

# **Growing as a person**

**The possibility of personal development for adults  
in treatment and education**

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# Contents

<b>Acknowledgements .....</b>	<b>6</b>
<b>List of papers .....</b>	<b>8</b>
<b>Summary .....</b>	<b>9</b>
<b>1 Introduction.....</b>	<b>11</b>
<b>2 Background and theoretical perspective.....</b>	<b>12</b>
<b>2.1 Scope of the study.....</b>	<b>12</b>
Descriptions of functioning above diagnostic criteria.....	12
Environmental conditions rather than genetic and/or physiological conditions .....	12
<b>2.2 Severe mental illness, sense of self and childhood trauma .....</b>	<b>13</b>
Sense of self and psychosis in recent research .....	14
What characterizes anomalous self-experience?.....	15
Sense of self and personality disorders.....	17
Severe mental illness and childhood trauma .....	18
<b>2.3 Developmental psychology and normal self-development .....</b>	<b>20</b>
Fundamental/primary relationships .....	20
Social community and reciprocity .....	23
Context and coherence .....	24
Time.....	26
Care, creativity and activity.....	26
<b>2.4 Health, recovery and empowerment.....</b>	<b>28</b>
Health.....	28
Recovery.....	30
Empowerment.....	33
<b>3 Context of the study: Education and treatment .....</b>	<b>36</b>
<b>3.1 The Danish schools .....</b>	<b>36</b>
The folk high school system .....	36
Day folk high schools.....	37
The day folk high schools in this study .....	38
<b>3.2 DPS and municipal mental health care in Norway .....</b>	<b>41</b>
The offer of DPS inpatient wards in this study .....	41

Municipal services when patients are not in the ward .....	43
<b>3.3 Demarcation in respect to other services .....</b>	<b>44</b>
<b>4 Aim and research questions .....</b>	<b>46</b>
<b>4.1 Paper 1 .....</b>	<b>46</b>
<b>4.2 Paper 2 .....</b>	<b>46</b>
<b>4.3 Paper 3 .....</b>	<b>47</b>
<b>5 Design and method .....</b>	<b>48</b>
<b>5.1 Design .....</b>	<b>48</b>
<b>5.2 Discussion of the selected design .....</b>	<b>48</b>
<b>5.3 Informants and inclusion .....</b>	<b>50</b>
Patients and students.....	50
Teachers and health care professionals .....	53
<b>5.4 Discussion of sample and inclusion.....</b>	<b>54</b>
The inclusion criteria do not specify diagnoses.....	54
Sample in relation to the inclusion criteria .....	56
Method for the recruitment and inclusion .....	57
Informants from two countries .....	58
The context's influence on the sample .....	58
<b>5.5 Discussion of selected context.....</b>	<b>59</b>
DPS is the most common specialist health services for the target group .....	59
Necessary refinements in the interests of the scope of the study.....	60
There is little research on the Danish day schools .....	60
The Danish day schools have an exceptional position in cultivating of clear framework and a professional foundation.....	61
The two settings should represent different models of understanding, yet have some relevant similarities .....	62
<b>5.6 Interview and adaptation of the interview .....</b>	<b>63</b>
Interview, adapted for students and patients.....	63
Interview, adapted for health care professionals and teachers.....	65
<b>5.7 Discussion of the interview and interview situation .....</b>	<b>66</b>
<b>5.8 Recording and transcription .....</b>	<b>68</b>
<b>5.9 Discussion of recording and transcription.....</b>	<b>69</b>
<b>5.10 Qualitative data analysis .....</b>	<b>69</b>

<b>5.11 Discussion of data analysis .....</b>	<b>71</b>
<b>5.12 Preconceptions.....</b>	<b>71</b>
<b>5.13 Ethical Considerations .....</b>	<b>73</b>
<b>6 Findings and interpretations from the three papers.....</b>	<b>76</b>
<b>6.1 Paper 1: Same diagnosis, different lives: A qualitative study of adults with severe mental illness in treatment and in education. ....</b>	<b>76</b>
Method and analysis .....	76
Research questions .....	76
Findings and interpretations .....	76
Summary across informants in this article .....	78
<b>6.2 Paper 2: Treating symptoms or assisting personal development: Can different environmental conditions effect personal development for patients with severe mental illness? A qualitative study .....</b>	<b>79</b>
Methods .....	79
Research questions .....	80
Findings and interpretations .....	80
Summary across informants in this article .....	83
<b>6.3 Paper 3: How can context affect teachers' and healthcare professionals' interactions with adults with mental illness? .....</b>	<b>83</b>
Method and informants .....	84
Research questions .....	84
Findings and interpretations .....	84
Summary across informants in this article .....	89
<b>7 Discussion of findings and interpretations .....</b>	<b>90</b>
<b>7.1 Relationships between health professionals and patients and between teachers and students.....</b>	<b>90</b>
Duration of relations .....	91
Intensity of relations .....	92
Reciprocity and quality of relationships.....	92
Relation as "base" and "safe haven" .....	93
Systemic constraints.....	94
<b>7.2 Social fellowship and reciprocity .....</b>	<b>95</b>
Friendship and usefulness.....	96
<b>7.3 Coherence across life domains .....</b>	<b>99</b>
Dependence and independence .....	101
Psychotherapy.....	101
<b>7.4 Development takes place over time .....</b>	<b>102</b>

Time limitation's impact on the staff's attitudes .....	103
<b>7.5 Everyday care, joy and activity .....</b>	<b>106</b>
Joy and play-based activities .....	107
Attitudes to joy and well-being .....	108
Attendance at schools vs day centres and gathering places .....	110
The importance of school subjects.....	111
<b>7.6 Health, recovery and empowerment.....</b>	<b>114</b>
Reduction in the use of psychotropic medication.....	116
Physical health.....	117
Empowerment, personal commitment and subjectivity.....	119
<b>7.7 The validity of the findings discussed in relation to method .....</b>	<b>122</b>
<b>8 Conclusions and implications .....</b>	<b>124</b>
<b>References.....</b>	<b>126</b>

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## List of papers

### Paper 1

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### Paper 2

Lauveng A, Tveiten S, Ekeland TJ, Ruud T (2016). How can context and discourse affect teachers' and mental health professionals' interactions with adults with mental illness? *Social Work in Mental Health*. Published online: 08 Sep 2016.

### Paper 3

Lauveng A, Tveiten S, Ekeland T-J, Ruud T (2016). Treating symptoms or assisting human development: Can different environmental conditions affect personal development for patients with severe mental illness? A qualitative study. *International Journal of Mental Health Systems* 10:8.



## Summary

Much research on severe mental illness, like psychosis, is focused on the illness itself – origins, symptoms, treatment, medication and genetics. In this thesis, I wanted to focus on which possible influence environmental conditions can have for personal development in patients with severe and enduring mental illness.

