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# The Nature of Recovery as Lived in Everyday Life:

Perspectives of individuals recovering from severe mental health problems

Thesis for the degree philosophiae doctor

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



#### NTNU

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I found him so balanced in a way... didn't have all kinds of programs of his own that we had to go through. I could talk about anything ...everyday life things that were important to me, not necessarily problems... I was the one who decided what to talk about. (quote from a woman informant referring to a meeting with a professional).

Inviting people to talk about their lived experiences of mental health problems and recovery is a challenging and educating endeavour. Challenging, because it reminds me of both clinical and everyday, life-in-general situations I wish had been dealt with in different ways both by myself and my colleagues: perhaps we could have been more patient, more courageous, or perhaps better listeners. Educating, because the stories of participating informants in these studies so clearly convey what recovery and helpful help is all about, about what's important in people's lives in general. We're all in the same boat, and sometimes on a rough sea.

This dissertation is the result of many efforts and contributions alongside my own. First and foremost, I wish to thank the women and men who shared their personal experiences with me: their struggles and strengths in everyday life and recovery-processes. Their courage, generosity and willpower to contribute to improving services and more helpful help have been invaluable, to me and hopefully to others. The reference-group, consisting of five individuals with lived experiences of mental health problems and as service recipients, followed the project from start to end. Their wisdom and attentiveness often reminded me of the need to think once again about findings, considering different ways of understanding situations, and sometimes just to take a step back.

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# The Nature of Recovery as Lived in Everyday Life: Perspectives of individuals recovering from severe mental health problems

#### 1. Introduction

The aims of this dissertation have been to explore, understand, and hopefully contribute to improving the situations of people in recovery from severe mental health problems. A central focus has been the everyday personal experience of living with mental distress, and especially the struggles and strategies associated with overcoming daily challenges. My major concern has not been a deficit-based, disease and treatment approach, but rather about how problems and consequences of being diagnosed and treated for severe mental health problems affect peoples' lives, especially looking at what can inform and guide the whole of society towards more hopeful, positive directions. I contend and will argue that an everyday life perspective is essential in this quest.

The research questions of this dissertation have developed and been refined during the past few years as my research has progressed. Working as a clinician and researcher, I had a growing interest in understanding and addressing the situation of people with severe mental health problems, more and more so within the context of their everyday life experiences. A common thread in the research and summarising discussion presented here is my concern of the increasingly popularity of the notion of recovery, a popularity which in my opinion invites a closer scrutiny of the paradoxes and challenges associated with this concept. Despite more frequent usage of the term 'recovery' in national policies, service development and practice, as well as in training and research, fundamental questions remain unasked and unaddressed.

As with other popular terms, 'recovery' is inconsistently understood and used, yet such 'roomy' notions can also be helpful in creating needed debates about what is happening and about what can happen differently.

This situation is of course not psychiatry's problem alone, but one entwined with broader and more continually discussed health issues with societal dimensions which are complex and difficult to unravel. Skålevåg (2003) has claimed that the history of psychiatry can be seen as a history of the construction of professions and institutions, about scientific truths, and a history about culture's relationship to 'insanity'. Psychiatry is still a relatively young discipline, still without any singly evident theoretical notions or models. Ongoing claims for an eclectic understanding and approach combined with a pragmatic integration of biomedical and humanistic modes of knowledge are in reality mostly still implemented within positivistic science traditions, albeit unconsciously. Part of this is the ongoing dominance of the medical hierarchy which legitimates the authority of the psychiatric profession.

Psychiatry, together with medicine in general, rests on a belief in diagnostic tools, embedded in a strongly individualistic view about illness based in a body-soul dualism where bodily processes are often regarded as the most central and valuable illness entity (see for ex. Nordvoll, 2002). International classification systems (such as DSM) were developed with good intentions: striving for differentiation of symptoms and signs which in turn would lead to diagnosis, prognosis, prescriptive directions and indicated treatments, as well as providing a basis for future research. According to Boyle (2005), there are two main reasons for using diagnosis in the mental health field. First, this line of thinking identifies mental disorders in the same way as other fields of medicine, thereby supporting psychiatry's claim as a branch of medicine, a position that is generally valued. Secondly, the question of diagnosis is central because it is based on classification, ordering 'like with like', and such universal generalisations are often claimed to be critical criteria for what is essential in science. Boyle also argues that the similarities between medical and psychiatric diagnoses are more apparent than real, since a classification system is only as 'good' as its underlying assumptions.

In the alliance between academia and survivor/user movements, certain common elements about 'recovery' can be identified and will be more thoroughly discussed in Chapter 2, and are fundamental to the way I position myself. As a basic introduction to the notion of recovery, I have found Curtis' writings (1997) helpful, where she describes recovery as a process of regaining what has been lost: rights, roles, responsibilities, decisions, potentials and supports. Furthermore, recovery is not necessarily about symptom elimination, but rather about what the affected person wants to achieve, her/his ways to realise own goals, and acknowledging that persons with lived experience have a significant say in knowing what types of support are helpful. This entails both inviting and embracing personal visions, enabling increased autonomy, and also adds the important dimension of hope for the life he/she wants to live.

A seldom named yet critical issue is the tendency of understanding recovery as only a personal, highly unique process, a direction which individualises problems and solutions in the same ways that traditional psychiatry has always done. This places even more responsibility on the individual person for her/his current situation and future opportunities, while ignoring the impact that environmental, social and material factors have in maintaining current distress as well as discovering ways towards recovery.

Also on the worrisome side: while individual life experience has long been recognised as having a central place in recovery, the consideration of everyday-life among clinicians and researchers is not given the recognition and priority one would thus expect given the holistic rhetoric so often proclaimed and heralded. A related sub-issue is the ongoing domination of medical and psychological language, hegemonic discourses, and general mind-sets in the mental health field.

Much work remains to discover a more useable language with regard to the subjective experiences in the recovery process, especially if one believes as I do that 'mental health' is much more than a health issue, but rather a life with societal, cultural, and political dimensions.

In contrast to the many hopeful aspects of the recovery-notion, there remains a rarelynamed yet fundamentally important question demanding attention: How can it be that the
same individuals struggling with serious mental health problems can be described and treated
in so extremely different ways by mental health services? Many informants in these studies
were met with pessimism in some settings, perceived and treated as severely mentally ill
patients with limited future hopes and in need of clinical treatment programmes prescribed
and monitored by professionals. In other settings, the same individuals might be met with
positive expectations for improving both their mental health distress and their overall life
situations, including that own efforts and informal supports were seen as likely sources of
significant help in addition to formal services, and that societal participation was the goal
rather than 'cure'.

With regard to terminology in this introduction, I use 'severe mental health problems' or 'mental distress' rather than 'mental illness' or 'mental suffering', while recognising that such phrases are inconsistently used and thankfully also increasingly debated. I find terms such as 'distress' and 'problems/consequences' better ways to incorporate the comprehensive, everyday-life experiences of the informant-participants in this dissertation's research studies. Their reported experiences are often devastating and painful yet also full of resilience and creativity, often an up-and-down cycle that can be dealt with rather than a progressive and chronic downward spiral. The hopeful rhetoric of 'recovery' stands in stark contrast to the language of the medical paradigm, which uses terms such as syndrome, diagnosis, illness, patient, treatment, and prognosis, to mention some.

All informants in these studies have been diagnosed with various psychiatric labels of psychosis, a broad set of medical diagnostic categories which have been of common interest in recovery research, since a primary interest of most recovery research is finding ways to understand and alleviate situations and conditions for people with mental health problems considered serious and enduring. I have been especially interested in critically examining what helps in the recovery process in everyday life contexts, and claim that this is substantially different from asking evaluative questions or seeking solutions solely within the existing mental health service system.

This dissertation is first and foremost about ordinary people with some extraordinary and challenging life experiences. In other words, the centre of attention is the person as opposed to the patient, life experiences as opposed to mental illness histories, contexts of everyday life as opposed to contexts of mental health services, and finally recovery as the individual's own subjective and social project as opposed to professionals' projects, while recognising the essential societal role in causation and solution.

#### 1.1 Central research questions and intentions

The general aim of this dissertation has been to contribute to the evolving work of exploring, understanding, and strengthening the recovery process for people with severe mental health problems, and to do so within the context of their everyday lives. The following research questions have been central:

- How can an everyday life research approach inform us about the process of recovery from severe mental health problems?
- How can professionals be of help in supporting individuals' recovery processes?

#### 1.2 Organisation of this dissertation

This dissertation contains two main parts: a theoretical framework for the five papers (Appendices I-IV), and secondly, a summary of findings with discussion. Chapter 2 presents the theoretical background for the three studies upon which the papers are based. Chapter 3 describes and discusses methodological approaches, followed by Chapter 4 which presents overall findings. Chapter 5 is a discussion emphasising four over-riding areas related to this dissertation research, one of which is methodological and the others of which are theoretical. Finally, Chapter 6 offers some concluding reflections and outlines possible implications.

#### 2. Theoretical background

#### Recovery in psychosis in an everyday life perspective

This section presents the theoretical framework for the papers included in this dissertation. Before providing a background for contextualising recovery in an everyday life perspective, I briefly want to elaborate my position with regard to the issue of the 'condition' of mental health, including the move from individualised, pathological notions (defined as mental health problems) towards societal, collective understandings (mental health).

#### 2.1 The complexities of defining severe mental health problems

A long-standing challenge within the medical disciplines has been the lack of clarity in differentiating between health and illness, including what characteristics or phenomena are used as 'illness entities' in the diagnosis process, and what 'getting better/or worse' means in the treatment/prognosis/monitoring process. This is especially true in the medical subspeciality field of psychiatry. Underlying issues of reliability such as criteria and standards used to categorise are the less-mentioned issues of diagnosis-validity and definition-power.

She further claims that it is not surprising that the foundational assumptions of the psychiatric classification system are problematic, since the basic focus of medicine has been bodily processes rather than behaviour and emotions.

Systematic psychiatric diagnosis has been challenged as faulty from several perspectives, including being blamed for creating more problems than it has solved. One fundamental criticism is that pathological discourses rarely consider the person's life circumstances, and where problems and symptoms are then identified in individualistic, inherent and internal ways (Read, 2004; Wilson & Beresford, 2002). Similar issues were raised by Basaglia (1987) who criticised mental health care systems for having a main interest in illness entities rather than in the person experiencing the mental distress and daily life consequences.

Investigating subjective experiences with psychosis from a phenomenological perspective (Davidson, 1992; 1994; Davidson, 2003; Larsen, 2004; Thornhill et al. 2004) reveals other relevant aspects, including that individuals diagnosed with psychosis draw on non-medical explanations to make sense of their problems. The limiting meaning and difficulties associated with diagnosis has been highlighted throughout the history of psychiatry, more recently so for example by Larsen (2004) who has called for a set of explanations rather than a single dominating one, in order to value individual experiences. Read (2004) augments this, suggesting thinking in terms of dimensions rather than discrete categories, such as 'normal/abnormal' behaviours, since thoughts and feelings vary over time and within different social contexts. As Shakespeare (2006) has repeatedly argued, dichotomies are rarely helpful and tend to polarise rather than resolve issues.

Individuals with first-hand ('lived') experience have criticised professionals as well as researchers in the mental health field for owning conceptualisation of their thoughts, emotions

and behaviours, perceiving them as defective and typically labelling them as biochemical or genetic imbalances (see for ex. Beresford, 2005; Boevink, 2005; Deegan, 1996; 1997a).

Such individualistic models for understanding and defining a person's experiences, circumstances, feelings and perceptions are essentially deficit models, based on assumptions of inadequacy and pathology of the person involved. Wilson and Beresford (2002) have challenged psychiatry's failure to pay attention to alternative understandings of mental health problems, raising vital questions as to how psychiatry can continue dominate the interpretation of mental distress as illness when there are well-argued challenges to such orthodoxies from a service user perspective and the subjective experiences from recovery (see also, Roets et al, forthcoming 2007). Such narrow medical perspectives place social science contributions outside of what I believe should be the core agenda, with resultant problematic impacts on appropriate service policy and development. In this regard, it becomes essential to examine how mental health problems are understood, what they may be expressions of, and in which ways they are conceptualised individually as well as socially (Kolstad, 1998; 2004). The medically-minded culture has for too long dominated efforts to understand and assist citizens with serious and enduring mental health distress. Listening to personal recovery stories, including the very real experiences of mental distress and the impact of diagnosis, can be crucially helpful in finding alterative routes towards getting on with a better life for many.

In order to better contextualise the condition of mental distress, I will briefly refer to some relevant sociology/social psychology literature. Howard Becker (1973) described problems associated with social categorisation and the sociology of deviance, to some extent building on Goffman's work about institutionalisation, labelling and stigma (Goffman 1961; 1963). The social processes of being labelled mentally ill are not new, and deserve to be revisited.

Thomas Scheff (1966) and Thomas Szasz (1974) were among the first to recognise the risks of labelling, more fundamentally asking if mental illness is merely a social construction.

These questions and perspectives paralleled Ivan Illich's work on the medicalisation of human experiences (1975/1966), and are more recently augmented by anthropologists using notions such as cultural shaping (Barret, 1996), and from the area of disability research, in particular the social/relational models of disability (Tøssebro, 2004; Shakespeare, 2006). These social/relational models locate much of the problem in societal conditions, and this line of thinking is of particular interest in this dissertation where many of the problems encountered are generated by social, physical and material barriers rather than a person's individual limitations. Although such social models have their roots in service transformations for people with physical and intellectual disabilities, the relevance for the mental health field should be obvious and better recognised. Social barriers such as inappropriate dwellings, sub-standard working conditions, poverty, and stigmatising discrimination are similar for most marginalised 'groups' in society. Rather than being restricted by orthodoxies, dichotomies and polarisation, Shakespeare (2006) calls for pluralism in research and also for open, rigorous debates. I believe attitudes and perspectives such as these would be helpful in developing the mental health field, where relationship of the individual to the societal/structural, and the biological to the social could and should have a more central place on the social-political agenda.

#### 2.2 An everyday life approach

This section introduces some aspects relevant for contextualising mental health problems in everyday life. Everyday life as a concept is difficult to capture because in many ways it is so self-evident and consequently often seems trivial. In a pragmatic way, everyday life may simply be observed and experienced as a contrast to holidays and celebrations.

It is what we take for granted, the detailed reality of our days, evenings and nights, the known yet unnoticed routines.

An interest in everyday life in the mental health field can be traced back to the moral treatment period during the late eighteenth and early nineteenth centuries (Slater & Roth, 1969) and particularly in Adolf Meyer's work of the early 20<sup>th</sup> century when activities of daily living in institutional settings were defined as the main treatment (Meyer, 1922). Meyer is often primarily remembered for his opposition to the dominance of the Kræpelinian diagnostic system. Although he accepted that classification may have a place, he argued that if diagnosis were to be meaningful, it should be secondary to the assessment of the patient as a person (Slater & Roth, 1969). Meyer also proposed that spending time in mutually useful and gratifying activities was fundamentally beneficial in the treatment of psychiatric patients. In those days, there were few alternative opportunities for defining and deciding one's pathway out of personal difficult situations, and often the only available residential alternative for individuals with mental health problems was the long-stay psychiatric hospital. Another significant source of knowledge when it comes to everyday life is the work of Erving Goffman (1961) who included psychiatric hospitals in his well-known analysis of 'total institutions', describing a bureaucratic, well-regulated organisation where men and women were expected to carry out daily activities such as sleeping, working, eating and relaxing with the same people and all under the same roof.

Following international principles of normalization and deinstitutionalisation, issues of everyday life as lived by others in the community appeared on the disability/mental health agenda (Cresswell et al, 1992; Dalgard, 1998; Dalgard & Tambs, 1997; Kristiansen, 1993). Previously known as patients and clients now should be known as citizens with rights, including the notion that segregation was not morally, socially, culturally or politically

acceptable, nor therapeutically helpful (NOU 2001:22) (Further elaboration of this deserves more attention than this introduction allows).

These previously disenfranchised citizens were also often in need of individualised, practical and flexible supports in their daily lives, in order to be included in communities participation and overcome societal barriers. This often meant taking on more active and contributing social roles such as worker, homeowner, neighbour, provider and colleague, an evaluator of relevant services, as well as finding ways to deal with the numerous practical issues involved with independent living. Mental health practitioners were also assigned new roles to various degrees as 'everyday life helpers', supporting people in their own homes and in locally-based community settings. Yet many human service workers discovered that their knowledge and skills from traditional mental health services was inadequate in relation to the new ways of understanding the needs of citizens with mental distress. Treatment and support programs transferred from institutional contexts into community mental health settings brings back associations to Goffman's descriptions (1961), where service-led structures were strongly regulated by internal and professionally-controlled procedures and agenda, rather than the everyday-life situations met by people with mental distress who were often quite suddenly allowed into a life outside of institutional walls, a life with many novelties for which they were poorly prepared.

