Polit & Hungler, 1999). The most important threats to causal inference and internal and external validity in quasi-experimental designs are tied to the selection of participants, statistical regression, mortality/drop out, response bias, history, diffusion of treatment, compensatory rivalry and resentful demoralization (Cook & Campbell, 1979; Polit & Hungler, 1999). In order to control for potential pre-existing difference between the groups, chi-square statistics with the demographic variables was computed before the multivariate analyses of variance in paper 4. Providers in the intervention and comparison groups did not differ on demographic variables, occupation, shift-arrangement, or management position. The statistical regression problem is of interest when conducting repeated measures and can lead to a belief in effects that do not exist (Skog, 2004). Peoples’ perceptions may fluctuate over time. We did control for the pre-measurement (T1) in the regression analyses in paper 4, which is important. As already mentioned, providers’ reports of user involvement may also be influenced by the patient population in the departments. There are no data to support this assumption in paper 4.

Mortality or drop-out is a threat to internal validity arising when subjects participating in the intervention or control group are required to provide data at several points in time (Cook & Campbell, 1979). There were 224 service providers in the study sample at T1. The response rate at T1 was 186 and dropped to 123 at T2. Some reasons for not responding to the second questionnaire were provided by

department leaders. These included retirement, maternity leave, long-term sick leave, moving, and changing jobs, and there was no reason to believe that there was any systematic drop out. There was a rather large amount of inpatients that did not respond to the questionnaire at T2. Low response rates have been a problem when conducting surveys of inpatients' experiences with mental health services using the PIPEQ and have implications for the limited generalizability of the results (Bjertnæs, Garratt, & Johannessen, 2006). This is an important issue to address in future survey with inpatients.

The issue of response bias cannot be ruled out (Netemeyer, et al., 2003). Socially desirability bias is the tendency of people to deny socially undesirable traits, to claim social desirable traits and to make statements that put them into a favorable light (Nederhof, 1985). User involvement is politically correct; it has positive connotations and is a desirable characteristic of mental health service delivery. Service providers may thus have trouble not endorsing its importance. As the measurement scales used in this thesis are self-assessment tools, there is a risk of social desirability bias. This might cause a discrepancy between what providers report and the actual level of user involvement. Providers in the intervention group might have overstated their user involvement at T2 in order to "perform well." To minimize this possible bias, the questionnaires were returned anonymously to the researcher. Reports from the patients' on their satisfaction with treatment and care were included to counterbalance this bias at T2.

There will always be events taking place at the same time as the carrying out of an intervention program in an organizational setting which cannot be controlled (Polit & Hungler, 1999). All such naturally occurring events pose alternative explanations for any differences found between the intervention group and comparison group. In paper 4 providers' reports on the involvement variables deteriorated or remained unchanged from T1 to T2 in the comparison group. Except for participation in the two surveys, there was, according to department leaders, no special attention to user involvement between the two measurements in the comparison group. Resentment and demoralization could be an explanation for the results (Cook &

Campbell, 1979). When the participants in the comparison group do not take part in the apparently desirable intervention, they respond by reporting less user involvement at T2. The development in the intervention group was stable or increased. A possible Hawthorn effect cannot be completely ruled out (Polit & Hungler, 1999). Awareness among the participants' that they were taking part in an intervention program may have had a positive impact on their reports.

There are elements in the intervention program that are relevant to external validity. External validity is a matter of replication (Cook & Campbell, 1979). The intervention program was conducted as part of the daily work organization and activities in the departments. Ordinary staff meetings were used for discussions of current user involvement practices, and the educational program was integrated in the ordinary schedule for patient and staff education in the departments. The complete manual for the intervention program is also available in Storm et al. (2009). These are all important elements in order to replicate the intervention program and assess the study results with a different study sample.

In a future research study, implementing the intervention program "Service user involvement in practice" it would be useful to increase the study sample of both inpatients and providers. To strengthen the research design, a clustered randomization design would be useful. This is a study design where study sites are randomly assigned either to the intervention or comparison group, providing the researcher with some more control over the threats to internal validity. Inclusion of a one-year follow-up measure would also increase the ability to assess the sustainability of the intervention and to make causal inferences about the impact of the intervention program.

5.5 Study implications

There has not been extensive quantitative research of service user involvement in inpatient mental health services. The study results suggest that further work is needed to ensure that user involvement is

sufficiently implemented in inpatient mental health care. Based on the extensive testing of the measurement scales in this thesis, it is believed that these could be helpful in increasing providers' attention to the core aspects of service user involvement. Measurement scales can be useful to describe groups of providers as low, medium, or high with regard to their reports of user involvement. Gathering survey data from service providers can also be a way to assess the need for service development in service user involvement. The studies in this thesis can be the first step in establishing a standardized measure which can be used to report on user involvement practices.