This is a qualitative study. I interviewed 14 patients with severe and enduring mental illness at two different district psychiatric centres (DPS) in Norway, and 14 health professionals at the same two DPS. I also interviewed fifteen students at two different Danish day folk schools for adults with mental health problems, and 14 employees (mainly teachers) at the same schools.

The focus of the interviews with patients and students were their description of their own daily lives, their relationships and how they experienced the possibility for personal development. The focus of the interviews with teachers and health workers were their descriptions of their daily work, social norms and values, and what impact they feel that the service had for their students and patients.

The purpose of this study was to explore whether, and if so to what extent, different environmental conditions influenced the experience of everyday life, the sense of self and the opportunities for personal and social development of people with severe and prolonged mental illness. The results are published in three papers.

Findings and interpretations in paper one and two showed that patients and students described their lives quite differently. The students experienced a supportive environment focused mostly on education. They described sustainable development in areas such as capacity for relationships, regulation of symptoms, subjective well-being, and integration in society. They also described higher quality of life, little loneliness, and greater satisfaction with life. Patients, on the other hand, experienced an environment focused more on treatment of their illness and less on personal development and interests. They described little development, much loneliness, poor quality of life, an objectifying attitude of themselves and others, and hopelessness.

Findings and interpretations in paper three showed that both teachers and health care professionals were engaged in their work and in the wellbeing of students and patients. However, they described marked differences in practice, including the amount of time spent with students/patients, the organization of their work, main tasks, amount of control over their tasks, and social structure. These differences seemed to affect relationships with students/patients, attitudes toward students/patients, norms and values, and opportunities for patient empowerment.

Even if more research obviously is needed, overall findings and interpretations from this thesis suggest that while existing psychiatric health care might be appropriate for limited short-term problems such as single-episode depression, a model with a supportive environment, stable relations and a possibility for learning, joy and development of interests, may improve personal development and mental health for persons with severe mental illness and disturbances in self-experience.

# 1 Introduction

People with severe, long term and complex mental health problems constitute a large proportion of patients in mental health care, and it is often difficult to provide good and effective health care to this group. Despite the use of considerable resources on individual patients in this group, many of them describe their experience of psychiatry as traumatic, and that they experience very poor and inefficient help, and sometimes even new trauma. Meanwhile, recent research shows a clear correlation between changes in self-perception and severe mental illness, and between childhood trauma and severe mental illness. There are also several studies showing that patients in this group may benefit from psychosocial and practical measures such as adapted housing, social support and adapted work. This makes it necessary to explore whether other measures beyond traditional psychiatric treatment may be appropriate to enhance the self-experience of these patients and improve the quality of life.

In this qualitative study, I explored how two different services, using different approaches, frameworks and theoretical foundations, are described by those who receive the services, and by the staff working there. I interviewed students and teachers in two schools for adults with psychiatric diagnoses, and patients and health workers at inpatient wards in two district psychiatric centres (DPS, the Norwegian version of community mental health centres). The focus in the interviews with patients and students were their descriptions of their own daily lives, relationships and personal development, and the impact of the different services they received. The focus in the interviews with teachers and health workers were their descriptions of their daily work, limits and values, and what impact they feel the services had on students/patients.

## **2 Background and theoretical perspective**

### ***2.1 Scope of the study***

The purpose of this study was to explore whether, and if so to what extent, different environmental conditions influenced the experience of everyday life, the sense of self and the opportunities for personal and social development of people with severe and prolonged mental illness.

In this context, I have chosen two thematic delimitations.

#### **Descriptions of functioning above diagnostic criteria**

I have chosen to use the term "severe and prolonged mental illness", and to use descriptions of functioning as the inclusion criteria for informants rather than specific diagnoses. There are several reasons for this, including practical reasons. But one of the reasons was that I wanted a clinical description of a patient group which is recognizable to most clinicians, across diagnoses. Many of these patients will have multiple diagnoses at the same time, others will receive different diagnoses over time. Diagnoses may include psychosis in general and schizophrenia in particular, but also some cases of severe personality disorder. I am aware that these are very different diagnoses in terms of symptoms, origins and treatment recommendations, and it would, therefore, be advantageous to keep them separate. However, in ordinary clinical practice, these conditions, and patients, are often *not* separated. Although there are some special treatments or services tailored to specific diagnoses, patients with different diagnoses often use the same types of services, such as district psychiatric centres (DPS). In this exploratory study, I therefore did not want to focus specifically on the differences between different diagnoses, but rather interview a clinically recognizable group of patients with severe, complex and long term mental illness.

#### **Environmental conditions rather than genetic and/or physiological conditions**

As I am a specialist in clinical community psychology, my main focus is on individuals' interaction with society, including the significance of different environmental conditions. This is my area of interest, and I have far less specific knowledge of any possible biological causes and pharmacological therapy. I recognize that personality disorders and

schizophrenia are believed to have different aetiologies, and that the biological components are probably more significant in schizophrenia. There is, however, still confusion around this issue, and research increasingly indicates that schizophrenia is probably not *one* condition, but rather different conditions, with different aetiologies which we cannot currently distinguish from each other (Kinderman & Cooke, 2000, Zipursky et al, 2013).

In addition, the biological component has yet to be clarified. There are probably different degrees of heredity in patients currently diagnosed with schizophrenia, it is likely that the inherited factor is a vulnerability to the illness rather than the illness itself (Zubin & Spring, 1977, Walder et al, 2014), and also that other factors contributions can be more important than genetic factors (Fosse, 2009, Read et al, 2014, Zipursky et al, 2012). The lack of biomarkers for psychiatric diagnosis (Venkatasubramanian, Keshavan, 2016) also contributes to the difficulty of relying only on biological causes.

Treatment with psychoactive drugs can obviously be very useful as stabilizing treatment for many patients with schizophrenia. But there is no curative drug therapy. In recent years, the harmful side effects of drug therapy also have received increased attention. Which is why patient organizations and national health authorities are requesting drug-free and drug-alternative therapies as substitutes for, or additions to, traditional drug therapy. According to this, the Ministry of Health and Care Services has instructed all hospitals to introduce medication-free treatments as an option in mental health services from 2016 (the Ministry of Health and Care Services, 2015). This instruction has led to much discussion. Many users, relatives and professionals are positively inclined, while others, especially professionals, are requesting more evidence that medication-free treatments are safe and justifiable interventions for patients with psychosis.

In this study, I have chosen to focus primarily on environmental conditions and not genetic causes. I recognize of course that this is not the whole picture, but it is the part of the picture that I, as a community psychologist, chose to focus on in this study.