Another aspect of community life for citizens with mental health problems is that of material and economic conditions. Living conditions surveys have a deeply-rooted tradition in Norway (Tøssebro & Kittelsaa, 2004), and areas such as housing, education, social contact, and income have long been objectively documented as well below-average for citizens with serious mental health problems (St meld 25 (1996-97)). Yet little of this knowledge has been translated into workable policy and strategic interventions.

The rhetoric and well-intended national objectives of community integration and societal participation often remain severely limited by individuals' personal financial situations.

In modern industrialised societies such as Norway, being involved in social activities is expected, such that living at the margins of these socially valued positions is likely to affect both perceptions of oneself as well as reinforcing the largely negative public stereotypes of 'who people with mental health problems are'. Simply stated, mastering daily life and participating in social life costs money, and not being able to afford such participation increases risk of societal devaluation.

During what we might call the deinstitutionalisation period, there have been changes in the provision of welfare in many countries with implications for community living. Wilton (2004) reports about Canadian experiences, asserting that little research attention has been focussed on daily community life for people with serious mental health problems, offering strong evidence that insufficient income has deleterious impacts on multiple life domains such as basic needs, family situations, social relations, leisure-interests and a general sense of self-esteem. Other studies (Cresswell et al, 1992; Elstad, 1984; Øverås, 2000) show that citizens with severe mental health problems are more isolated compared to age-peers with regard to social relations and occupation: many lived alone and relied solely on welfare benefits. Underlid's study (2005) about poverty in Norway identified a series of social and psychological consequences, such as feelings of shame and insecurity, reduced autonomy, and societal devaluation, asking how a well-resourced welfare state like Norway can ignore the multiple needs (psychological, social, etc) of a group of fellow citizens.

There appears to be a long way to go in understanding the ways that mental health problems interfere with, complicate, or otherwise influence an affected person's day-to-day activities, interests, experiences, and relationships,- despite long-standing evidence that psychiatric labels and histories are known to be correlated with social isolation and poverty.

Research exploring recovery from severe mental distress as a process within social and material environments (Borg et al, 2005; Borg & Kristiansen, forthcoming; Davidson & Roe, in press) appears to be needed, especially when we increasingly learn that the recovery process emerges and develops within ordinary life contexts, relationships, and pursuits (Davidson et al, 2005a). Improvement of mental health services may drown in its own quagmire without a broader set of investigative questions and societal strategies.

#### 2.3 Conceptualising everyday life

Introducing everyday life as a conceptual platform for understanding 'recovery' requires some clarifications. As discussed in more detail in paper I, Gullestad (1989) suggests two perspectives on everyday life which I have found relevant. The first dimension is organisational and functional, referring to the concrete, daily organisation of tasks and activities. Of interest here is not a single everyday life, but many lives, influenced in complex ways by culture, social class, occupation, gender, age and spiritual beliefs. It is about our patterns and systems of activities, what and how we do what we do, and the social and cultural contexts we move about in. Such issues in everyday life often go unnoticed, regarded as too ordinary or commonplace to warrant attention.

Gullestad's second dimension is everyday life as experienced. This is also known as the subjectivity of everyday life, or what phenomenology terms the 'life world' in contrast to the objective world of the sciences (Bengtsson, 1999; Husserl, 1970). Here the focus is on the human experience of meaning, about what is salient and important to the person rather than on objective facts per se. Daily life is also about the terrains of our acts and interactions with other people, and she emphasises how human beings attempt to integrate these various roles and parts of their lives in meaningful ways.

This integration crosses different social structures and arenas, such as home, work settings, parental duties, and leisure-time activities, to mention a few (Gullestad, 1989; Schutz, 1962/1999).

There are several reasons why an everyday life approach is suggested as essential in learning about the recovery process, something I became increasingly aware of as my research progressed. I return to this in the discussion section of this introduction but will briefly mention here the need to understand the processes of recovery on a broader level rather any singular or isolated perspective, whether it be medical or psychological or sociological context, to mention some. Mental health services as well as psychiatric research continue to be overly directed towards the individual person, where mental health problems are typically explained and treated as intra-psychic, biological and genetic phenomena, and where efforts predominantly deal with individual symptom relief while neglecting social, environmental and material conditions. Examining peoples' experiences of mental health problems in the context of their daily lives opens up for exploring and discovering what has been usually narrowly defined as a medical problem, instead of utilising theories from broader, non-medical traditions. By attempting to understand experiences and behaviours in ordinary environments, the activities, choices and strategies can be assessed in their naturalistic contexts, and one can better avoid personalising problems that are often likely to be mainly social and structural.

#### 2.4 Conceptualising recovery

In this part, I present some ways of conceptualising recovery, to some extent chronologically. Etymological references define recovery as meaning "to regain, to get again" (Skeat, 1978), or as Davidson et al (2005 b: 8) reiterate from the Webster dictionary:

- "1) return to a normal condition; 2) An act, instance, process, or period of recovering;
- 3) Something gained or restored in recovering; 4) The act of obtaining useable substances from unusable sources, as with waste material." Such definitions can be useful in attempting to clarify the different definitions and interpretations of recovery currently used. In the search for finding what these various interpretations might have in common or not, I would argue that we should return to the underlying and often implicit assumptions and beliefs about what is deemed normal or not, as well as about processes of individual/social change.

As previously stated, the notion of recovery in the present-day mental health field is not only inconsistently understood and used, but gaining in popularity despite lack of consensus. As Jacobsen (2001) wrote: "The meaning of recovery will vary, depending on who is asking and interpreting, in what context, to what audience, and for what purpose." Still, in the western part of the world, recovery seems increasingly popular, both as a user-controlled, grassroots-movement and empowerment strategy users/survivors, as well as for providing guidelines for clinical practice. Examples of the latter are statements from the USA President's New Freedom Commission on Mental Health in 2003 (Resnick et al, 2005) and at a national policy level in Great Britain where the National Institute of Mental Health views the term recovery as a steering principle (Wallcraft, 2005). Similar developments can be seen in other countries, although some like Norway have not to the same extent endorsed recovery as the overarching aim of mental health services, while many related features such as user-involvement, empowerment, human rights and citizenship are named as priorities at both national and local levels.

The conceptualisation of recovery appears to have arisen from two main sources: the user/consumer/survivor movement with first-hand experience from mental distress and recovery, and from professionals in services and research (Jacobsen & Curtis, 2000; Ralph & Corrigan, 2005).

The concept of mental health recovery has been mentioned in consumer/survivor self-help efforts since the 1930s (Ralph & Corrigan, 2005) and became more prominent in self-help writing, presentations and through social movements during the 1960s and 1970s (Boevink, 2006; Chamberlain, 1997; Coleman, 1999; Deegan, 1996; 1997a; Jacobsen & Curtis, 2000; Ridgway, 2001). The term 'recovery' has however also been used in traditional psychiatry where it has been more narrowly interpreted as a clinical outcome, occurring at a certain point in time which can be measured after an illness and when health is entirely is regained (Resnick et al, 2005), or also what Warner (1994) has termed 'total recovery' where all original symptoms described and diagnosed have disappeared subjectively and objectively.

Many historical and clinical/therapeutic factors contribute to the ongoing ambiguity surrounding the term recovery. Although the notion of chronicity is still attached to the descriptions and expectations of severe mental health diagnoses, recovery has been documented in longitudinal studies for many decades (Davidson & Strauss, 1995; Harrison et al, 2001; DeSisto et al. 1995; Harding et al. 1987; Harding, 2003; WHO, 1973; Strauss 1980; Warner, 1994). Challenging chronicity myths associated with labels of psychosis can be traced back to the International Pilot Study of Schizophrenia in the late 1960s, and to other international studies examining outcomes (Strauss & Carpenter, 1977; WHO, 1973). Findings consistently demonstrated a broad heterogeneity in outcomes for people with psychosis-labels over time, showing that those diagnosed and treated for schizophrenia were able to recover, and that severe mental illness was found not to pervade the entirety of the person's life (Davidson & Roe, in press).

The research literature on recovery from severe mental illness typically defines recovery as an outcome or as a process (Borg & Topor, 2003; Davidson, 2003; Davidson et al; 2005b; Jensen, 2006; Onken et al, 2002; Ralph & Corrigan, 2005). Davidson & Roe (in press) suggest alternative language: recovery *from* (outcome) versus recovery *in* (process).

The term heterogeneity is well accepted in outcome studies, and depending on where studies are carried out, at least 45% and up to 65% of each sample were found to experience partial to full recovery, meaning that their functions and symptoms improved over time (Davidson & Roe, in press). Harding (2003) refers to seven international long-term studies where at least 50-60% of each intact cohort studied across two to three decades significantly reclaimed their lives, in spite of persistent beliefs that this would be impossible. Longitudinal studies continue to confirm the prospects of recovery in severe mental illness, that improvement in well-being is the expected goal, and that this can happen with or without service practitioners and formal service initiatives (Borg & Kristiansen, under review; Davidson, 2003; Davidson al 2005a; Harding et al, 1987; Harding & Zahnister, 1994; Ralph & Corrigan, 2005; Topor, 2001; Warner, 1994).

Recovery as a process is greatly supported by reports from service users/survivors. This is understood as the process of finding ways of living and dealing with mental health problems and their consequences, and building on the person's strengths and interests in order to have a life and identity beyond that of a psychiatric patient. Recovery is seen as a way of working through problems and having an attitude toward life where living with occasional distress is possible (Borg & Topor, 2003; Davidson et al. 2005a; Jensen, 2006). Individuals with lived experience describe this not so much as being about symptom relief but rather as recapturing roles as a healthy person as opposed to being (solely) a psychiatric patient (Boevink, 2005; Curtis, 1997; Deegan, 1996; 1997a; Glover, 2005).

Deegan (1996) has described recovery this way: "not being 'cured' or symptom-free or stabilised, but rather a transformation of the self wherein one both accepts one's limitations and discovers a new world of possibility. This is one central paradox of recovery: in accepting what we cannot do or be, we begin to discover who we can be and what we can do. Thus, recovery is a process.

It is a way of life. It is an attitude and a way of approaching the day's challenges...not a linear process. Like the sea-rose, recovery has its seasons, its time of downward growth into the darkness to secure new roots and then the times of breaking out into the sunlight. But most of all recovery is a slow, deliberate process that occurs by poking through one little grain of sand at a time ".

Another discussion in attempts to conceptualise recovery, is whether it should be seen as primarily an individual process or a social one. A great part of the research field continues to characterise recovery in individualistic ways, where the person experiencing the problems is in focus and where recovery is seen as a deeply personal, unique process, and where overcoming challenges of the mental distress and environmental barriers is central. (Anthony, 1993; Deegan, 1996; 1997a). Rediscovering a sense of an active self and valuing one's own expertise and knowledge of what helps is emphasised here as well (Borg & Kristiansen 2003; Davidson & Strauss 1992; Deegan, 2005; Estroff, 1989; Strauss, 1989; 1996; Topor, 2001).

Resnick et al (2005) suggest a way of avoiding some confusion over the multifaceted notion of recovery by conceptualising recovery as an attitude or orientation. As an orientation, they place the recovery concept within the process-tradition, but which they believe can be expressed quantitatively and be used as outcome measures. They propose four domains to serve as an approach to conceptualise recovery: feeling empowered in one's life; self-perceptions of knowledge about available services and mental illness; satisfaction with quality of life, and hope and optimism for the future. Although this may be a valuable contribution to conceptualising recovery, this proposal may well fall short when it comes to recognising environment and social impacts which I believe deserve more attention.

In summing up, one may talk about an outcome orientation and a process orientation; and also an individual orientation and a social one where no strict lines are drawn between these orientations.

What most understandings have in common is the belief that individuals experiencing or diagnosed with a severe mental illness can no longer be seen and met as having a chronic debilitating disease, and that a meaningful life in the community without mental distress dominating everyday life is possible and to be expected.

Onken et al (2002) has advocated an ecologist perspective that I support, incorporating both individual and environmental elements as well as the relationships between them, with emphasis on interactions and transactions. Recovery can be viewed as a dynamic interplay of many forces that are complex, synergistic and linked.

In the context of this ecologist perspective, I will briefly refer to some characteristics of recovery that are summarised by in Paper IV (Borg & Kristiansen, under review).

First, recovery means 'taking back control and getting on with one's life', and managing most things most of the time. Recovery is not about cure nor necessarily about symptom relief, but rather about learning to live with and finding ways of overcoming barriers and gaining more control.

Recovery can be both a process in some situations and in others an outcome, both of a heterogenic character. The uniqueness of the process is often experienced as essential yet often goes unrecognized because of traditional treatment and rehabilitation approaches which tend to be standardised and typically based on diagnostic or functional categories.

Recovery is considered a dynamic and social process, incorporating individual as well as environmental perspectives and the relationships between the two, a life context approach implying among other things that regardless of one's aetiological perspective concerning the nature and cause of mental illness, it is in a person's everyday life that the numerous consequences need to be addressed. A recovery approach also includes the understanding that while the personal distress of mental health problems is often devastating, the social consequences are often even more disabling.

Finally, I will briefly mention some of the criticism towards recovery, since although the ideas are growing in popularity, there is also growing scepticism. One criticism is due to the tendency of new buzz-words that appear on the scene, while in fact making little difference (Beresford, 2005; Wallcraft, 2005). So-called recovery-oriented services can simply be experienced as more of the same, with patronising attitudes from service systems and practitioners, who have altered their language with otherwise very little change occurring. Many see recovery as idealistic and naïve, where power-issues not are taken into account, such as the imbalance between professional and service user.

An individualised recovery perspective typically pays minimal heed to environmental/material issues and social oppression, adding the burden of responsibility onto the individual. A last issue is that research closely associated with recovery is rarely incorporated in the more general discussions and developments in studying issues such as health and illness (Boorse, 1977; Juul Jensen & Andersen, 1994; Wackerhausen, 1994), salutogenesis (Antonovsky, 1991), and resilience (Borge, 2003). I would argue that there is much to gain in coupling these research areas more together, since recovery is about individuals working towards more general overall health, and additionally, there are good reasons for not making recovery 'too special' and endangering its isolation from related fields. Conceptualising recovery includes fundamental questions such as what is health and what is illness, issues about power and citizenship rights, and not least that people with mental health problems are first and foremost human beings and need to be met perceived and met in that way.

In this dissertation, recovery has been considered a dynamic process incorporating individual as well as environmental perspectives and also the relationships between the two. The integration of material, social and individual factors is considered essential in order to understand the recovery process as well as to understand how people alternatively may become or remain trapped in the role of mental patient.

#### 3. Data Material and Methodological Approach

This Chapter presents the three studies which form the basis for the five papers of this dissertation, including information about informants, methodological approaches and rationales, ethical considerations, and summary of the results presented in the five papers.

#### 3.1 Studies

This dissertation has utilised data from three different studies:

**Study 1** (findings presented in paper IV), using data from the a collaborative research project together with the Nordic Recovery Research Group (NRRG) (1);

**Study 2** (findings presented in papers I and IV), based on research work together with the International Recovery Research Group (IRRG) (2);

And, *Study 3* (findings presented in papers II and III), drawing on data from interviews carried out in Norway by myself.

A more explicit overview of these studies is described in Chapter 3.4.

<sup>(1)</sup> NRRG: Alain Topor and Johan Svensson, Västra Stockholm Psykiatriska Sektor, Sweden; Marit Borg, Elin Kufås and Carsten Bjerke, Blakstad sykehus, Norway.

<sup>(2)</sup> IRRG: Larry Davidson and Dave Sells, Yale University, USA; Izabel Marin and Roberto Mezzina, Trieste Mental Health Services, Italy; Alain Topor, Psykiatrin Södra, Stockholm; Sweden, Marit Borg, Buskerud University College, Norway

### Overview of the studies

Study	Informants	Research group	Nationality	Candidate Borg's contribution
Study 1	Total = 15: * 8 women and 7 men	In original study; 5 multi-disciplinary researchers 3 interviews carried out by candidate Borg.	In original study; Swedish and Norwegian In writing paper V: 2 Norwegian researchers	The candidate reanalysed all interviews with focus on helpful relations and wrote the paper. Co-author took part in analysis and reviewing the paper.
Study 2	Total = 12: * 7 women and 5 men	6 multi-disciplinary researchers  2 interviews were done by the candidate	Italian, American, Swedish and Norwegian	The candidate took part in analysis and reviews of the 8 papers (2 included herein). Background for paper III is the candidate's responsibility in analysis for the themes material resources and home, and writing the paper. Coauthors took part in reviews. In paper I, the candidate was responsible for the theme material resources and took part as 2nd author in method, background, & final reviews.
Study 3	Total = 13: * 7 women and 6 men	All interviews carried out by candidate	Norwegian	In paper I, the candidate did analysis, wrote the major part of paper, and the co-author participated in discussing findings and final reviews. In paper IV; the process of analysis was collaborative (see paper IV). The candidate wrote the major part of the paper and the co-author took more active part in method-chapter and reviewing the paper.

<sup>\*</sup> Four of the participants are included both in NRRG and IRRG, 2 Swedish (1 man and 1 woman) and 2 Norwegian (1 man and 1 woman). One female participant is included in both the NRRG-study and the candidate's individual study.