Our results suggest that an intervention program providing competence and training about methodologies promoting user involvement to organizational leaders, service providers, service user representatives, and inpatients can act as a first step toward increased user involvement, but more work is needed to enhance patients' self-advocacy. The challenge is to ensure that patients actually are included in decision-making. There is a danger that user involvement remains merely consultative in inpatient mental health care, focusing on patients' perspectives, but not necessarily taking those into account in the final decision-making. To develop user involvement in inpatient mental health services, inspiration can be found in literature on recovery-oriented care, person-centered care planning and shared-decision-making (Deegan & Drake, 2006; Davidson, Tondora, O'Connell, Kirk, Rockholz, et al., 2007). In person-centered care, planning providers address the person's strengths, hopes, and desires to reclaim a meaningful life in the community. In a shared-decision making model, providers engage in partnership and dialogue with the individual about expected and predicted impacts of different treatment alternatives, acknowledging the individual's experiences as expert knowledge. Providers play a role in offering choices and in educating the patient about the potential consequences and risks of the choices that are made. Person-centered care planning and shared-decision making will have implications for service users. Effective self-advocacy will depend on awareness of and efforts to claim one's own rights as a patient and a service user. It will require being prepared for treatment meetings and engaged in formulating one's own treatment goals. Some service users

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may benefit from training to promote their own advocacy. Others might find it useful to invite someone close to their treatment planning meetings. Most important, the patient's and service user's energy will guide the involvement process.

6 Conclusions

This thesis has contributed to the understanding of service user involvement in Community Mental Health Centers in Norway.

This research conceptualizes user involvement. We have developed a set of useful and related empirical concept or variables (“assisted patient involvement,” “patient collaboration,” “carer involvement,” “management support,” and “organizational user involvement”) to be used to measure user involvement. The extensive statistical analyses performed with the variables have been important in order to establish valid and standardized measures to providers. In this thesis these measures have provided useful data on provider-assessed user involvement practices in inpatient mental health departments. In future research studies, these variables can be useful to take into account when measuring service user involvement from the provider’s perspective.

The study results in paper 2 point to some important aspects with regard to implementation of user involvement in Norwegian CMHCs. By examining characteristics influencing on providers’ reports of individual and departmental user involvement, we found that the reports of “organizational user involvement” were low, and that there were institutional differences. Providers more often reported collaborating with patients and arranging for patient involvement in the planning of treatment and services. Although not surprising, working only evening/night shifts was associated with less individual user involvement. Such data can be helpful when assessing the need for service development in the area of user involvement.

Qualitative and quantitative data collection methods have been used in several of the studies in this thesis. This has been important for the conceptualization of service user involvement, and to reveal the differences in perspectives held by providers and inpatients on user involvement and involvement in treatment and care. In paper 3, patients

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reported few opportunities to have meaningful input in the decision-making regarding their care, while providers reported difficulty engaging patients in discussions or care planning. The results show that both inpatients and providers perceive themselves as facing complex and challenging tasks when it comes to service user involvement.

Not many studies have focused on implementation of user involvement in inpatient mental health care. In paper 4 we used quantitative survey data to assess the impact of the intervention program “Service user involvement in practice” on providers’ reports of user involvement and inpatients experiences with care. Our results suggest that turning both providers’ and inpatients’ attention to user involvement, and providing general competence about user involvement are necessary pre-conditions to stimulate user involvement. Providers, however, need specific training in methodology and approaches to increase user involvement in their daily work, and more work is needed to enhance patients’ self-advocacy.

The study results identified important issues to be attended to in the implementation of user involvement and in future research on user involvement in mental health services.

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..... **Part II**

8 List of Papers

Paper I

Storm, M., Hausken, K., & Mikkelsen, A. (2010). User Involvement in In-patient Mental Health Services: Operationalization, Empirical Testing, and Validation *Journal of Clinical Nursing*, 19, 1897-1907.

Paper II

Storm, M., Hausken, K., & Knudsen, K. (2010). Service user involvement in Community mental health centers: service providers' perspectives. *International Journal of Social Psychiatry*, in press

Paper III

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Paper IV

Storm, M., Knudsen, K., Davidson, L., Hausken, K., & Johannessen, J. O. (2010). 'Service user involvement in practice': The evaluation of an intervention program for service providers and inpatients in Norwegian Community Mental Health Centers *Psychosis*, in press