## ***2.2 Severe mental illness, sense of self and childhood trauma***

The relationship between severe mental illness, especially schizophrenia, and anomalous sense of self is not new. This is described in many classical theories of schizophrenia, for example by Benedetti (1964) and Winnicott (1965, 1971, 1986). The term schizophrenia, split

mind, suggests that anomalous sense of self historically have been central to the perception of the condition. The same is partly true for the severe personality disorders, as disorders of the personality structure and function are embedded in the concept of personality disorders. It is not just about symptoms coming in addition to a functioning personality, it is the core of personality and self that are affected. Despite the fact that this aspect for a long time has been a central part of the understanding of the most severe of mental disorders, the understanding has, however, been limited and often mixed with other models, for example specific psychoanalytic theories (Benedetti, 1964, Winnicot, 1965, 1971, 1986).

### **Sense of self and psychosis in recent research**

In recent years, however, disturbances in basic sense of self has been revived as a key research area and as an important concept in understanding psychosis (Nelson, Raballo, 2015 Henriksen & Parnas, 2012, Raballo et al., 2011). A normal sense of self means that the person has one (and only one) stable, bodily and well-defined experience of him/herself as a person, and that the person has a clear and automatic first-person perspective (Nelson, Raballo, 2015, Henriksen, Nordgaard, 2014).

However, in severe mental illness and especially schizophrenia, this experience may be changed. Changes to the sense of self, as that term is used today, refers to “*several structural shifts in such a basic selfhood (e.g. unstable first person perspective, diminished sense of presence, and loss of vital contact with reality)*” (Nelson, Raballo, 2015, p. 301).

For people who are vulnerable to schizophrenia or have developed schizophrenia, such changes in the sense of self may be expressed in different ways. Examples of this may be an unstable first-person perspective (talking about oneself in the third person), fuzzy or distorted perception of one’s own self, marked changes in thought flows and cognition, and/or lack of contact with reality. (Nelson, et al. 2013, Henriksen, Nordgaard, 2014, Parnas et al, 2005).

Changes to sense of self have also been associated with altered or impaired ability to metacognition and to social cognition (Lysaker et al, 2014, Borgenquast, Schweitzer, 2014). Studies have shown that therapy focusing on increasing patients' capacity for personal and social metacognition can give positive results (Borgenquast, Schweitzer, 2014).

Parnas, Jansson (2015) argues that changes in the sense of self must be regarded as a core symptom of schizophrenia, since it is more specific than other symptoms. Hallucinations, blunting of feelings and other things can occur with other disorders, while changes in the basic sense of self is typical of, and specific to, schizophrenia, and distinguishes it from other conditions (Parnas, Jansson, 2015)

### **What characterizes anomalous self-experience?**

Anomalous self-experience is a term which refers to various forms of fundamentally changed or impaired sense of self, of a type characteristic of schizophrenia. EASE (Examination of Anomalous Self-Experience, Parnas et al 2005) is a semi-structured, symptom-based checklist for exploring subjectively experienced changes in the basic sense of self. This instrument is often also used as a summary of what the change to the sense of self may imply. Because these changes are so fundamentally connected to how the world is perceived, and affect such fundamental aspects of perception and sense of self, the experience of changes will often be fluid and diffuse, and it may be hard to find words to describe what happens. EASE tries to facilitate expression of such experiences by presenting a variety of statements describing the altered sense of self. All these statements are based on statements from patients describing their own experiences. Each statement is read to the patient, who is then asked to assess the degree to which this statement applies to him/her. EASE is based on exploring the patient's own subjective experiences of changes, not on objective observable measurements done by others (e.g. clinicians or researchers). In addition to its diagnostic usefulness, EASE is also intended as a tool to help the patient describe and articulate his/her own experiences and to share these with clinicians. As mentioned above, EASE is also a tool to help clinicians and researchers label, categorize and obtain an overview of different kinds of changes in the basic sense of self.

EASE explores the altered sense of self within five different domains. These five domains and the description these are often used as a definition and conceptualization of what the changes in the basic sense of self may imply. It is therefore useful to briefly outline these domains here as an overview of anomalous self-experience, even if EASE is not used in this study. Each domain contains very many different experiences and subtypes, and only a brief and incomplete overview is provided here.

### *Cognition and Stream of Consciousness*

Normal consciousness should be fluent, consistent over time, perceived as being owned by a person, and be non-spatial (Parnas et al 2005). Experienced changes in this area may involve thought blocking, thought chaos, ambivalence, difficulty expressing thoughts in language, difficulty with short-term memory and/or attention, and an experience of the thoughts having spatial qualities (e.g. thoughts that are assembled in a pile or stuck on one side of the head) (Parnas et al 2005).

### *Self-awareness and presence*

A healthy sense of self should be automatic and unreflective. A person does not think about whether he/she exists or not, or ponders their own existence. This automatic sense of self consists of two parts: 1) An automatic and unreflective sense of self, including a first-person perspective and 2) an automatic and unreflective participation in social contexts. Changes within this domain may include an altered or disturbed first-person perspective, a sense of not existing, not belonging in this world, being a different person, or several people, or not having your own core. Other experiences may include not being influenced by things going on around you, or being affected too much, that the world is perceived as fundamentally different or unreal, or not knowing whether what is happening is happening to you or someone else (Parnas et al 2005).

### *Bodily experiences*

A normal body experience means that body and psyche are perceived as a natural entity, and the body is experienced "from within", as one self. The body is not perceived solely as an object (something you have), or solely as a subject (what you are), but a combination of these. Changes within this domain may imply that the body is perceived as changed, foreign or different. Parts of the body (e.g. the face) may look different in the mirror, or all or part of the body may be perceived as dead, altered, distorted or alien. A person may also experience altered kinaesthetic sensations or altered motor functions (Parnas et al 2005).

### *Demarcation/transitivism*

This domain is closely related to domain 2, sense awareness, but is distinguished as a separate domain, due to somewhat different symptomatology. A normal sense of self



involves clear boundaries between self and others, and a clear understanding of where the self ends and others begin. Changes within this domain can include body contact being perceived as very intimidating, a person feeling thin skinned or having no boundaries, a confusion of who oneself is and who others are, or becoming confused by when seeing oneself in a mirror due to not knowing who or where you are (Parnas et al 2005).

### *Existential reorientation*

This domain describes fundamental changes in, and reorientation of, the person's view of the world and his/her surroundings. Such changes may, for example, involve the person feeling unique, having unique or special abilities, being the only person in the world or the only real person, or having very special tasks. It may also include a feeling that the world does not really exist or is real, grandiosity, or magical ideas (Parnas et al 2005).

### **Sense of self and personality disorders**

As mentioned, basic anomalies of sense of self are considered characteristic of, and specific to, schizophrenia. Research has also been carried out on disturbances of sense of self in personality disorders, especially Borderline Personality Disorder (BPD). Disturbances of sense of self associated with these conditions is not as basic as with schizophrenia, and does not affect the thought processes or first-person perspective in the same way, but rather consists of a limited and unstable sense of self (Nelson et al 2013, Beeney et al 2016). Just as in schizophrenia, representations of others may also be affected, but again on a less fundamental level. In the case of BPD, this frequently appears as shifts between polarized perceptions of others as unambiguously positive or negative (Nelson et al, 2013, Beeney et al 2016). No correlation has been found between anomalies of basic sense of self (measured with EASE) and BPD, suggesting that although both conditions involve disturbances of sense of self, the disturbances involved are different (Nelson et al, 2013). The different types of disturbances of sense of self are however not mutually exclusive and can therefore occur in the same patient (Nelson et al, 2013).