#### 3.2 Informants in the three studies

In studies I and II, the informants were individuals who: (1) had experiences of severe mental illness; (2) had experiences as users of mental health services; (3) considered themselves as having recovered or as being in recovery from their mental illness; and (4) had not been hospitalized for psychiatric reasons for the last 2 years. Study III had the following inclusion criteria: (1) Had a permanent place to live; (2) Considered themselves as being in recovery or having recovered from severe mental illness; (3) Were coping satisfactorily with their lives; and (4) Had improved their lives with help from mental health services and/or with help from other sources.

Additional criteria for inclusion in these studies were being willing and able to articulate and describe one's own experiences of severe mental distress and recovery, and providing informed consent for recording data for the purposes of research and teaching. In order to protect anonymity, names of participants have been changed in all papers. The informants had a variety of both general life and mental health service user experiences. They had all accessed services in mental health settings ranging from in-patient care in hospitals to respite care provided by twenty-four hour community centres, some for extended periods. Most informants still had some contact with services, and this contact was mainly concerned with medication-monitoring, psychotherapy or supportive counselling provided by mental health staff once a week or once every fortnight.

A total number of 35 participants, 17 men and 18 women gave their consent to describe and discuss their life experiences for the purpose of these studies. Four of the participants are included both in NRRG and IRRG, 2 Swedish (1 man and 1 woman) and 2 Norwegian (1 man and 1 woman). One female participant is included in both the NRRG-study and the candidate's individual study.

Nationality: 20 Norwegian, 9 Swedish, 3 Italian, 3 USA citizens.

**Age-range at time of interviews**: 26-63 years old. (3 participants were in their late 20s, 13 participants in their 30s; 11 in their 40s, 7 in their 50s, and 1 in her 60s).

**Family -situation:** 26 were single (of whom 4 were divorced), 6 were married or partners, 3 were engaged to be married, 5 had children.

**Accommodation:** 28 owned or rented an apartment or house, 4 stayed with parents, 2 stayed with friends, 1 lived in a publicly-financed shelter.

**Work-situation/occupation:** 7 had ordinary waged full- time work, 11 had part time employment, 1 was a student, 4 did artistic work (authorship or painting), and 4 performed voluntary work, 2 worked in cooperatives, 6 were unemployed, of whom 3 had been working for many years and preferred unemployment in order to have a more peaceful life. 3 were unemployed and wanted to work.

**Age at the time when problems started**: 18 informants reported they first experienced mental health problems in childhood or as teenagers, 12 informants were in their 20s, 4 were in the 30s, and 1 in her 40s.

**Diagnosis:** The informants reported they have been diagnosed and/or treated for the following: 24 for schizophrenia, 1 for schizoid-personality disorder, 3 for paranoid psychosis, 1 for reactive psychosis, 3 for affective disorders, 1 for major depression with psychotic features, 1 for borderline psychotic personality, and 1 for severe personality disorders. Some had been given several diagnoses and the one named here is the one mentioned by the informant as being most frequently assigned.

#### 3.3 Methodological approach

The research studies included in this dissertation utilise inductive, qualitative research approaches, largely grounded within a phenomenological framework (Davidson 1992; 1994; 2003; Davidson et al, 2001; Kvale, 1983; 1992; 1997; Malterud, 2003; McCracken, 1988; Husserl, 1970), and with an ontological fidelity to the experiences reported by individuals having a history of mental health distress (Kristiansen, 2004). Trying to grasp and understand life world- perspectives and intentionality have been central (Bengtson, 1999; Husserl, 1970), including the individual's everyday life as both a practical and societal world (Schutz, 1962/1999) The focus is thus complex and multiple, grounded in individual experiences, yet where these individual experiences can only be understood when examined within broader contexts. Qualitative research on recovery in and from severe mental health problems represents a small but solid literature (Davidson, 2003). Initially the studies were mostly concerned with recovery as an subjective and highly personal experience (Anthony, 1993; Borg et al, 1998; Davidson & Strauss, 1992; Harding et al 1987; Strauss, 1989) but in later years the material and social aspects of recovery are more taken into account. Following this development, and in beginning to consider recovery as a social process as well as a personal and subjective phenomenon, an everyday life research approach seems to be necessary, as previously described.

Some critical issues form the foundation for these studies. First, the researchers acknowledge the existence of mental health problems as real for the persons affected by them, as manifested and experienced in very different ways, and also challenge notions such as causality, prognosis, and improvement measures based on clinical outcomes (Borg, 1999; Borg & Topor, 2003; Davidson & Strauss, 1995; Davidson et al, 2005a; Kristiansen, 2004; 2005; Mezzina et al, 2006a; Topor, 2001).

A central starting point in this research has been the epistemological belief that crucially important knowledge comes from individuals with lived experience of mental health problems, and that the central aim is to discover and interpret meaning rather than causality (Borg & Topor, 2003; Davidson, 2003; Jensen, 2006; Kleinman, 1988; Topor, 2001). Subjective experiences of the individuals and their whole life contexts are seen as vital in such inquiry, and replace traditional psychiatry's focus on objectivity, diagnosis, and decontextualised individual pathology (Beresford, 2005; Borg & Davidson, in press; Borg & Kristiansen, under review; Davidson, 2003; Kristiansen, 2004; Shakespeare, 2006; Strauss, 1996).

#### **Inquiry process**

All interviews took place in settings and times chosen by the participating informants. The majority of the interviews took place in peoples' homes, and in study 3 this was a particularly valuable source of added contextual knowledge about how peoples' living conditions. Interviews began by briefly describing the study's purpose: learning about recovery from severe mental distress with the help of persons with lived experience. The interviews proceeded with open questions such as "Could you tell me about how it all started" followed up by "Could you tell me about what has been helpful in your process of recovery?" in studies 1 and 2. Study 3 interviews began with the more open 'Grand Tour' question (McCracken, 1988): "Could you tell me a bit about your everyday life?".

The researchers were particularly interested in finding out about the informants' experiences of their daily situations, their ways of helping themselves and coping with challenging life situations, their experiences with mental health care professionals, services, and other sources of support, what had been important during recovery, and how they viewed their future.

In study 3, the themes of everyday life were in focus, asking more about where the informants spent their time, places they enjoyed, people they regularly met, what was important for them in daily life, and what recovery meant for her or him. Aspects of the recovery process that the informants identified as particularly central were examined further through in-depth questioning intended to capture the diversity of their experiences. The open-ended interviews were audio-taped, transcribed, and then returned to each informant for their review and amendments.

In study 1 candidate Borg re-analysed the interviews exploring topics concerning experiences and perspectives on helpful relationships with mental health care professionals more fully. A qualitative thematic method was used (Davidson et al, 2001; Kvale, 1983; 1997; Malterud, 2003) where summaries were developed inductively and then discussed with the co-author. In study 2, the data were analysed according to established qualitative procedures, as follows. First, the interviews were audio-taped and then transcribed, with non-English language interviews translated into English, which served as the common language for the team. Each of the members of the research team then separately read each interview and noted evident themes in writing. Second, consensus review and appraisal of themes for each transcript was conducted by the research group as a whole and recorded. Third, the researchers then separately reviewed the consensus notes for each transcript and determined themes common across interviews. Fourth, the research team met to perform a consensus review of common themes. Finally, review of all interview texts was conducted again to ensure that these themes did in fact describe the completed interviews (Davidson et al, 2001; Davidson, 2003). The candidate took part in all procedures of interview analysis, and had specific responsibility for the themes of material resources and home. In Study 3, the candidate did the analysis independently and results are presented in paper 1.

The interviews were re-analysed exploring topics concerning work, as work and the work settings had emerged as a recurring theme in the process of recovery. Selected material related to the meaning of work in peoples' lives provided the empirical basis for paper IV. Transcribed interview texts were analysed using a phenomenological four-step thematic approach. Each author carried out an independent two-phase inductive analysis, followed by collaborative phases of comparison, identification of higher-order themes, revision and verification (see paper IV). The candidate wrote the major part of the paper and the co-author took an active part in the method-chapter and reviewing the paper's final content. In study 3, the research process also included a reference group of five individuals with experience of recovery. Inspired by participatory research (Davidson et al., 2001), this group was involved in project design, interview content, and inclusion criteria, and in ongoing discussions during the analysis phase. Additionally the meaning of certain concepts was discussed. The group was run like a focus group organised by the candidate.

#### 3.4 Studies and papers

**Study 1,** presented in paper V, draws on material from a Nordic study (Borg, 1999; Borg & Topor, 1998; Topor, 2001). Fifteen participants from Sweden and Norway were interviewed about their process of recovery in severe mental illness. This paper explores helping relationships from the perspective of service recipient experiences. The aim was to understand the characteristics of helping relationships in mental health services, including the ways in which recovery-oriented professionals can most effectively collaborate with service recipients.

**Study 2** is presented in papers II and III and reports results from a multi-national study of the process of recovery in psychosis (Davidson et al, 2005a). Twelve participants from Italy, Sweden, the US, and Norway were informants in the study.

The research team included experienced investigators from each country and representing the disciplines of psychiatry, psychology, social work, and occupational therapy/health sciences. A qualitative analytic method was utilised to delineate several processes which people living with, and recovering from, severe mental health problems had described in detail as unfolding within the contexts of their everyday lives as a whole, both inside and outside of treatment and rehabilitation services. Intensive qualitative interviews with between two to four participants in each country were chosen from ongoing research projects for thematic and phenomenological analysis. Paper II presents the overall findings of the study and theoretical and methodological background. Paper III presents the importance of material resources, and in particular experiences of how having a home may contribute to recovery in various ways.

Study 3, presented in papers I and IV, draws on data from a qualitative research study exploring the everyday lives of individuals with severe mental health problems in Norway, with a central purpose of identifying what is helpful in the recovery process. A total of 13 individuals were interviewed about their everyday lives and experiences in recovery. The study was intended to contribute to a growing body of knowledge that attempts to explore, understand, and address severe mental health problems within the context of the person's everyday life. In paper II, the overall findings of experiences of recovery as lived in everyday life are presented, how problems and challenges that are associated with mental distress are experienced and addressed by the person within the context of his or her everyday life, and how difficulties and challenges are overcome. A recurring theme in these interviews was the value of having a job, and in paper III selected material related to the meaning of work in peoples' lives provided the empirical basis for this article. Work and the work setting were experienced as significant in the process of recovery, and findings about why work is important were identified and are presented and discussed.

#### 3.5 Ethical considerations

The ethics of qualitative research design pose distinctive demands on principles as informed consent, confidentiality and privacy, social justice and power issues (Shaw, 2003) and ethical considerations need to be included in all steps throughout the research process.

Kvale (1997) poses three ethical regulations in research involving human beings: informed consent, confidentiality, and consequences. In all three studies, the formal ethical research procedures were attended to as follows:

Study 1, drawing on material from the NRRG-project, was accepted by the Norwegian Regional Committee for Medical Research Ethics in 1996.

Study 2 was drawing on material from projects being evaluated by the national ethical regulations of the respective country. Study 3 was accepted by the (national) Social Science Data Service and at the regional level by the Region IV (Mid-Norway) Medical Ethics Committee in 2004. The names and identifying features of all informants were changed to protect their privacy and confidentiality.

I would briefly like to elaborate Kvale's ethical issue about consequences. Studies inviting individuals with mental health problems to reveal private and intimate details of their lives puts ethical demands on the researcher throughout the research process, both in planning, interview situations, analysis and reporting. Attentiveness in situations where the interviewer rules the interview and in analysis is crucial, and a way of approaching this challenge is to work in research teams, as in these three studies, by including research colleagues in the processes of the studies. Interviews are a sensitive and powerful method and although the intention may be to be warm, caring and empowering dialogues, power asymmetries must be highlighted (Kvale, forthcoming). Another method of attending to ethical issues in study 3 was the reference-group comprised by five individuals with lived experience who provided useful feedback and reflection underway.

Involving this expert group as advisors in project design, interview content, inclusion criteria, in ongoing discussions during the analysis phase, and in elaborating on certain concepts, gave important and constructive knowledge throughout the research process.

These studies support the contention that fundamental ethical issues exist in qualitative research, related to listening and interpreting the voices of 'others'. They are based on the epistemological belief that subjective reports of people with lived experience provide important and perhaps essential insights in the quest for new knowledge.

Finally, I would like to include some reflections about language as an ethical issue. Understanding recovery in the context of everyday living involves careful attention to the detailed descriptions of daily life as well as acknowledging the 'little things' and apparent trivialities that compromises everyday situations. The informants' stories involve intimacy and privacy that place challenging demands on capturing and representing these experiences in words in the paper presentations. Doing this in a language (English) that is neither that of most of the informants nor the candidate's native language are likely to entail some loss of detail, nuances, as well as some particular socio-cultural features. In writing the papers from the 3 studies, a way of meeting this challenge was to work in research teams with colleagues both having English as first language and having established expertise in qualitative research in the field of mental health.

# 4. Summary of results

**Study 1** draws on material from the NRRG-project and findings are presented in *Paper V*. 15 women and men from Sweden and Norway with experiences of severe mental illness were interviewed. The objective was to emphasise the person's life situation in recovery, including individual as well as social phenomena, and improvement and coping as well as illness-experiences.

Particular focus in this paper was investigating what was experienced as helpful in relationships with professionals, and certain common factors about helpful relationships were identified. First and foremost, the participants valued professionals who were willing to acknowledge their views and preferences on helpful help as well as to flexibly shape services to the needs of the individual service user. They emphasized professionals who conveyed hope, shared power, were available when needed, were open regarding the diversity in what helps, and were willing to stretch the boundaries of what is traditionally considered as the 'professional' role as described in paper V. Recovery-oriented professionals were described as those who had the courage to deal with the complexities and the individuality of the change process, and were able to use their professional skills and expertise in a collaborative partnership with the service user. The perspectives and preferences of service users have been ignored for far too long and are still rarely taken seriously when it comes to the needed fundamental changes in understanding of the implications of mental health problems for the person, her/his environment, and changes required in service design and provision towards a more partnership-oriented approach. Most of what has been identified in this study concerning what supports people on their recovery journey will not occur unless the individual needing help is genuinely respected and listened to, as someone with knowledge and competence, not only about what hurts, but perhaps more importantly about what helps.

**Study 2** draw on material from the international project (IRRG) and is presented in *Paper II*, aimed at describing processes of recovery in severe mental illness through the exploration of first-person accounts using interviews conducted in Italy, Norway, Sweden, and the United States with a total of twelve individuals.

Common themes in the persons' recovery process were identified in each of the following areas: 1) how the individual deals with his or her difficulties; 2) the role of material resources; 3) the various roles of formal and informal health systems; 4) the roles, and absence, of significant others; and 5) the roles of social and cultural factors. The impact of social and material resources was obvious in the informants' stories when talking about the value of a stable home, of work and meaningful occupations, and of engaging in various community activities.

Furthermore the person's determination to overcome the mental health problems, the benefits of helpful medication, the support of peers and user-groups, and participation in various psychosocial interventions were emphasised. All in all, the informants' stories called attention to the basic human need to be accepted as, and to accept oneself as, an ordinary person who exists beyond the mental health problems. Cultural differences between participants from each country were noted primarily in the nature of the opportunities and supports offered rather than in the nature of the experiences and processes described.

Poverty, unemployment, substandard living conditions and homelessness were identified as being among the major social struggles faced in recovery. *Paper III* is aiming at investigating and describing the benefits of material resources, particularly the notion of having a home. All informants' stories suggested the importance of a secure base. They varied in their explanations of what transforms the physical structure of a dwelling into a place that feels like a home. Certain aspects were highlighted: home as a place for growth, development, and control; home as a means for balancing the need for socialising with privacy; and home as a future goal, a place to long for and dream about. The home was referred to as a place of order in the overall turmoil of daily life, contributing to stability and continuity in an often chaotic and unpredictable existence.

The informants' discussions of home makes it obvious that home is more than a physical structure, providing feelings of security, and even belonging and having a place within the community. They reflected both their desires and efforts to express personal ideas and values through the process of making a 'home', which may be best construed as expressions of self and identity.

In describing their social situations, the informants conveyed that equally important about material resources were their immaterial meanings, or the positive instrumental and emotional comforts they often afforded.

The contextual aspects of recovery became very clear, as well as person-environment interactions and the ways in which the person's environment influence both social opportunities and barriers. Being poor and homeless is evidently a serious barrier to a person's recovery, as much as having opportunities for work, hobbies, and having sufficient money to invite a friend home for dinner can be of great support. In conceptualising recovery, the impact of material and social factors must be included.

**Study 3** investigated recovery within the context of the person's everyday life and the aim of *Paper I* was to explore and describe recovery as the process unfolds in everyday life, with emphasise on capturing and recognising the simplicity as well as the complexity of daily life. This qualitative study was based on interviews with thirteen individuals in Norway who have experienced severe mental health problems and recovery over many years. Four areas of everyday life experiences in recovery were identified: 1) having a normal life; 2) just doing it; 3) making life easier; and 4) being good to yourself.