Sense of self can also be affected by other types of personality disorders, such as narcissistic personality disorder (Lambert et al, 2014, Krizan, Johar 2015). However, these are often even less fundamental disorders, which generally only affect some specific aspects of the sense of self.

## **Severe mental illness and childhood trauma**

As mentioned above, there are most likely many different causes of severe mental illness. For schizophrenia, the origins are probably compound, and might include both biological and psychosocial factors (Fosse, 2009, Read et al, 2014, Zipursky et al, 2012). Much research has been done over recent years on the relationship between developmental trauma and severe mental illness, especially on psychosis and BPD (Cotter et al., 2015, Varese et al., 2012, Moskowitz et.al. (ed), 2008, Read et al., 2006). As childhood trauma is usually considered as a loss of one or both parents (or other primary caregiver) during childhood, neglect, and/or physical, sexual or psychological abuse.

Trauma outside the home can also cause severe damage. Leraya et al (2015) found that adults who had been bullied by peers had a greater chance of developing mental health problems in adulthood than adults who had been abused by parents (Leraya et al., 2015)

Varese et al. (2012) carried out a meta-analysis of 36 different studies, with three different designs, and found that the risk of developing a psychosis increased significantly if the person had experienced one or more developmental traumas. This tendency was stable, regardless of the study design. Other meta-analyses (Read et al. 2006, Skehan et al, 2012) have shown similar results. It also seems that there may be a dose/response relationship between trauma and the severity of subsequent symptoms (Read et al, 2013 Skehan et al., 2012). People who have experienced physical and sexual abuse, have earlier longer and more frequent admissions to psychiatric hospitals, have a greater risk of suicide, and generally have more severe symptoms.

There has also been some research on the relationship between specific developmental trauma and specific psychotic symptoms (Bentall et al, 2014). They found a possible link between aberrant communication of parents and thought disorders in the child, between sexual abuse and verbal hallucinations and between attachment disorders (neglect, growing up in an institution) and paranoia. These results must however be considered as preliminary, and more research will be needed to confirm whether they are valid (Bentall et al, 2014).

In addition to developmental trauma, other social and contextual factors, such as poverty, social inequality and/or belonging to an ethnic minority may increase the risk of developing both psychosis and other severe mental illnesses (Read et al, 2013, Read, 2010)

Despite these clear relationships between experienced developmental trauma and subsequent severe mental illness, there is still significant shortcomings in health professionals' focus on asking patients, especially psychotic patients, about childhood trauma, and also referring to relevant trauma treatment (Ormhaug et al., 2012, Sampson, Read, 2016).

Within child psychiatry, there is an increasing focus on trauma-informed treatment for children who have experienced various types of trauma. Historically there has been a tendency to treat behavioural problems in children by focusing on symptoms and disruptive behaviour. However, newer approaches are aimed more at repairing the trauma (Bath, 2008, 2015, Siegel, 2012, Hagen et al, 2016). This treatment is particularly focused on helping the child develop strategies for coping, relieving anxiety, and gradually increasing the child's capacity to build relationships. Helping the child regulate emotions and activation is central to this work, and to keep the child within his/her tolerance window, in which activation is neither too high or too low (Siegel, 2012).

Play seems to be particularly important to children who have experienced trauma, and is probably necessary for the brain to heal after trauma (Perroni, 2014; Panksepp & Biven, 2012). *Play-based activities are probably also important to adults* (Siegel, 2012, Perroni, 2014; Panksepp & Biven, 2012).

However, trauma informed treatment presupposes that the trauma is known. This is not always the case. Ormhaug et al. (2012) found that even though a large proportion of children who were referred for treatment in a child and adolescent psychiatric outpatient clinic had experienced trauma, this was rarely mentioned in the referral. It is, therefore, particularly important that the health professionals actively asks about traumatic experiences as a routine part of the assessment, both for children and adults (Ormhaug et al., 2012, Sampson, Read, 2016)

## **2.3 Developmental psychology and normal self-development**

As the sense of self seems to be, in various ways, an important part of the problems both for people with schizophrenia and personality disorders (particularly BPD), and associations have been identified between developmental trauma and severe mental illness, it is relevant to look at what factors are believed to affect normal development of sense of self. Which factors that are considered most important will of course vary between the different theories, and it is not possible to go through all developmental theories in this thesis. I have, therefore, chosen to focus on factors that are considered central in several different theories, and which are also perceived as relevant to this study.

### **Fundamental/primary relationships**

The importance of fundamental or primary relationships are crucial to most theories regarding psychological development.

Winnicott is known for the classic statement that "there is no such thing as an infant, only an infant and a mother" (Winnicott, 1969, in Winnicott, 1971), and it shows how much importance he attributes to the relationship between child and caregiver. One of Winnicott's key concepts is *mirroring* (Winnicott, 1971). Winnicott says that when the child looks at his/her mother's face, the child sees him/herself. At the same time, the mother looks at the child, and her facial expression is related to what she sees in the child (Winnicott, 1971). When the baby smiles at the mother, and she smiles back, the child receives a confirmation of who she/he is, an acknowledgement that may eventually develop into a notion of being wanted and accepted. According to Winnicott's theories, it is important that the child is reflected and accepted in many different emotional expressions. If a child believes that s/he is only accepted when s/he is happy, or only when s/he is sad, this may provide guidelines for what the child later experiences, and which emotions she/he feels is allowed to express in relationships with others. According to Winnicott, mirroring is critical to a safe self-development, along with other factors such as *holding* (see the section below on joy and quality of life). Although Winnicott does not directly use the term sense of self, his descriptions of a confident self-experience are largely in agreement with the description of what constitutes a normal sense of self, with an acceptance of feelings and a natural integration of the first-person perspective.

According to Winnicott, if the basic conditions, including holding and mirroring, have been poor, or the child has experienced too much deceit, the sense of self will be weakened, and the child and youth will experience a lack a sense of continuity and coherence in life (Winnicott, 1971, Winnicott, 1986). This is reminiscent of the descriptions of the changes to the basic sense of self that are described in EASE, and is in agreement with the findings describing the association between childhood trauma and subsequent severe mental illness. This and subsequent theories do not only provide descriptions of what might be missing from the patient's childhood. It also suggests which factors that may be important to give the person a possibility to develop a more confident sense of self, for example, through a confident relationship with a contact person or therapist.

In his object relations theory, Fairbairn (1952) describes how negative experiences from childhood can affect patterns later in life (Fairbairn, 1952). According to Fairbairn's theories, the child is fundamentally primed to interact with the environment. If the child is well received by the parents in a supportive interaction, s/he will develop good inner representations of others. These representations may later be transferred to other people, with the child expecting that s/he will be received in a satisfactory manner by other people. If, however, the child is rejected, or subjected to violence or neglect, s/he will not develop such confident inner representations. Since the child is naturally focused on, and needs, interaction, s/he will nevertheless do whatever it takes to maintain interaction, even when this is destructive. According to Fairbairn, this can lead to the child choosing to separate the evil and the good aspects of their parents. The good aspects are retained, and the evil aspects are either overlooked or attributed to the child, who then thinks that the parents are good and that the child is evil and deserves the abuse. According to Fairbairn, this pattern could continue into future relationships, and might explain how children who have experienced abuse at home choose spouses (and other significant relations) that also mistreat them, because they feel more confident in such relationships. Good, safe relationships may paradoxically feel more unsafe, both because they are alien and because they challenge the fundamental organization that the child needed to survive her/his childhood.

Stern (1985) describes a developmental model for self-perception, in which different aspects of relations and interactions are essential in the various phases. He provides an approximate

age for when a type of self-perception starts, and at what age this is particularly relevant. The model is not, however, a phase model, and Stern assumes that development within the various areas continues and is adjusted throughout life. This is interesting in relation to this study, because it gives information about the types of relationships that may be relevant to affecting different parts of self-development and self-perception, also in adults.

According to Stern (1985), the first form of self-experience, the emergent self, begins in the first weeks of the infant's life. This self is primarily sentient and coordinates impressions from various sense modalities into meaningful patterns, e.g. so that they can recognize the mother based on voice, face recognition and smell. Here too we see parallels with the immediate and sensing self, which is described as a normal or undamaged sense of self.

The next form of self-perception occurs when the child is 2-3 months old, and Stern calls this *the core self* (Stern, 1985). Stern describes this as a physical self-perception, where non-verbal meaning and context are based on bodily experiences. The child feels that s/he can be an active part and make things happen. S/he begins to distinguish between behaviour s/he initiates and behaviour initiated by others. This distinction between *I* and *you* are fundamental to a normal sense of self. Damage to this experience can result in insecurity as to who owns the person's own thoughts, who controls the person's own actions, etc. - descriptions that are typical examples of anomalous self-perception, as described in EASE.

From about the age of 6 month, the development of a *subjective self* begins, according to Stern (1985). This immediate subjectivity is described as central to a normal sense of self. The child now has better motor control and experiences her/his own will and intention as well as the ability to focused attention. The child now realises that s/he can share his/her own experiences with others (reach for a toy, push away food), and also share the experiences of others, (look in the direction someone is pointing). Interaction is still non-verbal, and consists of the caregiver tuning into the child's experiences and reflecting these back. According to Stern (1985), if some emotions are tuned in by the caregiver and others are not, this will lead to selective tuning, giving the child a perception of which feelings can be shared with others, and which cannot be shared.

At 12-18 months, the child develops a *verbal self-perception* (Stern, 1985). The child has already experienced non-verbal interaction and communication, now the words are added, providing new opportunities to share experiences. Stern makes it clear that language skills

are not solely positive, but entails a duality. On the one hand, language provides new and better opportunities for communication and the sharing of experience, and a greater closeness to other people. On the other hand, language has limitations for conveying the immediate and the experienced, and entails the possibility of alienation from the immediate experience. Stern distinguishes between "experience that is lived" and "experience that is told," and says that language can be used to distort experiences, which may eventually lead to psychopathological development (Stern, 1985).

From when the child is approximately three years old, the final area of the self, *the narrative self* (Stern, 1985) begins to develop. This includes the ability to form narrative stories about oneself and one's situation, and to put individual experiences into a shared context. The child is an active participant in this process of creating stories about his/herself and others. But stories always occur in a social context, where the interaction with others affects the narrative that is formed (Stern 1985).

### **Social community and reciprocity**

In the child's first weeks and months, the ties between the child and the primary caregiver are the most important. However, as the child grows, and later, when we are adults, it becomes increasingly important to participate in various social contexts, including contexts that requires mutual cooperation between individuals. This mutual interaction is central to what Bronfenbrenner describes as the *proximal processes* (Bronfenbrenner, 2005), which he considers to be the driving force behind all development (more on this below). The same reciprocity is also an important part of several of the various types of self-perception in Stern's model of development. According to Stern, from the age of six months, with the development of the subjective self (Stern 1985), the child is not only focused on being mirrored, but also on mutual cooperation and on sharing experiences and feelings (pointing, showing toys, etc.). The importance of reciprocity and interaction is then further strengthened when the child/person develops first a verbal self and later a narrative self. This development makes it possible to use language and stories to share experiences and information, and also to construct a social and personal reality (Stern 1985). This provides new opportunities, but it can also be limiting, depending on the qualities of the social context. If the qualities of the social contexts are too limited, the developing person might

develop a narrative self that is not consistent with his/her fundamental, sentient self (Stern 1985).

### **Context and coherence**

Just as it is not possible to look at the child without considering the relationship between the mother (caregiver) and the child (Winnicott, 1969, in Winnicott, 1971), it is not possible to focus on the individual relationship between the child and caregiver without considering the social context in which this relationship exists. This is true for parents and children, and also for the relation between patients and health care providers, and between students and teachers. The focus for this study is to explore how different environments, including the norms and social roles in these environments, may affect the patients' and students' development. The exploration of social roles in different social structures and systems are also the focus in Bronfenbrenner's (1979) ecological model. He states that the child (or adult) is an active participant in various environments, and that all relationships exist in different environments, which in turn are linked to each other.

Bronfenbrenner (1979) defines four different types of such environments or systems. The first of these environments is the micro system, and this system is the one that deals, to the greatest degree with primary or basic relationships. Bronfenbrenner (1979) defines the micro system as a pattern of activities, social roles and interpersonal relationships. This specific pattern is experienced in a given environment, and it is the combination of activities, relations, and roles, in that given environment, that constitutes the microsystem.

(Bronfenbrenner, 1979). This environment is a system in which people have direct contact with each other, a system the child is a part of and which includes activities, symbols and roles. As in the other theories, relationships are considered as utterly important, and the micro system involves dyads, e.g. the mother/child dyad, where people have a mutual and lasting relationship (Bronfenbrenner, 1979).

Proximal processes might be an important part of a micro system. As mentioned above, Bronfenbrenner (2005) describes proximal processes as the driving force behind development. A proximal process is characterized as an event that occurs regularly over a period of time, involving several people, e.g. a dyadic relationship, and that this relationship



is reciprocal. Given these conditions, the activity can be developed over time and become increasingly complex.