Employing an everyday perspective is challenging, since as the many interwoven details of everyday life are so taken for granted and to risk being invisible. However, when it comes to understanding recovery, the trivialities of everyday life must be seen as anything but trivial.

As opposed to abstract diagnostic categories or symptoms, these trivialities are what individuals with experiences of mental health problems talk about, because these experiences affect their everyday life in a variety of concrete and practical ways, and often represented significant turning points. Several of the participants of the study described a life full of interests, skills, and expertise which they had acquired before their illness onset that remained useful to them in their recovery, and that reminded them of how life could be. They presented themselves as human beings in a social and cultural context, in which social norms and culturally-valued activities were as much part of their daily lives as for people in general.

In addition, ordinary environments and activities emerged as the preferred arenas for recovery in contrast to mental health service settings. The participants talked about the value and meaning of people believing in them or expressing expectations of their competence and actions. They emphasised on the value of maintaining their position and role as a family member or friend as opposed to being a 'mental patient'. Within this context of ordinary life, mental health services and professional competence had a rightful place and proved to be invaluable in many situations. But even in these cases, the key competence of practitioners was to allow participants to be human and to be ordinary, with all of the rights, responsibilities, and requirements that being ordinary citizens involves.

The aim of *Paper IV* was to explore the meaning of work in recovery. Work is important for a variety of reasons in most peoples' lives, yet this seems to be forgotten when it comes to citizens with long-term mental health problems And although there is general agreement that work is a crucial part of rehabilitation and social inclusion goals, we know little about the actual impact of work in recovery from severe mental illness. Findings indicate certain ways that work supports the recovery process: having an active working role, being in ordinary work settings, balancing rest and activity, and having sympathetic and flexible work environments.

Experiences of being included in ordinary work roles and settings were found to be significant in the recovery process. In spite of professionals' pessimistic views on the informants' work capacities, many individuals increasingly found they were able to do well in ordinary work roles despite periodic or ongoing mental distress, if their work environments were supportive and flexible and they felt safe and welcomed at work. On the other hand the need to be challenged, to test and develop skills, overcome barriers, and meet novelties were emphasised. This gave opportunities to discover one's own limits as well as potentials and was important for personal development and gaining control.

Being together with ordinary people in ordinary settings helped many realise that a life with ups and downs is not unusual or pathological. Being confronted with the expectations of others was experienced as a sign of respect and hope.

Employment for everyone who wants to work is a central intention of Norwegian welfare policy and is associated with positive values such as social inclusion, active participation, and self-respect. However, many professionals in mental health services are referred to as being more sceptical and discouraging than supportive. To be met and acknowledged as ordinary, as one of the common crowd, was given crucial meaning in the informants' stories. Being an employee with problems in need of occasional personal support is very different from being a psychiatric patient receiving standardised rehabilitative work-training.

#### 5. Discussion

Methodological, empirical and theoretical reflections

This chapter is a discussion of the findings of the three studies related to the overall research questions:

- How can an everyday life research approach inform us about the process of recovery from severe mental health problems?
- How can professionals be of help and support individuals' recovery processes?

Four areas will be emphasised, one methodological discussion of what is referred to as 'an everyday life approach'. The others are theoretical discussions of the empirical findings: 'contextualising recovery', 'the paradoxes of simplicity' and 'recovery-orientated services'.

### 5.1 An everyday life research approach

The common research purpose in all three studies has been investigating and understanding individual recovery processes contextualised in daily social life. A central epistemological element is my belief in eliciting knowledge through personal reports of recovery, and trusting the validity of lived experience accounts as an invaluable information-source. This includes seeing people as fellow citizens, as well as their role as intentional, active agents in informing others to understand. The overall objective has been learning about the lives of people with severe and often ongoing mental distress: how they perceive their situations, how they overcome and deal with various circumstances, what they find helpful, and what are experienced as recovery-nurturing environments.

In using the phrase 'everyday life research approach', I mean contextualising individual experiences in daily life, looking at 'mental health problems' in ways connected to personal roles, relationships, arenas and ambitions, as well as surrounding social, cultural and economic/material conditions. As emphasised by Larsen (2004), it is essential to appreciate the person with mental health problems as someone often making great efforts to come to terms with surrounding societal cultural expectations, norms, values and perceptions.

The extremity of their previous and sometimes ongoing experiences is at times extremely difficult and stressful in our western societies which expect and value adaptation to cultural norms.

Two contrasting tendencies of modern society can be seen as embedded in daily life (Skårderud, 2001): that of integration and that of self-realisation. On one hand, there are formal strategies for integration with organised efforts and institutions having the objective of developing inclusive communities, including various European directives and long-standing intentions of the Scandinavian Welfare states. On the other hand, there is the ideal of liberation of the modern human being with strong emphasis on self-realisation and individual achievements, representing a fragmenting contrast to integration efforts and collective thinking.

These contrasting ideals are very present in contexts where individuals with mental health problems struggle to find ways of sorting out their life situations.

By exploring recovery as a process, the social impacts of (and on) mental distress are more likely to be unveiled, as well as the complex interaction and dynamics between individual and societal factors. Attention is also more attuned to the subjective meaning of mental health problems: how experiences of distress as well as strengths and resilience affect daily life, as well as the presence or absence of environmental/societal opportunities such as housing, educational and employment options and the occasional need for relevant mental health services. When asking people about life experiences instead of illness experiences, about everyday life as opposed to psychiatric services, about recovery as the person's own project as opposed to professionally designed programmes, one quite simply learns more about the person one meet and her/his life situation at large.

As emphasised particularly in papers I and IV, there are several reasons for utilising an everyday life approach when studying recovery. First and foremost, much of what was learned in these studies would not have been possible without exploring each person's whole life situation and within their own contexts.

Examining an extended life picture provides a larger context which assists in analysis of an overall situation rather than relying on information from previously defined problem areas and isolated parts of life, aiding in understanding why a problem becomes a problem and what is helpful and why. This was particularly evident in study 3. By asking the apparently simple question "Could you tell me a bit about your everyday life?", informants were invited to talk about their life situation as a whole. The "everyday life research approach" offers a coherent organising framework for the variety of factors, biological, psychological, and social, which impact mental distress as well as recovery.

Secondly, the informants' experience of meaning, of what was important to her/him and how the individual concretely and practically worked on maintaining an ordinary life was embedded in their life situation. Thus a 'life context approach' the concept used by Davidson and Strauss (1995), removes attention from what is identified as illness or deviance and instead to capacities and resources and creative solutions. Eliciting data and knowledge through phenomenological approaches invites to explore choices and intentions as well as for discovering life outside the problem areas (Davidson & Strauss, 1995; Davidson, 2003; Davidson & Stayner, 1997; Larsen, 2004). It also reveals how the informants actually have tried and still tried to carry on as usual in spite of their mental distress. Gullestad (1989) is emphasising on how human beings make great efforts of integrating the various roles and parts of their lives. This is often particularly challenging for individuals with extreme experiences and existential struggles due to mental distress. Still, much of what is described as crucial in the attempts of getting on with life, is maintaining their daily function and tasks, involving integration of roles that crosses different social structures and parts, like private home, work, parental duties, and leisure to mention a few.

Third, in order to bring our understanding of severe mental health problems forward investigating the competence and wisdom of people's lived experiences we need to apply methodologies that encompass diversity, with attention to the dynamics between the person the

environment, the dynamics and continuum of wellness and illness, and seeing the medical and psychological as well as the social and cultural. Referring to what John S. Strauss (1996: 206) has called attention to: "Subjectivity is a major part of our field and we know so incredibly little about it. In thinking about science, at least *our* science, we might need to make some major methodological conceptual changes, even changes in how we write papers and judge research to grasp what subjectivity involves. We can't assume that it needs to be reduced, as though on some procrustean bed, to those mental experiences that can be viewed in fragments and easily rated with reliable scales".

An everyday life approach means investigating what is often considered as common sense, meaning something that is 'a given', something that is reasonable to deduce without excessive search for explanation. In other words, common sense issues are often so self-evident and thus unquestionable that they risk falling outside areas of needed research. However, the 'little things' in everyday daily life that most people do take for granted, are often of great concern for individuals in recovery, often important milestones and turning points.

One final decisive aspect in terms of developing knowledge grounded in other peoples' stories is what Kristiansen (2004) has termed theoretical fidelity, explaining that interpreting the voice of the person being interviewed is intimately entangled with issues of the researcher's stance, including which theories one selects or disregards when attempting to understand empirical material. Fidelity refers to whose interests are likely to be served, thus combining aspects of standpoint and knowledge production, as well as issues of the relevance and potential usefulness of findings. This is particularly critical when it comes to individuals with experiences of psychosis, due to the tradition of psychiatry to see them as be incapable of taking own care of their health interests and life situation, and thus having others take control over parts of their lives.

### 5.2 Contextualising recovery

Informants in these studies expressed and revealed in various ways a wish to be 'ordinary', referring to this as 'having my life back' or 'getting on with business as usual', being seen and seeing oneself as a regular citizen, expected to pay bills and maintain the household, and do something useful and meaningful. They valued and saw it as significant to keep their places and roles as a family member or friend or neighbour and one to be counted on. Informants referred to the impact of 'feeling ordinary' as both providing meaning and convening hope, as well as helping out in combating some of the daily strains and stresses that mental health problems often entail.

In the descriptions of how the informants dealt with difficult situations, there was one recurrent feature: they used strategies much the same as we would all apply, which they often called 'normal'. These previously-known mental health patients were 'more fundamentally human than otherwise' as Davidson has written (2001), referring to a term introduced by decades ago by psychiatrist Harry Stack Sullivan. Many also told about feeling occasionally unstable and having a life with many ups and downs, confirming previous research findings described as 'the coexistence of competence and dysfunction' (Davidson & Strauss, 1995) and as 'being ill and well at the same time' (Borg & Topor, 2003; Topor, 2001). Most importantly, they wanted to be perceived and met as having resources, skills, and courage that made recovery possible and more probable. A life experience of ups and downs may perhaps better be considered as a natural part of human diversity, part of the ingredients of human existence, not only individuals with mental distress, but for everyone in this world.

'Being ordinary', as typically described in the interviews, involved spending time in usual, valued environments, together with regular 'normal' people, and performing ordinary tasks and activities in mostly usual ways. This ordinariness takes on a very concrete meaning in these studies, often about practical activities such as doing shopping, keeping one's home

and garden nice and tidy, taking care of the children, and going to work. The meaning of these daily tasks for people with serious mental health problems is not different from the meaning of the same tasks for people in general. Contextualising recovery provides a framework for paying heed to and capturing the impact of daily life's simplicity and complexity, in addition to acknowledging that what most people with mental health problems want is not different than that of others in society.

As previously mentioned, one critique raised about the notion of recovery is that of individualising this condition and process (Beresford, 2005; Cornett, 2003; Davidson, 2003; Mezzina et al, 2005a; Sells et al, 2005; Wallcraft, 2005), and not taking seriously into account social and environmental aspects which influence and limit people's opportunities. In conceptualising recovery as an individual process, both the efforts of the individual as well as the professional are directed towards individually-directed solutions, aimed at helping the person to adjust to society rather than efforts directed at changing the environment and broader societal structures and attitudes. This critique has its parallels in the family of social-relational models understanding disability as a societal process (Shakespeare, 2006), rejecting an individualised understanding of disability and locating the disabled person's problems in broader, societal contexts. These social models share basic political commitments to improve the lives of disabled people, by promoting social inclusion and removing barriers which limit people's inclusion.

In the three studies referred to here recovery is seen more as social than an individual process (Borg & Topor, 2003; Borg & Davidson, in press; Borg & Kristiansen, under review; Davidson et al, 2005; Mezzina et al, 2006, a & b; Sells et al, 2005; Topor et al, 2005). Informants presented themselves as individuals in social and cultural contexts, where social codes, and culturally-favoured activities and roles were as much part of their daily lives as for others in society, illustrated by this woman's comment about the impact of having a job:

Well, I've been rather poorly at times, maybe more than I realised myself... but I've been functioning well at work, and got good feedback and letters of reference.

Recovery-nurturing environments such as having a job in a supportive work environment, a home to take care of and enjoy, a friendly parish, pleasant nature nearby for walks, and caring for and encouraging families and friends are typical examples of ordinary pleasures portrayed in these studies as crucial. Ordinary environments and activities emerged as the most favoured and helpful arenas for recovery, in contrast to mental health service settings. Everyday life arenas represented meaning and invited the individuals to participate in conversations on general topics, as opposed to remaining confined to talking about problems, limitations, and illness. Being included in ordinary environments also seemed to provide more opportunities to be given greater expectations, and informants were clear about how important it was that others trusted them, believed in them, and expected competence and achievement.

One great challenge when it comes to the informants' persistent and repeated struggles to 'be ordinary' and belong to a community is the ways in which people with long-term mental distress are described in textbooks, as predominantly ill, fragile, vulnerable, and somehow not-up-to-standard. Such perceptions are paralleled by reports of how one is met in services and in the community, as different in less valued ways compared to other human beings. Many of the informants in these studies presented a starkly contrasting reality, showing tremendous inner strengths, endurance, and resilience, often making great efforts to fulfil their tasks and duties, and in addition having worries about not being 'good enough' or doing what others expected. Being placed in diagnostic categories often produced discomfort and even fear, revealed both in these studies as well as in other research literature by people with lived experience.

Furthermore, both as noted by the informants and in other research (Larsen, 2004) the specific diagnosis may also fail to give meaning to the individual, who in attempts to understand their situation draws on resources form the cultural repertoire that makes sense. What is frequently described is the humiliation and pain of 'being met' as a medical diagnosis rather than a person in a social situation (Boevink, 2005; Deegan, 1997b; Jensen, 2006; Wilson & Beresford, 2002). This 'otherness' is reinforced in a number of ways for people experiencing psychosis. Through psychiatry's purpose of identifying mental illness, as well as through the many regulations for citizens classified as disabled, a categorisation into polarised groupings occurs: of normal/not-normal, well/ill, us/them. This is a major barrier to the intentions of genuine citizenship, opportunities to participate and belong in local communities.

Adults with mental health problems are often some of the most disadvantaged people in society when it comes to work, income, housing, participation in social and cultural activities and events After years of mental health and social policy and action programs aiming at citizenship, the basic humanness and 'normality' of men and women experiencing mental health problems is still not truly acknowledged by the majority of society or the mental health services. The strength and endurance conveyed as crucial in recovery by those with lived experience is an alarming paradox to this alienation and marginalisation.

### 5.3 The paradoxes of simplicity

As discussed previously, much of everyday life is taken-for-granted and exists as unnoticed routines and even trivialities. It is about all the things we simply do, often without thinking about it. Yet as the findings of these studies reveal, it is these small bits of life that are often of critical importance in an individual's recovery process.

When it comes to understanding severe mental health problems and recovery, the trivialities of every day life are anything but trivial. The findings of these studies support the notion of recovery as an integrated part of lived life. Recovery is described by the informants as a continuous and practical process, dealing with daily tasks and challenges in a variety of contexts where actions and activities can be planned or events that just happen, any of which may have a great impact on the individual's situation.

Another theme in these studies is the value of 'little things'. The informants told about wide ranges of things they could do to make life easier that might be ignored as important information by others, like professionals. Developing one's own skills and strategies for dealing with the consequences of mental health problems, and building on strengths and pleasures seem to make it easier to tackle burdens and encounter troubles, and to maintain hope and belief in one's capacity to recover.

This brings me over to some of the paradoxes of simplicity when considering the idea of evidence-based practise as a golden standard for professional's health care practice. A question to be raised following the findings presented here as well as other recovery research projects (Davidson, 2003; Davidson et al, 2005 a; Jensen, 2006; Ridgeway, 2001; Thornhill et al, 2004; Topor, 2001), is the failure to capture the complexity of service users' health problems, and the social explanations and implications of many standard psychiatric procedures, such as diagnostic instruments, functional check-lists or symptom-focused tools which are considered valued and valid in services. Instead of clarifying problem areas and guiding practitioners, many of them create illusions of simplicity. Human life is complex, and human beings, experiences and relationships cannot be reduced to neat categories and measurable items. Wilson & Beresford (2002) draw attention to the failure of psychiatric discourses to pay attention to alternative understandings to an individualised medical view, and through the diagnostic procedures which single out individuals with mental health problems as somehow significantly different than most people.

Research has also been conducted to understand how individuals create and find meaning in their illness experiences drawing on cultural repertoires, suggesting a system of explanations rather than one mainstream medical perspective (Larsen, 2004). As emphasised by the informants in these studies, mental health problems as well as recovery are best understood and dealt with in the framework of everyday life. Recovery was by one woman described as "functioning as normal" meaning "the normal things of hanging on, and doing those things we have to do, like shopping and cleaning and paying bills and having resources to keep on living." Men and women with mental health problems are intentional, social, meaning-seeking human beings with a life outside their mental illness, as the informants of these studies clearly transmitted. Recovery happened in the details and triviality of their everyday life, in all kinds of contexts and often mostly outside professional arenas.