The second system Bronfenbrenner describes is the mesosystem. A mesosystem consists of the relationship between two or more environments in which the person is an active participant. (Bronfenbrenner, 1979). For children, this may be the home and school, or home and friends. For adult patients, this may be different treatment providers, or the connection between the inpatient ward and the home environment. The connection between the two systems may be the child's participation in both environments, but there may also be other connections, for instance the teacher and parents might have contact with each other, or, for the adult patient, various treatment providers can cooperate in the treatment of the patient.

The third system, the ecosystem, consists of two or more environments where the child (or adult) is *not* a participant in all the environments, but is nevertheless affected by decisions taken in the environments in which the child does not participate (Bronfenbrenner, 1979). For a child, this may include factors in the parents' workplace, or in the parents' network. For adult patients, this can include social norms at the hospital s/he receive her/his treatment, or the standards of the education the therapist has received. This effect may also be mutual. The child, or adult, is not only affected by factors in the ecosystem, but may also affect the environment s/he is not a part of, by her/his relation to people that are part of the ecosystem (Bronfenbrenner, 1979). For instance, a relation between a therapist and a specific patient might in turn affect or change standards and norms for all the staff at the hospital, including staff the patient never met.

The fourth system is the macro-system (Bronfenbrenner, 1979). This is the overarching system, which defines roles (e.g. the role of the "child", "patient" or "student") and defines the guidelines for organization of activities and interactions. The macro-system consists of cultural and political guidelines, which form the framework for specific actions and interactions. However, also this system is based on reciprocity. The culture not only affects the participants in the system, but is also created by the participants. Roles such as "patient" and "therapist", "student" and "teacher" are defined in our community, and have specific expectations and norms. However, these social roles are also shaped by the persons filling the roles, and are in a continuous development over time.

## **Time**

Time is a key element in several of the descriptions of primary and social relations, emphasizing that stability over time is necessary to developing a good and safe relationship.

Time is also a fundamental element in all development, since all development requires descriptions of changes over time. As mentioned above, Bronfenbrenner (2005) considers time as a key element in the proximal processes, in combination with interaction and reciprocity. It is only when an activity is repeated regularly, with a certain frequency and over a certain period, that development can be expected. This repetition, within the same safe system or relationship, gives the person(s) the opportunity to gradually develop the activity and skill and to make the activity more complex and complicated over time.

We find similar arguments in the Stern's (1985) model of development. Development is always a process that takes place over time, and it is time, interacting with other factors, such as a safe and supportive environment, that enables the development of greater skills and more complex actions. However, time is a limited resource in healthcare, and newer psychiatric treatments often focus on short term interventions. Where patients were previously hospitalized for a very long time, admissions now are much shorter. Although there may be many advantages to this, also for the patients, it is still necessary to remember that time, in combination with other factors (such as stable relations), are fundamental for all development.

## **Care, creativity and activity**

As mentioned above, *holding* is one of Winnicott's central concepts (1971), along with mirroring. The term holding can be understood quite concrete, as the parent holding the child, but also include all forms for empathetic and individually adapted care. The parents should provide a safe and adapted routine in which the child receives food, sleep and individually adapted care. Adaptation is a key concept here, as it is essential that the care takes into account the child's immediate needs, and is not primarily based on the adults' needs or desires (Winnicott, 1971).

Just as Stern (1985) emphasizes the perceptive self in infants, Winnicott says that the infant's identity in this first period is related to the body, and that the physical bodily care is affirmative and strengthens identity. If the child receives good enough (not perfect, but good

enough) care in this period, s/he will achieve a basic sense of "being" (Winnicott, 1971, 1984). This focus on everyday conditions (food, sleep, safety, adapted routines) is also very important for adults, and should be specifically emphasised in work with patients with illnesses of such severity that they cannot always manage to ensure such routines themselves.

Play and activities are also central to Winnicott's theories (1971, 1986), and are closely related to the subjective experience: *It is in playing, and only in playing, that the individual child or adult is able to be creative and to use the whole personality, and it is only in being creative that the individual discovers the self.* (Winnicott, 1971, p. 573) Winnicott argues that if the child's relations have been sufficiently good and safe, the child - and later the adult - could use play and play-based activities (for adults, this will often involve various cultural, artistic or creative activities, which Winnicott equates with play) to create their own representations of reality. These activities create a *potential space* in which we relate to facts, but also ascribe different meaning and content to these facts. We can think about it in different ways and deal with them flexibly. This playful approach allows us to find new solutions or to look at our own experiences in new ways (Winnicott, 1971). Winnicott also claims that this playfulness and flexibility is necessary to overcome trauma and loss, and to process them flexibly (Winnicott, 1971, 1986). This views are similar to those of newer trauma theories (Perroni, 2014; Panksepp & Biven, 2012), that also state the importance of different forms of play and creativity to overcome trauma. This is also supported by research which shows that creative forms of therapy, such as music therapy (Solli et al. 2013) and art therapy (Thompson, 2016) may be useful approaches for adult patients, including patients with severe mental disorders. Patients reports that these kinds of creative treatments give them both reduced symptoms and better self-perception (Solli et al., 2013, Thompson, 2016), which corresponds well with Winnicott's theories on the association between play/creativity and self-perception (Winnicott, 1971, 1986).

Stern's (1985) and Bronfenbrenner's (1979) theories also emphasize activity and creativity. However, these theories do not solely emphasize the importance of the activity itself, but also the importance of sharing activities with others. As the child grows up (and for adults), an important part of self-development is based on the sharing of activities. It is important that someone is genuinely interested in what the child (the adults) is occupied with, and that

activities can be shared in reciprocal fellowships. For adult patients, this may include the ability to use various creative expressive methods in therapy (art therapy, music therapy). But it may also include that someone is interested in whatever the patient is occupied with, especially interest that goes beyond symptoms and illness. This correspond well with the statement from patients, telling that they miss that someone is interested in them, as persons, and not only in their diagnosis.

## ***2.4 Health, recovery and empowerment***

If talking about improvement is to make sense, we must first define what is meant by health, and also gain an understanding of the different types of recovery. I will therefore briefly go through this here, specifically focusing on mental health. Empowerment is not directly related to health and recovery processes, but has been a central concept in the mental health field in recent years. The term is much used as personal recovery to describe a process where the patient is an active participant and defines his/her improvement and development. It is, therefore, appropriate to briefly review this term here.

### **Health**

WHO defines health as "a state of complete physical, mental and social wellbeing and not merely the absence of illness and afflictions." (WHO, 1946). This is a rather extreme definition of health, and it will in practice be unrealistic for many people, including people who work and believe themselves to be healthy. WHO has since issued a different definition of health, i.e. health is "the ability to live an economically and socially productive life" (WHO, 1970). However, this has not been so widely recognized or used.

There are other definitions of health. Lie (1996) emphasizes the ability to meet everyday demands as being central to health. Antonovsky (1979) describes a sense of coherence and meaning, which provides the person with the ability to cope with and recover from severe psychological stress and to prevent post-traumatic injuries (Antonovsky, 1979). These descriptions are clearly more realistic, and emphasize the fact that health does not only affect the individual, but just as much interactions between the individual and society. This is particularly evident in Lie's definition (Lie 1996), which states that a person can improve their health in two ways - either by improving the ability to implement the requirements

(through training, treatment or simply over time), or by changing the requirements in the everyday life.

This approach, with health as an interplay between the individual and society, is continued by Huber et al (2011). They review different definitions of physical, mental and social health, criticize WHO's definition, and suggest as conclusion the following new definition: "health [is] the ability to adapt and to self manage" (Huber et al, 2011). They also assume that health occurs in the interaction between individuals and society, but this definition emphasizes that the individual's ability to adapt is central, and reciprocity is thus absent.

However, many of these definitions solely emphasize on function as a measure of health. Although this is of course relevant, it is also relevant to consider the individual's subjective experience, as well as more objective health measurements. It is entirely possible to function in the society while subjectively experiencing pain, and it is also possible to function while suffering severe and/or life-threatening undiagnosed illnesses (e.g. cancer or severe hypertension).

In everyday life, we often think of health and illness as extremes on the same continuum. You can have good health or impaired health before passing over a threshold into illness, and possibly becoming sicker and very sick. And of course, the process can also go the opposite way, from illness to health. However, it has also been argued that health and illness are not extremes on the same continuum, but rather represent two different continuums (Keyes, 2007). According to this model, a person may have good or impaired mental health (measured using, for example, factors such as perceived meaning, personal development and context, interests, friends/network, participation in/contribution to society (Keyes, 2007)). Regardless of one's health, the same person may have or not have diagnosable symptoms of illness (Keyes, 2007). Take, for example, a person with poor mental health (recently divorced, limited network, not following up interests, experiencing stagnation, hopelessness and loss of interest), but cannot (currently) be diagnosed with clinical depression or another mental illness. Conversely, imagine a person with clear symptoms of mental illness (hearing voices, with limited delusions, increased fatigue), but simultaneously enjoys good mental health, (has friends, enjoys personal development, actively participates in his/her interests and volunteer work, takes assignments as an experience consultant and generally perceives the meaning and context of life). Although this distinction may provide

good clinical meaning, it is important to point out that factors do, of course, affect each other - if a person lives, over time, in a situation involving very poor mental health, there is a risk of becoming ill; and vice versa, an ill person with good quality of life and good mental health may, over time, become less ill.

## **Recovery**

Recovery is about the individual's improvement processes and has often been used recently for people recovering from severe mental illness.

Recovery is a personal process and it is important to distinguish this from treatment and rehabilitation, or other processes controlled by clinicians and healthcare. Recovery usually describes an internal process. But similarly to the distinction between mental health as a subjective and personal experience and mental illness as a diagnosable phenomenon (Keyes, 2007), we can distinguish between clinical and personal recovery (Slade, 2009).

Clinical recovery means an outcome which is observable to others, assessed by an expert, and where the definition of recovery is the same for different patients (Slade, 2009). Such a definition might for example be that the person has previously received a credible diagnosis (of schizophrenia), but does not now meet the diagnostic criteria, has not been admitted for five years, enjoys normal psychosocial functioning (GAF over 65) and uses little or no psychotropic drugs (Torgalsbøen, 1999).

Personal recovery is, however, a subjectively experienced state, defined by the individual him/herself. It is a constantly evolving process, not a definitive result, and progress is not linear. It is a personal process during which one changes as a person, and which involves changes in values, goals, attitudes, emotion, habits and skills (Anthony, 1993). This process *may* involve less symptoms and increased psychosocial functioning, but it *must* not mean that. It may also mean living with the limitations the illness imposes, but in a way that gives more meaning and hope, and better relationships with both yourself and other people (Anthony 1993, Slade 2009). Personal recovery can be achieved in various ways, but will always require individual solutions, action by the person, and a personal and subjective assessment of whether recovery has been achieved.

Even though recovery and recovery-based treatment has been driven by user movements, some critical voices have been heard in recent years. Some users believe that the one-sided focus on good results can be stressful for those who do not achieve clinical recovery. Others argue that recovery, as it is often used in clinical practice, is another new, patriarchal measurement that focuses more on clinical recovery than on personal experience, and which ignores social and societal factors, powerlessness and stigmatization. (Recovery in the bin, website.)

Neale et al. (2015) had four different groups of people with experience of current and past drug use to evaluate 76 different measurements of recovery from addiction. The measurements were developed by experienced treatment providers. All of the measurements were rejected by the people with personal experience of drug abuse, for a number of different reasons (Neale et al., 2015). The conclusion was that users with personal experience considered recovery a personal development and an internal process, and found that the externally observed, clinically assessed measurements did not capture the complexity and paradoxes of either substance abuse or the improvement process.

The distinction between clinical and personal recovery is the most common. But social recovery has also been used as a concept and, as mentioned above, the social aspect of recovery is the most important for many users. Social recovery is about how an individual's surroundings can hinder or promote individual improvement processes, which Glover (2005) calls recovery-nutritious surroundings. It is important to distinguish this from the treatment. Recovery is always an active and personal process, initiated and driven by the person him/herself. But the context in which the individual lives can promote or hinder this process. This can be about the individual's immediate surroundings (friends, colleagues, family, etc.) and the social structures that surround the person (e.g. social differences, subsidies, norms and culture). Social recovery is closely linked to personal recovery, and they are often mentioned together. But there is, generally, less research on this than on structural empowerment. The importance of social factors on recovery are however known. People who have experienced recovery often highlight the social and practical aspects as very important to their recovery process; often more important than traditional treatment (Topor et al, 2011, Topor, 2004). The same applies to economic factors (Ljungqvist et al, 2015, Topor et al, 2014), work (Borg et al, 2013) and other factors (Topor et al, 2011, Topor, 2004). This is

also related to research mentioned on poverty, stigmatisation and social inequality as risk factors in the development of severe mental illness.

Relationships with treatment providers (Ljungberg et al, 2015 Topor et al, 2015) and others (Topor, 2004) seem to be very important. Slade (2009) distinguishes between three major types of relationships: True relationships, partnerships and distant relationships. A true relationship is a relationship that is personal and genuine, in which both parties can express who they really are, and also see the other as the person he/she is. This type of relationship is general, and is generally found in private relationships, outside psychiatry and the public health service. A professional relationship will always involve some inequality, health professionals will always have more responsibility than the patient, and patients will not be expected to always see the other person for who he/she really is.