# 5.4 Recovery-oriented professionals and services

Following the experiences and advice of the informants of these studies, how can we go about doing more of what is found helpful? In other words, how can services be more oriented towards everyday life and recovery, and how can the roles of health-and social workers be more attuned to the needs and preferences of women and men seeking professional help?

First, the informants gave many examples of helpful professionals that had been supportive in a variety of ways, from prescribing medication that worked and had few side effects, being a good listener, offering practical advice in everyday life, or simply going to a café or art exhibition together. In general, little attention was given to the professionals' methods and models; instead we found concrete and informative examples of their ways of interacting and having what might be called practical competencies.

Being a recovery-oriented professional seem to necessitate an open attitude towards what kind of support actually helps, perhaps taking the dog for a walk or working in the garden. This does not mean that specialist knowledge and experience were seen as unimportant or irrelevant. Rather, a recovery-orientation seems to involve professionals who are genuinely interested in the person's everyday situation, in how the mental health problems actually affected her or his daily life, acknowledge the 'little things' that may have great value and impact for the person, and not undervalue what may be recognised as trivialities. It means being curious and open for dealing with the richness and the unpredictability of life in general, as well as the frequent paradoxes of an individual's recovery process. Such a recovery orientation also requires learning how to apply one's expertise in a more collaborative way, and adopting a more person-and-resource-centered approach rather than an illness-based. This includes being open to service users' own agendas, as illustrated by this comment:

'I found him so balanced in a way... didn't have all kinds of programs of his own that we had to go through. I could talk about anything ...everyday life things that were important to me, not necessarily problems... I was the one who decided what to talk about '.

Secondly, the informants expressed with great vehemence the desire and human right to be seen and met as a person not as a diagnosis. Several mentioned the humiliation when professionals appeared to be only concerned with deviance, disability and symptoms. They wanted to be recognised and accepted as the persons they were, having both strengths and weaknesses, and individuals in social settings with many roles, not only that of the patient role.

'Respect when we meet. A little imagination... treated as a human being. I guess that's what they've had in common, those I've met in psychiatry that have been helpful. That they are not afraid to tell me that they don't understand how I feel. You don't have to understand my situation to be human'. This is an example of one informant characterises human and openminded professionals, respectful, and with some imagination, and not striving to appear as an expert or as 'knowing everything'. Services need to refocus and re-orient the one-sided perspective of what quality and high standards of care and treatment is all about, away from policy-oriented procedures dealing with 'patient satisfaction', numbers of out-patient consultations, and patients' flow charts. Quality standards placing more emphasis on service users' preferences and patients' rights appear to be required. In order to evaluate the desirable qualities of recovery-orientation in staff, simple questions such as these might be useful:

- Do I support the individuals in what they see as urgent everyday life issues?
- Do I follow the service user's own agenda at the moment? How do I know?
- Do I show and transmit expectations and hope for recovery?
- Am I currently assisting her or him in finding the community environments he or she wants to be part of?
- Do I give the individual the privilege of deciding where and when to meet, and is our time together negotiable?
- Do I focus on the person's strengths and skills?

The service users will of course thus also be evaluators, and these are merely some concrete suggestions of what it could mean to for a provider to have a recovery-oriented service. Focusing on common goals and service recipient feedback in treatment is being introduced and implemented in various services systems, and the outcome-informed approach is an important and interesting advance in the discussion

of developing more of what is referred to as practise-based evidence (Miller et al, 2004).

A third aspect of recovery oriented professionals and services is about planning. Many efforts have been done in services with the objective of developing an efficient organisation, with standardised procedures, management techniques and service delivery programs. Yet, by carefully listening to the informants' voices and learning form their experiences, professionals and their managers need to accept that everyday life events and recovery may be hard to plan or predict. In spite of whatever is developed and implemented as part of treatment and rehabilitation, things happen and people find other, at times unorthodox, ways of dealing with problems occurs. Participants in these studies recommended that practitioners as well as people in recovery to remain open to opportunities which present themselves, no matter how small, which might make life a bit easier or better.

A fourth area revealed in these studies as essential in service delivery is understanding and supporting peoples' recovery as an integrated part of everyday life, as opposed to a fragmented issue isolated from social and cultural contexts. Following on from this, there is a need to shift practice towards more social support and environmental change as valuable therapeutic interventions, in addition to the more traditional approaches in psycho-social rehabilitation. Professionals will not be very supportive if everyday life concerns are excluded from the agenda. The experiences of recovery as described in these studies are integrated in and appear as very concrete parts of daily life. In developing collaborative relationships with service users, these findings do not suggest a need for more competence in instrumental skills, but rather the skills of being sensitive to fellow human being's dreams, wishes and preferences,

understanding what the individual sees as problematic, and the skills of creating comfortable and safe situations where everything can be talked about and addressed.

A fifth way of supporting recovery is to appreciate ordinary environments and activities as preferred contexts in contrast to mental health service settings. Places such work, nature, cafes, home, gyms and churches were named as valuable arenas. This does not mean that in-patient services, outpatient clinics or 'clubhouses' were not appreciated as useful or necessary. However, the crucial feature of every day life is that it offers the individual arenas to try things out; to practice 'being ordinary', alongside ordinary fellow citizens as role models, so to speak simply by just being there. Professionals need to use creativity, courage and expertise to provide such support, allowing and enabling persons to be ordinary citizens with all the rights and obligations that this includes. Everyday life tasks need to be addressed as part of the practitioners' agenda, as well as if not more than such issues as psychic insight or medication compliance. With regard to community inclusion and citizenship, mental health research can draw much knowledge and experience developed in the field of disability research. It is actually surprising that there is not more interest for linking these research fields more together. Mental health services and research are often discovering what is already known elsewhere, and 're-inventing the wheel'.

Finally, a dilemma many professionals as well as policymakers are facing is the paradox of trying to humanise services and implement person-centred help on the one hand, and on the other hand are expected to fulfil demands of the new public management trend, with its frameworks for quality control and standardised treatment guidelines based on evidence-based-medicine (EBM). Tor-Johan Ekeland (1999) has raised the timely question as to whether EBM should be seen as quality assurance or as an instrumental mistake. He argues that there are severe problems in generalising from empirical trials to clinical practise, and that there are serious ideological implications such as the idea that one can manualise and de-contextualise professional help in

mental health services. As stated earlier, what people who use services appreciate is professionals who are open-minded about ways to help and who set up individualised and flexible supports instead of trying to adjust and fit service-users into existing service programmes, routines and structures.

Professionals have to deal with countless paradoxes and dilemmas in practice, a central one being finding ways to support everyday life and a 'recovery orientation' in a service culture which increasingly favours the development of more stream-lined systems in new public management. Although EBM has provided valuable knowledge for practise, there remains a major problem in the power imbalance between sciences and other ways of knowledge acquisition, when EBM is claimed to be on the top of the hierarchy of scientific knowledge, developed largely through clinically controlled trials and statistical analysis. The evidence-hierarchy is even more critical, as Martinsen (2005) states, when it appears to put 'professional judgement' aside and is presented and used in ways which are apparently blind to power issues.

I tend to agree with Holmes et al (2006) who have suggested working towards creating a space of freedom, one that can pose a threat to the current scientific order in Evidence Based Health Care and health sciences as a whole, and begin to deconstruct these regimes of power.

In closing, I want to quote from the experiences of Helen Glover, a woman with the eminence of double competence, as a service user and as a professional. She has written: (2005: 4) "Many services and practitioners would be greatly satisfied if a recovery 'model' could be manualised so that they simply could implement. The risk of doing so would serve further to reinforce the dominant object-based service delivery and take from the uniqueness and flexibility required in discovering and supporting a recovery space.".......

"Our need or desire to package and model 'recovery' will be one of the major threats to embracing an authentic recovery based framework, one driven by lived wisdom. Put simply, recovery- oriented practice cannot be franchised".

# 6. Conclusions and implications

This dissertation's research suggests and argues that 'recovery' needs to be seen as an integrated part of peoples' everyday lives, and at least as much a social as a personal and unique process. The informants of these studies inform us that recovery is about living. Life continued, although often along a bumpy road, while she or he struggled to find ways to deal with the consequences of severe mental health problems. As with people in general, much was learned through life experiences: they grew and developed, experienced and often successfully resolved crises. Yet simplifying recovery to merely a question of ordinary life experiences is a faulty and potentially risky conclusion, one which would be a disservice to many vulnerable people, a contention I will now elaborate based on the research studies.

First, although psychosis and other severe mental health problems are reported as frightening, painful, and accompanied with feelings of hopelessness, despair and often chaotic life circumstances, individuals in recovery repeatedly and clearly convey a wish to be understood and met as active agents in shaping their own lives, as opposed to patients or clients with chronic, debilitating diseases. They describe a life with interests, skills, and expertise, often acquired before problems started but which remained useful in their recovery process, reminding them of how life could be. Their expertise is more than that of a 'user-expert' perspective; they have often discovered and developed very creative and unique life strategies, sometimes even at a survival level.

Secondly, recovery environments make a difference, often a large one. Ordinary environments and activities became increasingly evident as the most strikingly helpful arenas for recovery, in contrast to mental health service settings and especially life in a psychiatric

institution. Being included and participating in ordinary community arenas and activities, ordinary work settings, and a home of one's own comprised participants' preferred life worlds. Connected to this preference for everyday situations is also the pre-requisite for such participation: access to sufficient material resources such as income, available and appropriate housing, education and employment opportunities with supports, and quite fundamentally, communities that are welcoming, accepting and supportive.

Third, in understanding recovery, the trivialities of everyday life must be seen as anything but trivial. These trivialities are what individuals with lived experience of serious mental distress often talk about, and seemingly small things can be hugely significant in their own lives and struggles. A major point about trivialities is that the self-evident is often actually nearly invisible, and the should-be-obvious often not obvious to most of society.

Fourth, an 'everyday life research approach' invites and in fact demands that the researcher search for ways to contextualise individuals' experiences in their daily community-based lives, closely connected to their social roles, their societal, cultural and material conditions, as well as their personal interests, goals, hopes, resources, and dreams. Much of what we found about why and how everyday life conditions are important in the recovery process would probably not have been possible without exploring each person's whole life situation and experiences within the person's own contexts.

And fifth, recovery is difficult if not impossible to plan. Understanding recovery as an integrated part of life requires an openness to life's unpredictability. Unexpected events and circumstances are a naturally-occurring part of daily life, something many people with severe mental health stress know very well, yet one which is challenging for services and professionals who have been taught or mandated to favour standards, procedures, and quality assessment guidelines within the context of new public management, and based on effectiveness and implicit predictability.

Being a recovery-oriented professional seems to incorporate an open attitude about what actually might be helpful, including simple and often surprising things. This includes a genuine understanding and respect for the individual's everyday life situations and experiences, coupled with the ability to see the broader roots of causation and hope.

Where do we go from here? Two final points: I believe we need to continue developing and substantiating an 'everyday life research approach" within mental health research, both methodologically, conceptually and as a part of expanding the knowledge base for community mental health care developments. It is, after all, within ordinary life situations and environments mental health problems seem most likely to be understood and successfully dealt with. There is an urgent need to enhance the status of everyday life in research as well as in service delivery practice, remembering that especially the trivial is not so trivial.

This is a crucial element in debates concerning the limitations of evidence-based practice. Additionally, a debate about the worth of academic publishing is called for: often the most prestigious scientific journals have criteria which are a mismatch with everyday life research's re-stating the obvious and demanding universal generalisations where unique and crucial messages will remain unnamed and unnoticed.

Given the complexity of the condition of mental health problems, the recovery process, and contexts of service delivery and communities, efforts for finding successful ways of inviting and utilising implementing service users' experiences are greatly needed, especially in identifying what actually helps. Evaluation efforts only looking at the existing service system are likely to miss the salient aspects of what actually is a 'measure of quality'. As recovery gains in popularity, there are many services and practitioners who seek 'recovery models' and prescriptive manuals offering recipes for 'how to do it', a trend that jeopardises the central dimensions of the recovery process.

On the other hand, implementation does require certain systematising and strategic choices, and some set of principled guidelines about how to proceed and act seems very much needed. Central to such efforts must be a fundamental belief and genuine respect of the service recipient with lived experience as a skilled, competent, social and cultural human being and fellow citizen.

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# List of papers

# Paper I

Borg, M. & Davidson, L. (accepted for publication, in press). The Nature of recovery as lived in everyday life experience. *Journal of Mental Health*.

### Paper II

Davidson, L., Borg, M., Marin, I., Topor, A., Mezzina, R. & Sells, D. (2005). Processes of recovery in serious mental illness: Findings from a multi-national study. *American Journal of Psychiatric Rehabilitation*, 8 (3), 177-201.

# Paper III

Borg, M., Sells, D., Topor, A., Mezzina, R., Marin, I. & Davidson, L. (2005). What makes a house a home: The role of material resources in recovery from severe mental illness. *American Journal of Psychiatric Rehabilitation*, 8 (3), 243-256.

# Paper IV

Borg, M. & Kristiansen, K.( submitted manuscript under review). Working on the edge. Everyday life research from Norway on the meaning of work for people recovering in psychosis.

### Paper V

Borg, M. & Kristiansen, K.(2004). Recovery-oriented professionals. Helping relations in mental health services. *Journal of Mental Health*, 13(5), 493-505

# Paper I

Running head: Recovery and everyday life

## The Nature of Recovery as Lived in Everyday Life Experience

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Nearly thirty years ago, the Italian mental health reformer, Franco Basaglia (1987), criticized mental health care and practitioners for placing their main interest in illness entities rather than in the person experiencing the illness. From within the confines of the institution, Basaglia bemoaned the fact that when symptoms are not viewed within the context of the person's everyday life they become simply representations of an illness entity. Divorced from their natural occurrence within the social world, they come to be taken merely as reflective of diseases that are categorized in texts on psychopathology. It then only takes one additional small step in this same direction to equate the person with the illness, subsuming his or her humanity entirely.

Even though the institutions which Basaglia criticized for the most part no longer exist, his insights may be just as relevant today. Despite the fact that people with mental health problems have lived the majority of their lives outside of hospital settings for much of these previous thirty years, we still understand little about the ways in which symptoms and problems become manifest within the person's social environment and their impact on his or her daily life. That is, we do not yet fully understand the ways in which these symptoms and problems may interfere with, complicate, or otherwise effect the person's day-to-day experiences, relationships, and pursuits. But if recovery from and in serious mental illness takes place within this social and material environment (Borg et al., 2005; Davidson & Roe, in press), and unfolds within the context of these same experiences, relationships, and pursuits (Davidson et al., 2005), then this is precisely the kind of understanding practitioners will need to accrue in order to be effective supporters of the person's own efforts to recover.

The present study was intended to contribute to a growing body of knowledge that attempts to explore, understand, and address severe mental health problems within the context of the person's everyday life. Drawing primarily on qualitative methods, this body of knowledge stems from a rigorous curiosity about the person who continues to exist behind,

beneath, or beside a severe mental illness and about how the problems and challenges that are associated with the illness are experienced and addressed by this person within the context of his or her everyday life. Adopting an "everyday life" perspective, for example, highlights the importance of acknowledging the impact of "little things" in the person's life, such as meals, birthdays, or recreation; experiences and events which might otherwise be overlooked in studies that focus solely on illness and impairment (Davidson et al., 2006). Prior to introducing the objective and methods of this study in more detail, we provide a bit of a background about this approach to recovery.

## Perspectives on Recovery and Everyday Life

Suggesting everyday life as a platform for understanding recovery requires some clarification. According to Gullestad (1989), the sphere of everyday life may be invisible precisely because it is too visible. As a result, she suggests two perspectives on everyday life that may help to elucidate its various components which are relevant for the present project. The first dimension is *organisational and functional* and refers to the concrete and daily organisation of tasks and activities. Here we do not talk about a single everyday life, but many, influenced in complex ways by culture, social class, occupation, gender, age, and spiritual beliefs. It is about our patterns and systems of activities, what we do, how we do things, and the social and cultural contexts we live and move about in; issues in everyday life that are often unnoticed or regarded as too ordinary or commonplace to warrant attention.

The second dimension she identifies is everyday life as *experienced*. This has been referred to as subjectivity or what phenomenologists have described as the "life world" in contrast to the objective world of the natural sciences (Husserl, 1970). Here the focus is on the human experience of meaning, of what is salient and important to the person, rather than on facts or events per se. Daily life is also the terrain for our acts and our interactions with other people, and Gullestad emphasises how human beings attempt to integrate the various

roles and parts of their lives through these experiences. This integration crosses different social structures and roles, like private home, work life, parental duties, and leisure to mention only a few (Gullestad, 1989; Schutz, 1999).

There is a range of practical skills which we often take for granted that are required to negotiate these different roles and activities in our lives. Navigating one's everyday life is made possible by having and making tacit use of a stock of practical knowledge that lies ready to hand, emphasizing that human experiences evolve in social as well as historical contexts. This is true of experiences of recovery as well, involving a dynamic process incorporating individual as well as material and social issues and in which the person is an active agent in his or her own life. Like everyone else, people with mental health problems need and possess to various degrees such a stock of knowledge, and attempt to develop practical and social routines to sustain and maintain their daily lives. Once we acknowledge the importance of this sphere of everyday life and its various components, our major challenge both as researchers and as practitioners is in making explicit, capturing, and recognizing the simplicity as well as the complexity of daily life among individuals with severe mental illnesses.

## **Objective and Methods**

The objective of the present study is to explore how individuals with severe mental illnesses experience the illness and its consequences within the context of their daily lives, and how they overcome these challenges and other barriers to find their place, a sense of meaning and purpose, and a valued social role as members of their community. Following previous research (Borg & Topor, 2003; Davidson, 2003; Davidson et al., 2005) we employed a narrative, phenomenological approach involving in-depth qualitative interviews intended to elicit information about participants' experiences, material and social situations, actions, and choices. Our questions were open-ended in nature and concerned all areas of

daily life, focusing on existential, social, and material issues as well as issues of health and illness. Follow-up questions were oriented to eliciting further information from participants, encouraging them to tell rich stories full of descriptive detail (Davidson, 2003). Additional information about the empirical phenomenological method used is provided below.

## **Participants**

A total of seven women and six men were interviewed about their everyday lives and experiences. The interviews took place in settings chosen by the participants themselves, which in all cases except three was the person's own home. The study included people who:

1) Had a permanent place to live; 2) Considered themselves as being in recovery or having recovered from severe mental illness; 3) Were coping satisfactorily with their lives; and 4) Had improved their lives with help from mental health services and/or with help from other sources. Participants had varied histories and experiences with different types of services and support systems, and had varied social situations. Their ages were between 26 and 54 years old. Two were married, two were engaged, nine were single, two had children, six had higher education (degree from college or university), and two had ordinary jobs and income while the others were receiving disability payments but were all working part-time. Several reported having or having had financial problems that were a hindrance to a meaningful life in the community.

In terms of clinical presentation, ten participants had been treated for schizophrenia, one for reactive psychosis, one for manic depression, and one for paranoia. Time since illness onset ranged from under ten to over 35 years. Three people viewed themselves as having recovered from their illness, meaning they no longer experienced signs or symptoms of the mental health problems they were treated for, two experienced voices that still gave them trouble but felt they had gradually gotten more control over them, and the rest only had minor reminders of illness experiences, and, from their perspective, were living an ordinary life.

## **Procedures**

Interviews were carried out by the first author during the time period 2004-2005. Each participant was interviewed twice, the first time in person and the second time either in person or by telephone, following participants' preferences. The average length of each interview was between one to two hours. All but two of the interviews were audio-taped, transcribed into text, and then returned to each participant for review, approval, and possible alterations. Two participants did not feel comfortable being audio-taped and in these cases notes were taken and returned to the individuals for comments and verification instead.

The research process also included a reference group of five individuals with experience with recovery. Inspired by participatory research (Davidson et al., 1997), this group was involved in project design, interview content, and inclusion criteria, and in ongoing discussions during the analysis phase. Additionally the meaning of certain concepts was discussed. The group was run like a focus group organised by the first author. The contribution of the reference group was important in providing opportunities for in-depth discussions with people having first hand knowledge and expertise as well as providing a more comprehensive way of understanding the recovery process and people's lived experiences in a contextual way (Cresswell, 1998; Davidson, 2003).

A thematic and step-wise approach was taken to analysis of the interviews. This approach involved analysis of individual interviews for units of meaning related to everyday life, and then analysis across individual interviews, followed by grouping the material into provisional thematic categories. The third step involved returning to the interview transcripts to verify and supplement key findings. These findings were also continually discussed with the reference group; a step considered critical to the ensuring the trustworthiness of the study and its validation (Cresswell, 1998; Malterud, 2003). The study received prior approval from the National Social Science Data Service and at the regional level from the Region IV (Mid-

Norway) Medical Ethics Committee. Finally, we have changed the names and identifying features of the participants to protect their privacy.

## **Findings**

We identified four major themes described as being normal, just doing it, making life easier, and being good to yourself. Each of these is described in more detail below.

## Being normal

Achieving normality takes on very concrete meaning in the participants' stories. What seems most crucial to "being normal" is spending time in ordinary environments with ordinary people. As one participant whom we will call Susanne described:

Ah, I would describe it [recovery] probably as functioning as normal, in term of ... I work and that takes a big, big chunk of my time and energy, probably too much. I am married, and that's a big chunk that, yeah a very central part. I think the normal things of hanging on and doing those things we have to do, like shopping and cleaning and paying bills and having resources to keep living.

Rather than some lofty pursuit of health or well-being, being normal, from the perspective of the study participants, was described in these kinds of practical terms: shopping, cleaning, and paying bills. These and other activities of daily life which otherwise may be taken for granted, but when they are experienced as difficult become embarrassing, troublesome, and annoying. The stories told in this study are for the most part about individuals trying to get on with their lives in these mundane and practical ways in spite of mental health problems, being occupied with the independent pursuit of ordinary activities.

At other times, however, participants like Nina experienced consequences of their mental illness that had to be managed in order to maintain her life in a normal setting. Nina, for example, tired easily but found her ability to cope nonetheless to be very gratifying:

These things like having to deal with bills, dealing with insurance companies, dealing

with all kinds of practical things ... You struggle to get things done, to make things function in an alright way ... and all this responsibility. I'm alone. Many are two and that can actually be easier. When you're alone you have all these practical things and you're responsible for them yourself, a lot and all by yourself. But at the same time you don't want to swap with anybody, because it's wonderful too. And it's such a satisfaction that you actually can cope with it. That I find very positive.

A struggle and frightening at times when it came to all the responsibility that everyday life involved, but Nina wouldn't have had it any other way. She felt pleasure and pride in being independent and accepted the worries associated with this.

Experiences of being normal also involved being situated in common social settings and environments, and fulfilling common roles, like being with parents, siblings, or spouses and children. The family represented continuity and stability. Being a mother to her children required Anna to take them to the school bus in the morning despite the fact that her heavy medication made her look a bit odd and other children on the bus commented on it. Continuing to be a mother and taking care of these daily responsibilities was extremely important for her and, in addition to accompanying her children to the bus, involved making sure that her children's clothes were clean and neat, that they had food and drinks in their lunch bags, that dinner was ready when they returned home, and that she was able to join in on parents' evenings.

Family life offered regularity in contact and activities, like having dinner together during the week, taking the family dog for walks, or visiting and helping each other with practical things, like many families often do. This did not necessarily mean that it was the person with mental health problems who was helped. Giving and taking more generally was emphasized and this seemed to be based more on traditional family patterns than illness-related roles. When Anna was admitted to the acute admission ward, and described herself as

very psychotic, for example, her sister called her as usual and discussed their brother's birthday present. And in the often chaotic environment of the acute ward, she rang her children every evening at 8:00 p.m. to say goodnight and to sing their regular prayer song.

Having a job was also a part of being normal. This was not necessarily an 8:00 a.m. to 4:00 p.m. job, but a work situation that was experienced as valuable and meaningful, and in a regular setting as opposed to sheltered occupation. Working gave participants a chance to spend time in ordinary environments and offered respite from psychiatric settings which were experienced as artificial. Participants enjoyed talking about the headlines in their local newspaper, for example, or about anything else that could come up at lunch breaks. They wanted to learn more about the world around them and be in contexts in which normality was expected of them. A few participants held ordinary jobs but most had jobs that had been adjusted to the person's needs in some ways, mainly in terms of flexibility in working hours.

What 'being normal' can seem to add up to is finding or being introduced to situations that permitted and supported the participants in stepping out of the problematic arenas of their lives (e.g., psychiatric settings) in order to be just an ordinary person carrying out ordinary activities, offering the person the feeling of being one of the (normal) crowd as opposed to being a mental patient among other mental patients.

## Just doing it

In addition to resuming ordinary activities with ordinary people, being in recovery appears to require the person to do something concrete to improve his or her situation, as Susanne explained:

I identify with the Nike slogan: "Just do it!" Just do it! It's about having to do it.

Yeah, really... I probably think about the things that I don't think it is, and that about when someone else decides for me ... When I read about recovery written as goaldriven ...that can only be written by practitioners because how many of us get up in

the morning and say: How am I going towards my goals today? That is not something that you do.

Rather than being the planful, rational, and stepwise process suggested by treatment plans, initiating recovery appears to be experienced as a somewhat desperate effort to break out of a cycle of recurrent problems associated with mental illness, like hearing voices, losing touch with friends, or being preoccupied by worries. Participants reported various ways of finding sources of hope and inspiration to carry on and of discovering pathways toward a better life. Despite the tug of despair, they never gave up and highlighted the importance of continuing to believe in their capacity to recover. As Susanne suggested, the practicalities of recovery can be summed up as "just doing it"; being creative in dealing with your problems, looking again and again for new solutions, and discovering what works for you.

In addition to believing in themselves, participants founds that positive expectations and having the faith of other people were helpful. Susanne talked about her husband as a very important supporter who did not accept her staying in bed all day. Anna mentioned her family who never had given up and continued to expect her to get well. In spite of her distress, they expected her to get up each morning to take care of the house and the children. And Johanne referred to her boss:

We have a friendly fight between us, where we ... I challenge him to do work better and he does it best of course ... And then I really have to keep it up and he puts high demands on me that are pretty high for me, actually, so I strive for them ... And that's good to have. It's okay that I haven't reached the top, that I can do even better, that I have something to reach for, that he has high expectations.

Participants described recovery as involving action, as "doing it." In the context of the individual's life situation, he and she works alone and together with others, finding out how they can live with the presence of side effects like obesity and drowsiness, or live with

unemployment, lack of energy, and being poor, or with worries about what using medication could do to their bodies over the years. Recovery was described as an integrated part of life, in which a central issue was about discovering ways to be in charge and in which finding a sense of balance between rest and activity was essential.

For some participants, accepting that they had mental health problems meant accepting limitations in their lives, not being able to take part in as much as they used to or would have liked to do. "Just doing it" did not imply that these choices or actions were easy or straightforward, but that they were essential to moving ahead in life, regardless of how goal-directed or planned it might be and regardless of all of the other competing issues and demands.

In all of this, discovering the value of "little things" and finding pleasure in managing small tasks others might see as trivial were highlighted. Even if life turned out differently than expected, participants felt there were opportunities in their future. And although many mentioned that in the back of their minds they worried at times about getting sick again, hopes and dreams for a better life, and expectations of getting well, were nonetheless very present.

## Making life easier

'Making life easier' referred to social situations, other people, and coping strategies that were experienced as helpful in the recovery process. Although most of the participants had some contact with practitioners, often general/primary care practitioners, and used some kind of medication, it was in the context of everyday life that they worked on their recovery, tried things out, failed and succeeded, and fell down and got up on their feet again. Within this context, participants recognized and appreciated many factors that were supportive and important in their being able to get on with their lives.

As one source of support, participants described many professionals who were

helpful, and identified their helpfulness as various ways in which they contributed to making their struggles more bearable and/or improving their daily life situations. Emma exemplified this in describing a good practitioner she had met:

I experienced him as very wise and kind of ... it didn't seem like he practiced any theories on me, but rather responded to what I said and had experienced. He had a lot of experience in his profession, but seemed very wise to me, and very ... like ... he understood more about me than I did and sort of reflected when I said something and then could better understand what I had talked about.

Practitioners who were available, who recognized the need for assistance or support in all kinds of practical matters, and who did not give the impression of primarily being interested in symptoms and problems were highly valued. The stories of recovery participants told included many paradoxes and unpredictable situations, revealing that "getting on with life" is not easily planned and does not always follow a well-defined or pre-determined pathway. Having service systems available also made life easier. For Martin one special hospital ward offered him a sense of security:

Yes, I've used one ward at the hospital as an asylum, collaborate with them when problems get worse. I've got a deal when I can go there without all kinds of bureaucracies. I can just call and then go there.

Another aspect referred to as helpful was having adequate material and instrumental resources, like having a home you could feel safe in and get pleasure from. As Anna mentioned: "I like sitting by the kitchen table and thinking things over ... I really like that. I sit in the kitchen on a tall chair ... It is a good place." Similarly, Paul described:

On not so good days I stay at home in the apartment, try to find peace here.

Otherwise I enjoy walking and cycling ... I have lived here for 6 years. Have a rental contract for 1-2 years at the time. Like it here. It's central.

Home was described as a place where the person could relax and find peace. A safe place was central in order cope with all the daily challenges. Several participants expressed gratitude for a pleasant home where they had made great efforts in decorating and furnishing it in their own way. Having the home as a platform from where they could approach the larger community was also important. From their home they could find ways to encounter and form relationships with the community, like going for a walk in the park or in the woods nearby, going to work, to church, to hobbies like swimming or gardening or bicycling, or to meet friends. As for most of us, having a stable income and accommodation made living easier, with or without mental distress..

In several instances, participants' references to material resources were implicit in their discussions of activities that fostered recovery. Pursuing interests, making your home neat and pleasant, being with friends, and in general being occupied with meaningful activities were described as helpful:

It's important to have things to do that give meaning. I go for walks a lot in the area here, maybe start the day by turning on the PC, then take a turn tidying. For me it is important to have 1-3 things to do that are good. Situations of doing nothing promote illness for people with serious mental illness. I need some on-going projects ... those are good things.

Although people found different pathways to recovery, some general themes emerged, like endurance, not giving in, and finding out what makes life easier. George used alcohol as self-medication for a long period in order to cope with voices and anxiety until he developed his own meditation method and found professional help. Martin experienced troublesome voices and visions but has found some ways of keeping them at a manageable distance by enjoyable occupations. Emma prayed every evening. She found it relieving and relaxing with evening prayers when she could go through the day's events and find peace before bedtime:

"It gives an inner peace in crisis, praying, and by that keep things in place." Paul found a kitten outside his apartment building. He wrote a letter one year after the initial interview as he wanted to inform us about what really had made a difference in his recovery. Finding this kitten made him think less about the voices and troublesome sides of life. And having a cat required of him to go out and get cat food and this again brought him in contact with new people through talking about his cat. Participants appeared to find ways to use available opportunities and events to engage in meaningful and pleasurable activities that offered respite to, and carried them beyond limitations imposed by, illness.

## Being good to yourself

A variety of situations were mentioned that created good feelings, gave peace for a shorter or longer while, or gave participants pleasant memories to look back to for comfort. Spoiling yourself, giving yourself a treat, and taking care of your body were examples of "self-nutrition" or "vitamins" mentioned in the interviews:

I feel I get so much back for the good experiences, and I can take them up again if
I feel down and low, then I can think about the good moments. I find good experiences
so important. You get much more out of them than things and that kind.

People often need vitamins as supplemental nourishment in order to build up and maintain vital bodily processes and to prevent illness. In recovery, finding useful kinds of "vitamins" appeared essential. In the above, Emma talked about some of the things that kept her going. Being good to yourself could be a solitary activity, as in Kristin enjoying her evenings alone by the TV, or when George was meditating, listening to music, or watching debate programs. It could also be a social event, as it was for Emma when she met her friends at cafés or travelled with them to cities in Europe.

Activities in the community bring up a crucial issue in recovery which pertains to cost. Taking care of yourself, like pursuing hobbies and interests and enjoying the company

of friends, requires resources. Having a car was necessary for Johanne in order to maintain contact with her old neighbours. They meant a lot to her. Travelling and visits to cafés required Emma to sacrifice fixing up her flat. And the dream of a holiday might seem far away for Frank as his financial situation was hazardous. The immaterial meaning of material resources was very clear and great consideration was often given to how to spend a limited amount of money.

In addition to social or individual events, "vitamins" involved concentrating on a healthy life style. As Susanne said:

A really nice part for the moment is keeping healthy. I have put a lot of energy into trying to get fit and healthy and the commitment to anything that will keep me well ...

Several participants had developed expertise on health food and diets and established new routines for their meals. Some went to the gym, had regular walks, or were concerned with staying in a good physical shape.

Historically, patients and clients have been viewed as being on the receiving end of their relationships with others, and rarely have had the opportunity of giving back. In the narratives in this study the wish to give back came forth as a prominent theme. This wish involved sharing their experiences in writing or talks, offering advice or practical help to others, or just being a decent fellow human being by helping out in whatever way was needed in the neighbourhood. Emma gave this example:

I have given priority to giving, treating people well ... when I've had the opportunity. Not just to be that kind, but I somehow like giving more than receiving. Friends say that I am a caring person. I write rhymes on birthday cards and things like that to special people, mainly girlfriends ... Yes, I enjoy when people show they appreciate me and therefore I want to show them that I appreciate them.

As the participants in this study tell us, being good to yourself may involve being good to

others as well. Human relations and friendships are developed through sharing, caring, and reciprocity. Always being in the position of receiving and always being the one who is helped represents an unbalance that participants found it important to redress.

#### **Discussion**

Four areas of everyday life experiences in recovery were elicited through this study; the importance of having a normal life; initiating recovery by "just doing it"; finding ways to make life easier, and the value of being good to yourself. In response to the descriptions offered above, which characterize each of these themes in everyday terms, it is reasonable for readers to wonder, however, what any of this has to do with severe mental illness, as one of our colleagues asked upon reading a draft of these findings. The struggles that participants described seem like the same common human struggles we all share, and few of their solutions had anything specific to do with their illnesses. How can exploring everyday life issues in this way be helpful for individuals with mental illness, or for those practitioners who are dedicated to assisting them in their recovery?

These are good questions and a reminder of the significance of Gullestad's (1989) point made earlier about everyday life being invisible because it is too visible. In order to give our colleague and sympathetic readers some answers, we would like to focus in closing on four implications which this approach generates that have utility for practice.

First, when it comes to understanding recovery, the trivialities of everyday life must be seen as anything but trivial. As opposed to abstract diagnostic categories or symptoms which occur in a pure state (i.e., in a vacuum), these trivialities are what individuals with lived experiences of mental illness mainly talk about, because mental illness poses practical problems and affects their everyday life in a variety of ways. The participants in this study mentioned disturbing voices, fatigue, poverty, side effects of medication like drowsiness and obesity, anxiety, and sleep disturbances. Mental illness had among other things caused them

difficulties in fulfilling their education and vocational aspirations, organizing their daily lives, paying their bills, and making and keeping friends. As reported in prior research (Mezzina et al., 2006), these findings support the view that recovery is an inevitably social process as well as an integrated part of the person's daily life. Recovery is described by the participants as an ongoing process that unfolds in a variety of contexts, in which actions and activities can be planned or events can happen in unplanned ways that have great impact on the individual's situation. It is these small bits of life that are often experienced as being of critical importance in an individual's recovery process.

Second, individuals being diagnosed with schizophrenia or other severe mental illnesses do not describe a life history characterised by a disintegrated sense of self or by having lost their overall ability to function. Persons experiencing severe mental illness appear not to loose themselves entirely (Davidson, 2003; Strauss, 1996; Topor, 2001). As seen in the findings above, participants described a life full of interests, skills, and expertise which they had acquired before illness onset that remained useful to them in their recovery, and that reminded them of how life could be. They reported on material and social conditions that were helpful and on their own determination and hard work as central elements. Participants presented themselves as individuals in a social and cultural context, in which social norms and culturally-favoured activities were as much part of their daily lives as for people in general; activities like going to the gym, going for walks, or supporting your family. Self-care was also a highlighted area. Examples of physical self-care, emotional self-care, and spiritual self-care were mentioned, as well as coping strategies developed in creative ways.

When participants described things they could do to make life easier, they mentioned examples like the intense pleasure of standing under a tree and enjoying nature, meditation, music, gardening, or beating your own record on the exercise machine. Building on strengths and pleasures make it easier to carry burdens and encounter troubles, and to maintain their

belief in their capacity to recover. Participants also described situations of being ill and well at the same time, but most importantly they had resources, skills, and courage that made recovery possible. Human problems and symptoms cannot be understood or interpreted divorced from this context of the person's overall life.

Third, normal environments and activities emerged as the most common and effective arenas for recovery in contrast to mental health service settings. Ordinary community arenas, ordinary work, and ordinary homes comprised participants' preferred life worlds. These arenas gave meaning and invited them to participate in discussions of general topics as opposed to remaining confined to a discourse focused on illness. Most of the participants also talked about the value and meaning of people believing in them or expressing expectations of competence and action. In addition, they had kept their position and role as a family member or friend or neighbour as opposed to being "mad" or becoming only a "mental patient." Within this context of normal life, mental health services and professional competence had a rightful place and proved to be invaluable in many situations. But even in these cases, the key competence of practitioners was to allow participants to be human and to be normal, with all of the rights, responsibilities, and requirements that being ordinary citizens involve.

This brings us to the fourth, and final, implication for practice. Rehabilitation and treatment programs will do well to elicit, listen to, and appreciate both the dramas and the trivialities of everyday life, as well as the individual's own expertise in managing these tasks. Living conditions, income, employment/unemployment, and social interactions outside of treatment settings are central to processes of recovery and cannot be seen as lying outside of the scope of clinical or rehabilitative practice. People with severe mental illnesses are neither defined by, nor limited to, their symptoms or diagnosis. Conceptualizing recovery within the context of the person's everyday life moves us beyond the simple assertion that mental illness is a brain disease. This does not mean that clients' suffering and difficulties are given less

consideration or ignored. Neither does it mean that they are treated in a less empathic way. But it does emphasize the need to view practical, material/instrumental, and social support and environmental accommodations as valuable therapeutic interventions, on a par with more traditional interventions like medication and psychotherapy. Everyday life tasks and skills need to be addressed as part of the practitioners' agenda, as well as if not more than such issues as insight or medication compliance.

Finally, the skills to be assessed and addressed are not only those of conventional psychiatric rehabilitation, such as social skills and employment skills, but the skills involved in establishing and maintaining a comfortable sense of home (on a limited income), skills involved in pursuing pleasant and enjoyable social and recreational activities (with or without others), and skills involved in giving back to others and in sustaining a connection to a sense of meaning and purpose that is greater than oneself.

According to the participants in this study, recovery is hard to plan. In spite of whatever may be developed and implemented as part of treatment and rehabilitation, things happen and people find other, and at times unorthodox, ways to manage their illnesses and reestablish their lives. Participants underscored that practitioners as well as people in recovery need to remain open to opportunities which present themselves, no matter how small, which can make life a bit easier or better, like Paul unexpectedly finding a cat. Understanding recovery in the context of everyday life offers us insights into how people can live full and rewarding lives despite the ongoing presence of long-lasting mental health problems. As a result, it can encourage us to shift from viewing our clients primarily in terms of deviance to becoming equally, if not more, interested in supporting their efforts to function as citizens.

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## Paper II

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## Paper III

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# Paper IV

## Working on the edge:

Everyday life research from Norway on the meaning of work for people recovering from severe mental health distress

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#### **INTRODUCTION**

The importance of work for people in general is well documented from health, psychological, social, economic, and political perspectives. Employment has been significantly correlated with better physical health and psychological well-being (Elstad, 1994; O'Hagan, 1984). Since employment is a primary source of financial resources, it is also related to acquiring adequate housing, education and social participation (Carling, 1995), as well as being a source of mastery and self-realisation. The role of worker in most societies is associated with positive identity, status as adult and as a contributing member of society (Kristiansen, 1993; Wolfenberger, 1993). Correspondently, unemployment has been correlated with poor health, low self-esteem, risk of societal devaluation and social exclusion (Bartley, 1994; Marwaha & Johnson, 2005; Halvorsen, 1994).

Although a substantial amount of research shows that vocational performance is not correlated with psychiatric symptoms (Anthony et al, 1995), there continue to exist few real employment opportunities for people with serious mental health problems. High levels of unemployment prevail among people with mental distress in most countries with developed market economies (Waghorn & Lloyd, 2005).

This article draws on data from a qualitative research study exploring the everyday lives of individuals with severe mental distress in Norway, with a central purpose of identifying what is helpful in the recovery process. Thirteen individuals with histories of severe mental distress who considered themselves to be in recovery were interviewed. A recurring theme in the interviews was that work and the work setting had been significant in the process of recovery, and selected material related to the meaning of work in peoples' lives provides the empirical basis for this article.

The objective of this article is to identify and discuss the role that work plays in the recovery process, particularly why and how work contributes in successfully struggling with mental health problems and getting on with daily life in the community.

#### **BACKGROUND**

Most people with mental health problems want to work, yet this is often coupled with expressions of self-doubt and worries about actual possibilities (Marwaha & Johnson, 2005; Bond *et al.*, 2001). A Norwegian study assessing community reintegration of people with schizophrenia labels seven years after hospital discharge found that 94% were unemployed and 47% were socially isolated (Melle *et al.*, 2000). Poor success rates are often due to societal barriers such as public attitudes rather than personal deficits (Marwaha & Johnson, 2005; Roets *et al.*, forthcoming). Marwaha and Johnson's informants named stigma as a major obstacle in finding or maintaining jobs, and the Roets *et al.*, study (forthcoming) found that people with histories of mental distress seeking employment often 'lose the game before it starts' due to societal prejudices and low expectations. Unemployment has been named a cardinal feature of the patterns characterising the lives of people with serious mental health problems (McGurk & Mueser, 2004).

Many myths continue to impede development in the area of employment for people with mental health labels, most notably the long-standing belief that schizophrenia is a chronic and incurable disease (Harding & Zahnister, 1994; Warner, 1994). Such mind-sets create low expectations which in turn generate and reinforce pessimistic societal attitudes, including those of potential employers, and are often internalised by the individual him/herself, thus becoming vicious circle of negative self-fulfilling prophecies (Mezzina *et a.l.*, 2006; Roets *et al.*, forthcoming).

Contemporary practice in psychiatric rehabilitation has been strongly influenced by the orientation that people with serious mental health problems have an underlying psychobiological weakness that develops into severe disorder when daily life stress overwhelms personal coping abilities (Krupa, 2004). This line of thinking includes both the view that mental health problems negatively impact on work skills and performances, and additionally that the demands of work tasks and work settings may even provoke or worsen problems.

Krupa additionally warns of the limitations of such frameworks, arguing that the benefits of employment are likely to remain undiscovered, and simultaneously the deleterious consequences of unemployment are unacknowledged. This is exacerbated by general debates on unemployment and social benefits which typically view the unemployed beneficiary as a client with personal deficits in need of therapeutic intervention and activation from others, understandings which tend to create and reinforce a passive victim role rather than one of active agency (Halvorsen, 2005). The difficulties associated with locating the problem and solution of mental disorders within the individual person are illustrated by Warner's (1994) analysis of how political and economic forces shape and reinforce societal responses and treatment philosophies for people with severe mental distress. Resultant policies and programmes will typically be aimed at reforming the individual rather than changing societal barriers or discovering ways to support individuals in their own ways and in their own contexts.

## Recovery and everyday life

The notion of recovery in mental health research is relatively recent, and as with many new terms is inconsistently understood and used and even somewhat contested. Yet some defining characteristics are typically mentioned (Borg & Topor, 2003; Davidson, 2003; Davidson et al, 2005; Kristiansen, 2005; Ralph & Corrigan, 2005; Topor, 2001; Wallcraft, 2005) and are briefly described here.

First, recovery means 'taking back control and getting on with one's life', and managing most things most of the time, albeit in one's own ways or at one's own pace. Recovery is not about cure nor necessarily about symptom eradication, but rather about learning to live with and gaining more control over what is distressful. Recovery is a process, not an outcome, and this process shows great variation from individual to individual. The uniqueness of the recovery process is often experienced as essential yet often goes unrecognized because of traditional rehabilitation approaches which tend to be standardized and typically based on diagnostic categories. Recovery is considered a dynamic and social process, incorporating individual as well as environmental perspectives and the relationships between the two, a life context approach implying among other things that regardless of one's aetiological perspective regarding the nature and cause of mental illness, it is in a person's everyday life that the numerous consequences need to be addressed (Borg & Davidson, in press; Davidson & Strauss, 1995; Repper & Perkins, 2003). A recovery approach also includes the understanding that while the personal distress of mental health problems is often devastating, the social consequences are often even more disabling (Beresford, 2005). Lastly, recovery research has an underlying belief that individuals with serious mental illness histories and labels are themselves experts in identifying what is helpful in their own recovery process. Yet entire areas of psychiatric rehabilitation remain unevaluated from a service recipient perspective, perhaps most notably the domain of work and employment (Brun & Rapp, 2001).

## The Norwegian context

The national population of Norway of slightly less than five million people is spread out over a large geographical area. Norway has comprehensive, publicly-funded state welfare programs where work for all citizens has been on the political agenda for over half a century. The unemployment rate is consistently low when compared internationally, and the average standard of living is among the highest in the world. Norwegian national policy and intervention strategies have a long-standing explicit aim to identify and address the situation of disadvantaged groups, with a central objective to support individuals in the transition from public assistance to self-sufficiency, including having a decent standard of income and living conditions.

Norway is nearing completion of a ten year national initiative to restructure mental health services. Fundamental are the transition from institution-based care to supported living in local communities, the recognition of citizenship rights, and the importance of service-user participation (St meld 25 (1996-97)). With regard to employment, the National Ministry of Labour and Social Inclusion is responsible for labour policy and safe working environments, as well as issues of anti-poverty welfare and societal integration. A common criticism from people with mental health problems is that the service system is fragmented and the burden for coordinating help and support from many sectors is often up to the affected individual and their families.

## METHODOLOGICAL APPROACH AND RATIONALES

#### Introduction

This study was influenced by a phenomenological tradition, an approach which examines and interprets the subjective reports of individuals with lived experience, exploring

a certain phenomenon and striving to discover aspects of social reality with a purpose of contributing to theoretical or practical advances (Cresswell, 1998; Davidson *et al.*, 2001). The research reported here returned to previously collected data from a broader study exploring recovery and everyday life in general (Borg & Davidson, in press). Drawing on existing data for analysis from a different perspective or with more focussed questions is not unusual in qualitative research, especially a more in-depth investigation of themes already identified. The phenomenon under closer scrutiny was the meaning of work in everyday life with regard to the recovery process.

#### **Investigative approach**

An everyday-life orientation was used, a method of inquiry which includes how research questions are formulated and why, as well as study design features such as content, method, settings for information collection and theories used to understand and discuss empirical findings. The content of interview questions concerned all areas of daily life, using an informal 'conversation' style, and took place in settings chosen by the informants themselves, which in all cases except three was the person's own home. Interviews began with the open 'grand-tour' question (McCracken, 1998) 'could you tell me a bit about your everyday life?' Such an approach allows the informant to steer initial directions and content, and often reveals information about an individual's priorities about what is important in life.

Interviews were carried out by the first author during the time-period 2004-2005. Each informant was interviewed two times, the second time in person or by telephone following informants' preferences. Average length of each interview was one to two hours. All but two interviews were audio-taped, transcribed into written texts, and then returned to each participating informant for review, approval and possible alterations. Two informants felt it awkward with audio-taping and instead notes were taken and returned to the individuals for comments and verification.

The research process also included a reference group of five individuals with experience from recovery in severe mental illness. Inspired from methods in participatory research (Davidson *et al.*, 2001), this group was involved in project design, interview content, inclusion criteria and involved in ongoing discussions during analysis. Additionally, the meaning of certain concepts was discussed, including everyday life, normality, and recovery, as well as issues of money, human rights, home-life and community connectedness. The contribution of the reference group was important in at least two ways: first by providing opportunities for in-depth discussions with people having first hand knowledge and expertise, and second, providing a more comprehensive way of understanding the recovery process and people's lived experiences in a contextual way.

#### **Informants**

Inclusion criteria for participating in this study were individuals who (1) considered themselves in recovery from serious mental illness; (2) had a permanent place to live; (3) felt they were coping satisfactorily with their lives; and (4) had improved their lives with help from mental health services or other external sources. Informants were recruited using purposeful, strategic sampling, a combination of what Patton (2002) terms 'snowball' coupled with 'maximum variation' techniques, seeking individuals with a richness of personal yet varied experience.

Six men and seven women were interviewed with an age range of 26 to 54 years. Informants had varied histories with regard to social situations, education, employment, and contact with formalised services including hospitalization. Two were married, two were engaged, nine were single, and two had children. Six had education at the college level or above. Ten had been diagnosed and treated for schizophrenia, one for reactive psychosis, one for bi-polar disorder and one for psychotic paranoia. Three people felt they were recovered from their mental distress and no longer manifested or experienced signs and symptoms.

The ten others reported that their distress was under control so that they could manage their daily lives and participate in community life. Nine informants had some contact with services, mainly regarding medication and general supportive consultations on their own initiatives.

With regard to work, most were engaged in part-time employment with incomes supplemented by social security benefits.

Two were employed fulltime in ordinary waged jobs. The three who were unemployed were over the age of fifty with higher education and long employment histories and experiences from ordinary working life and who described that in their later years it was enjoyable to have opportunities to have a less demanding life, often choosing instead to do voluntary work and have more time to take more care of themselves. A few had created their own jobs, such as authoring books or being involved in education or service provision assessments. One younger man was unemployed, but described sorting out his everyday life as work that he felt he needed to do before he could get a paid job. Almost no one in this study mentioned support from others in finding work; accomplishments were instead the result of own initiatives.

## **Analysis**

The interview data were systemised according to established qualitative procedures by means of thematic and phenomenological analysis (Davidson, 2003; Cresswell, 1998). The thematic and step-wise approach employed was an expansion of the methodology applied by Davidson *et al.*(2001) The first two steps involved analysis of individual interviews for units of meaning related to work, and then across individual interviews, followed by grouping the material into provisional thematic categories. These first steps were carried out independently by each author. The third phase involved comparing findings and modifying the categories, as well as searching for connections and higher-order issues. In the fourth phase, authors returned to the interview transcripts to verify and supplement findings and discussions.

Concepts, findings and discussions were also continually discussed with the reference group, considered critical to the trustworthiness of the study and its validation.

#### **Ethical considerations**

In Norway, all research study designs are examined, approved and followed up at both national and regional levels. This study was accepted by the (national) Social Science Data Service and at the regional level by the Region IV (Mid-Norway) Medical Ethics Committee. These standards include issues of informed consent, confidentiality, anonymity, study design, and plans for distribution of findings. In addition to abiding to legally established mandates and codes of ethics, we support the contention that other, quite fundamental ethical issues exist in qualitative research, related to listening and interpreting the voices of 'others' (Barron, 1999; Traustadóttir, 2001). This study was based on the epistemological belief that subjective reports of people with lived experience provide important and perhaps essential insights in the quest for new knowledge. For at least a century people with psychosis have been described clinically and legally as disoriented and untrustworthy, and their verbal and behavioural expressions have primarily been used to uncover patterns of signs and symptoms for diagnosis and subsequent treatments (Harding & Zahnister, 1994, Topor, 2001), including Kræplin's hegemonic legacy describing such syndromes as chronic and even deteriorating (Davidson, 2003). The subjective voice of especially those diagnosed with schizophrenia has only recently been listened to and deemed credible (Davidson, 2003; Strauss, 1989; Strauss, 1996; Topor; 2001). An emergent trend is that listening to, recording, and distributing the voices of those long-silenced is necessary and even sufficient for social change. Such efforts may have popularity more because of political correctness than a basis in empirical knowledge and social change, and in any case, unanalysed subjective reports lead to the additional ethical dilemma of leaving interpretation up to each reader (Gustavsson, 2004).

#### **CENTRAL FINDINGS**

On inviting informants to tell about their everyday lives, many responded immediately with comments about how busy they were, especially emphasising that work took a large amount of time and energy. Analysis revealed that although these women and men had experienced seriously troublesome times and occasionally still had very difficult periods, they were also resourceful, persistent, goal-oriented, resilient and creative in finding ways to get on with their lives. While such attributes have previously been identified as central in the overall recovery process, what is presented and discussed here are central themes related to work.

### Being and becoming: active workers not passive patients

Central in the recovery process was having a work situation that enabled, permitted and supported stepping out of the problematic arenas of life and 'being and becoming someone'. Davidson has termed this 'a life outside of mental illness' (2003), or in Boevink's words 'from being a disorder to dealing with life' (2006). After years of being known and treated as a psychiatric patient, often including long periods of heavy medication, social isolation and hospitalization, being able to obtain and fulfil the requirements of a work role provided more valued status and titles, more valued identities, self-confidence, respect from others, and a feeling of inclusion in ordinary roles and communities, as Joanne's comment illustrates:

I've got a lot of responsibility at work...haven't thought much about the titles he uses...he calls me head of purchasing, elected union representative, assistant director. I know the whole system here...he was on holiday for six weeks and I ran the whole place: ordered supplies, audited accounts...

Doing something worthwhile and being involved in things not related to one's own problems was consistently apparent in the accounts of this study. It was not necessarily paid

work they were concerned with, but work activities needed to be of some importance to others, somehow useful and respected by fellow human beings. Examples were voluntary work for organizations and writing about mental health issues for the public. Susanne talked about the voluntary work she did for an organization:

So that was my daily kind of commitment... and I got this sense of self-esteem.... They gave me responsibility. Even at times when I was in the hospital, it was always like that. This became a very important part of my life...I didn't see it as rehabilitation or getting better, just something I did, and I got a sense of self doing it.

Goffman (1961) informed us nearly a half century ago that the mental health client role can be so dominating that there is little place for alternative, more valued roles. The informants in this study mastered a number of work roles and revealed strong degrees of active personal agency. Being busy in one's own ways seemed to require taking some degree of control over decision-making and planning, including an inner feeling that one was contributing instead of being on the receiving end.

'Being' is intrinsically interwoven with 'becoming': one learns about becoming more competent in the ordinary world by simply being there and participating in valued ways and settings. Several mentioned the importance of being together with others having ordinary discussions such as at work-breaks, about what was happening in the world, about opinions and reactions. Being surrounded by people without problems enhanced feelings of being 'okay', as well as having opportunities to grow and develop.

# Belonging: an ordinary working life

Most of the men and women in this study had spent much time in psychiatric service contexts, where the frame of reference for entry was their disorder and diagnosis. Having ordinary work situations, even if only part-time or voluntary, was seen as being on the right track, of being included and connected to communities. They expressed joy and satisfaction of

being part of and able to function in ordinary settings, and many described their work as providing feelings of being 'normal' again. In Johanne's words this meant being a 'part of real life' and included in a 'regular group having ordinary conversations'. And as Nina said:

I have appointments every day, and maybe my week is a bit too demanding...I have collapsed a bit and been extremely tired, but all in all it feels very good to function.... feel I am on the run again...

Although these ordinary settings were occasionally described as demanding or stressful, informants chose to prioritise such settings, preferring to practise dealing with barriers that appeared. Nina felt great hope and relief in letting go of the psychiatric environments she had been part of for four years, explaining that she had struggled to hold on to her own process of development and recovery when surrounded by others who appeared very ill. Although she said she had received some help in treatment settings, entering a work environment was a relief and an important step on her recovery path. And Johanne found it helpful with the informal talks at lunch and break-times:

I really believe in being with healthy people... They have expectations about me.... don't bother listening to all my miseries and the negative...In fact they tell me off when they are fed up with my talking about problems...My attention is turned away from me, and then I get interested in what others are concerned with,...feel a part of life instead of being someone ill.

Other informants emphasised the social aspects of the job, especially the companionship and felt that work was the most important factor in everyday life. Friendly colleagues seemed to make life easier.

Friendship and reciprocity are important in human life in general and in recovery. Work can be a context offering opportunities for team-work, partnership and sharing, making friendships, providing arenas for discovering and trying out old and new talents and finding

ways of overcoming difficulties alone or with help of others. Very fundamentally, regular work roles and settings provided a sense of belonging and a related sense of collective positive identity, not to a diagnostic category with individualised pathology but to a social grouping of ordinary and socially-valued workers (Barron, 2005)

#### Balancing: not too much, not too little

While having a job was described as very important, finding a balance between rest and work and other daily obligations was frequently described as essential. For example, Irene had been working in health or social services through her recovery process and talked about such difficulties:

I usually had a 60 or 70% job in addition to my university studies...had less student-loans that way, but...this was really why I've become unwell again.

Finding a balance of 'not too much and not too little' often involved trying out how many hours working a week seemed manageable. Most worked a few hours a day or every other day, while others worked more or less a full work-week. Some told that although actual working hours were limited, they used many hours before or after work contemplating issues related to work, including as planning the tasks of the working day ahead, or reflecting back on the work done and unwinding when returning home. In addition, several mentioned the need for sufficient sleep and adequate time for relaxation.

Having a job sometimes meant less participation in other activities, such as saying no to movie invitations, less time for hobbies, or going early to bed every night before a working day. However, employment seemed to have such importance in the recovery process that these costs were something they just learned to accept, by developing practical routines and taking control, as Emma had accomplished:

This emphasis on balance between rest and activity is not surprising. I really need to have control, and if I feel I don't have it I get worried. If I experience not being able to cope, or things just become too much, I lose my perspective...that's when I get manic and psychotic... having control is pretty essential for me.

Several expressed awareness that being inactive, becoming bored or socially isolated could be as or more harmful than having lives that were too eventful and busy. Extremes on both sides of the energy scale seemed to be an obstacle in the recovery process. When Susanne trusted the advice from some professionals to not take on a demanding job, she accepted being in a work situation that was not stimulating, and she links this to her quickly becoming poorly again, adding:

I need to be challenged, live a life where I can be pushed... I need opportunities to do something creative... I call this working on the edge, to have something at the edge...

Working on one's recovery combined with having a job was described as demanding, time-consuming, and stressful, but well worth the extra effort and daily planning. Many mentioned the need for much energy and focus in meeting demands at work as well as the practicalities of life, such as paying bills, cleaning the house, or taking care of one's children. Many tasks require concentration, especially if one is hearing disturbing voices or experiencing anxiety, and the use of psycho-tropic medications was often discussed in this connection. Finding the right medication had long been a great concern for several, who told about unwanted side-effects such as drowsiness, feeling uninspired or emotionally flat, or becoming overweight, all of which negatively impacted on their daily life performance and especially at work. In order to cope with pressure and tension, some found activities such as meditation and yoga helpful in their search for a balanced everyday life. George explained that meditation had a crucial position in his recovery process, using a method he developed which he felt helped in keeping focussed and which served to gradually eliminate his anxiety.

A busy life and meaningful work also seemed to provide a much-appreciated regularity and predictability. Having a reason to get out of bed in the morning, being faced with known routines and expectations, being counted on to perform known duties and tasks were found to be helpful in finding an inner balance. This is not surprising considering the chaos, uncertainty, and insecurity the individuals in this study and other people with mental distress have often experienced. The informants in this study consistently portrayed competence in finding ways of being an employee despite their mental distress and associated problems. Routines that balanced rest and work seemed to make it possible to function at work even on days when they felt incompetent or miserable.

### Believing in you: the importance of supportive and flexible environments

Many supportive factors in their work settings were recognised and appreciated, as important aspects in their being able to succeed at work. This included sympathetic and flexible managers, understanding and helpful co-workers, and especially being with others who believed that they could and would succeed, people who transmitted messages of trust and hope. When met with expectations and positive beliefs, informants in this study experienced increased self-confidence, and felt pride and satisfaction with their accomplishments.

Both Kristin and Susanne had previously heard from mental health professionals that they would not be able to cope or manage jobs they were trained for, yet managed to follow their own inner convictions and successfully challenged professional advice. Emma found that others believed in her even when she herself was unsure:

Well, I have been rather poorly at times, maybe more than I realised myself, but I've been functioning well at work, and got good feedback and letters of reference.

Both Kristin and Anders mentioned the significance of a working culture that tolerated their troubles, feeling that they could go to work even when they felt vulnerable or miserable.

Flexible environments made it possible to try out new things as well as actively contribute their skills albeit occasionally in somewhat different ways.

Although employment for everyone who wants to work is a central intention of Norwegian welfare policy, many professionals seem to remain more sceptical than inspiring and supportive. When met with low expectations, people are more likely to fail and also internalise failures as their own, a vicious circle of self-fulfilling prophecy (Roets *et al.*, in press). Of fundamental importance was an understanding within the work setting that allowed one to be both well and yet ill at the same time (Davidson & Strauss, 1995; Topor, 2001). This is related to the role of hope and belief in the recovery process (Glover, 2002; Kristiansen, 2005; Russinova, 1999).

Here is an obvious contradiction to beliefs underlying rehabilitation efforts which are designed for step-wise improvement, typically organised as a gradual progression along a continuum of settings. This is also supported by the claim of the 'father of supported employment' Marc Gold that train-and-then-place models should be replaced by on-the-job training, an approach which subsequently has been substantiated by research (Bond *et al.*, 2001; Gold, 1980). What the informants in this study strongly portrayed was the centrality of the work setting in their recovery process, if arenas provided flexible, supportive and safe spaces, and signalled that the work done was a contribution.

#### **DISCUSSION**

# Working at but not over the edge

Experiencing being included in ordinary work roles and settings was found to be central in the recovery process. Individuals who previously had experienced low expectations about getting a job found they were able to perform well in ordinary work roles despite periodic or ongoing mental distress, if their subjective experiences were positive and if work

environments were supportive and flexible. Individuals were often 'working at the edge', in terms of what many may consider a real job or a full work week. Many were living on the fringes of society, somewhat participating and being included in local communities but still somewhat marginalised. Yet 'working at the edge' also has positive connotations. Many informants expressed the need to be challenged, to test and develop skills, overcome barriers, and meet novelties. Discovering and learning about one's own limits as well as potentials was important for personal development and gaining control, in other words not going 'over the edge'. Being together with ordinary, 'normal' people in ordinary settings helped many realize that a life with ups and downs is not unusual or pathological, as Wilson and Beresford (2002) have stated. Being confronted with the expectations of others was experienced as a sign of respect and hope.

# **Humanity: simple yet complex**

In the informants' detailed stories of how they went about finding and maintaining work, enjoyed pleasure at work and dealt with difficult situations, they used strategies much the same as we would all apply in similar circumstances, which they often referred to as 'normal'. Work provides an arena for trying out new things, a social place to spend time and enjoy the company of others, and for having disagreements as well as collaborating with other people. A real job provides opportunities to be given and also take on responsibility, to be useful, and to do something worthwhile. To our great concern, after years of mental health and social policy and action programs aimed at citizenship and social inclusion, the basic humanness of men and women experiencing mental health problems is often still not acknowledged. Individuals being diagnosed with for instance schizophrenia easily become 'them' as opposed to 'us', and are often defined as different, special, and vulnerable and in need of specialised rather than generic services.

The strength and endurance conveyed as crucial in recovery by those with lived experience is an alarming paradox to this alienation and marginalisation. As Wilson and Beresford (2002:144) state: "the world does not consist of 'normals' and 'the mentally ill'; it consists of *people*, all of whom may experience mental and emotional distress at some time(s) in their lives". The dangers of stereotypical understandings of the experiences of mental distress are very real. People are not perceived or treated as the active agents they actually are in shaping their own lives, including having their voices listened to and respected (Deegan, 1988, Boevink, 2006, Borg & Kristiansen, 2004, Roets *et al.*, in press). With current trends idealizing new public management, evidence-based practice, and efficiency of rehabilitation treatment programs, it may be worthwhile to step back a bit and pay more attention to the individual person, daily life, ambitions, future goals and personal strategies about moving on.

# Everyday life: trivial yet essential in recovery research?

There are several reasons why we contend that an everyday life approach may be essential in learning about the recovery process. First, what is discovered is likely to be quite different if the content of questions is only about one life area (such as work) or if the interview context is the researcher's office or the rehabilitation setting. An everyday life perspective acknowledges a 'person-not-patient' view, and the focus is shifted from individual pathology to daily life, community participation and social roles. Much of what we found in this study about why and how work is important for people in their recovery process probably would not have been possible without exploring each person's whole life situation and experiences and within their own contexts. This whole life picture gives a larger context which effects analysis of an overall situation rather than a part of life, and this larger context is important in identifying what is helpful and why, as well as interests and resources to build on. Examples from this study are the relative importance of the work role compared to other social roles, and the balancing of work activities with leisure and restful rhythms.

In Norway, an everyday life perspective is explicitly connected to a civil rights perspective, where each individual's personhood, humanity and citizenship are acknowledged and respected. Everyday life studies and living conditions surveys include the purpose of unveiling patterns of inequity for certain sub-populations which in turn form a basis for subsequent social policy reform (Tøssebro & Kittelsaa, 2004).

Studying everyday life is deceptive: What appears to be simple is actually complex and elusive. Much of everyday life is so taken-for-granted that it risks becoming invisible, and when named may appear trivial or mere common sense (Gullestad, 1989; Smith, 1987). Yet it is these small bits of life that are often of critical importance in an individual's recovery process, such as having to get out of bed early each day to walk the dog before going to work. Identifying such details is not only important to a single person's unique recovery, but such information about the 'intimacy of life' is also considered essential in meeting the criterium of trustworthiness in the analysis of qualitative data (Latour & Woolgar, 1979).

Qualitative research approaches such as narrative inquiry and ethnographic participation-observation studies are increasingly gaining popularity in clinical and therapeutic settings, and while this quite likely provides a wider understanding of what is happening in these situations, we would argue that this is all too often taking place in narrow contexts outside of a person's overall everyday life. This is likely to mean that what is discovered as helpful will be limited to the investigated setting, such that rehabilitation program features may be labelled as helpful while whole areas of daily life remain hidden from analysis and for discovering future arenas for moving forward.

# CONCLUDING REMARKS: RE-STATING THE OBVIOUS THAT IS NOT SO OBVIOUS

Qualitative inquiry seldom provides conclusions in the sense of final results. This article may not reveal new information about the meaning of work for people in general in most societies, a claim which is central to our concluding points. In fact we chose to conclude with some questions. Why should we be surprised to discover that work for people with mental health problems is connected to feeling better about one's identity, social status, development and belongingness? Why be surprised to learn that small, everyday details are important in the individual life process? Or why be surprised that those who provide useful tasks and have contributing roles are more positively perceived and accepted by others in society?

Our central concluding comment is that the obvious is perhaps not so obvious, judging from many rehabilitation efforts. The meaning of work for people with serious mental distress is not different from the meaning of work for people in general, but is less likely to be investigated or noticed. Or perhaps work is even more important for people who are at risk of societal devaluation, exclusion and feelings of low esteem? Being an employee with problems in need of occasional personal support is very different from being a psychiatric patient receiving standardised rehabilitative work-training programmes. Recognising all people as fellow human beings with citizenship rights demands an approach that is coherent with such rhetoric, where one's basic humanity and everyday life are acknowledged as primary and of central importance for further research. The trivial is often not so obvious, but may be crucial to many people in recovery from severe mental distress.

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# Paper V

Paper V is not included due to copyright