At the other end of the scale, we find distant relationships. These are common in psychiatry and are contextual and influenced by therapeutic interventions and models (Slade, 2009). The treatment provider's view of the patient is coloured by the therapeutic model used by the health worker, interpretations of the patient's statements and behaviour are affected by the therapeutic model, and interventions are based on the model's recommendations. Slade (2009) points out that this is a common model in psychiatry, and that while it may work in some cases, the unequal distribution of power makes real development and recovery difficult to achieve. As this model implies that the health worker knows best what interventions the other needs, it will also be difficult to achieve the immediate, personal experience of "I am, I sense, I know what is good for me", precisely because the model stipulates that it is someone else who knows what the patient needs.

Slade (2009) points out that the different models are on a continuum, and that the division of power will vary, even within a specific relationship. He therefore considers all three types of relationships as legitimate, but simultaneously highlights the partnership model which is best suited to recovery-oriented practices. As the name implies, this relationship type is based on cooperation and partnership, in which the health worker and patient work together. The health worker has more responsibility, and does not require the patient to pay as much attention as in a real relationship, while both parties recognize each other as partners, and the health worker accepts that the patient can define his/her own needs and interests. The problems are described in the patient's language, not professional



terminology, and the goal is more personal development than symptom reduction (Slade, 2009).

## **Empowerment**

Empowerment is a key concept in social psychology (Orford, 2008), and has, in recent years, been increasingly used also in clinical psychology. The concept is partly developed by user movements in collaboration with clinicians and health policy makers, and it has been central in the development of laws and practices that put more emphasis on user participation, both at individual and system levels. The intention is to change the hierarchical system which has historically been general in psychiatry, and to replace it with a system that gives more influence and responsibility to the individual patient.

Empowerment is, however, a very complex and complicated concept that has been interpreted and defined in several different ways (Rappaport, 1987, Zimmerman, 1995, Gutierrez, 1990, Scriven & Stiddard 2003, Orford, 2008), and which has been used in a variety of contexts in recent decades. Traynor (2003) sees a basis for the empowerment mindset in the UN Declaration (1948), the first article of which says that "all human beings are born free and equal in dignity and rights" (UN 1948). However, this can only be interpreted as a forerunner of the thinking from which the empowerment concept arose. In the United States and Europe, empowerment was not in common use until the 1980s, as a reaction to the increased trend toward medicalisation and individual approaches (Jacobs, 2010). Even earlier, empowerment and related concepts and understanding models were used in Latin America, particularly in relation to social psychology (Freire, 1970).

However, the definitions of empowerment vary a lot. Rappaport (1987) defined empowerment as "a process, a mechanism by which people, organisations and communities gain mastery over their life" (Rappaport, 1987). We see that Rappaport defines empowerment as both something that concerns individuals but which may also concern a group or a society. Empowerment can thus exist at several levels (individuals, groups, communities), and this clarification is consistent to most commonly used definitions of empowerment (Rappaport 1987, Zimmerman, 1995, Gutierrez 1990, Scriven & Stiddard 2003, Orford 2008).

We can, at each of these levels (individual, group, community), again distinguish between various forms of empowerment. Rappaport describes empowerment as both “a psychological sense of personal control or influence and a concern with actual social influence, political power, and legal rights.” (Rappaport, 1987) In this, Rappaport differentiates between the psychological experience of having control, and the actual influence of a person or group. He believes that the empowerment concept includes both of these elements.

A distinction is often made between structural empowerment, which deals with the actual balance of power, and psychological empowerment (Zimmerman, 1995). In his definition of psychological empowerment, Zimmermann (1995) emphasizes the perception of having control, an active attitude to life and a reflective understanding of the environment in which the person participates. For Zimmerman, psychological empowerment mainly relates to the individual, and he specifies other processes relevant to an organizational level. He also says that these processes cannot be clearly distinguished from each other and focusing on the individual's own experience does not mean that we can ignore the importance of socio-political and contextual factors. According to Zimmerman, psychological empowerment will consist of various components. An intra personal component, an interactional component and a behavioural component. (Zimmerman, 1995). Other researchers have also emphasized various personal and psychological factors, (self-efficacy, personal responsibility for change and other ways of thinking, feeling and acting) as central to empowerment (Gutierrez, 1990, Ozer, E. & Bandura, A., 1990).

Gutierrez (1990) defines empowerment as a process that increases individual, interpersonal and/or political power, so that individuals can take the initiative to change (improve) their living conditions. This definition also accommodates, therefore, the subjective and personal aspects of empowerment, and awareness of the importance of real, internal personnel and/or political power.

Even though Zimmerman stresses that psychological empowerment cannot be understood without taking into account the context in which the individual lives, the concept of psychological empowerment has been criticized for individualizing social conditions and placing the responsibility for the unfortunate circumstances on the individual - without taking sufficient account of real power imbalances and social inequalities (Orford 2008).

As with recovery, it may be discussed whether empowerment is a process or a result (Freire, 1970, Anderson & Funnel, 2010, Rissel, 1994 Orford 2008). It is probably both. As a process, empowerment is the development a human, an organization or a society experiences in its efforts to achieve a greater degree of control and influence (Rappaport, 1987).

Empowerment as a result is thus the result of this process. As a concept, empowerment is generally more concerned with solutions and results than causes and problems (Gibson, 1991), and empowerment as a result is thus a consequence of this. Empowerment is also very complex and complicated, and it is impossible to measure this in dichotomies and say that a person is or is not empowered. Given that dynamic, the multidimensional and relational aspects of empowerment will also vary widely in terms of in which context, at what time, and in relation to what situations and relationships, and empowerment as a result may be very difficult to define in practice. The possibility of influence over one's own life is also very relevant to patients in psychiatry, perhaps especially to patients with severe and enduring mental illness, who often feel that others make decisions for them. The emphasis on transferring power is central, but active attitude and subjectivity are also relevant, especially as the first-person perspective of some of these patients may be impaired (Parnas et al, 2005).

### **3 Context of the study: Education and treatment**

The purpose of this study is to explore whether, and if so to what extent, different environmental conditions impact the experience of everyday life, the sense of self and the opportunities for personal and social development of people with long-term and severe mental disorders.

To explore this, I needed informants who received services that had different theoretical foundation. More specifically, I wanted to explore a service based on a medical psychiatric model, and a service based on a non-medical model, but which still provided services adapted to persons with long-term and complex mental health issues.

Based on this background, I chose to interview patients and treatment providers in two Norwegian DPSs (community mental health centres), and students and teachers in two different Danish schools for adults with severe mental disorders. DPS is a very common service for patients with serious mental disorders, and is central to the medical services Norway has for this group of patients. The Danish schools are an example of a comprehensive service, specifically tailored to this group of patients, but where the service is provided within a different framework than the medical.

In the following, I will give a brief description of the various services and what systems they are a part of. The description of the Norwegian health system will be less thorough than the description of the Danish school system, as I assume that the organization of the Norwegian healthcare service is well known, while the Danish school system is probably less known. After describing the different models, I will discuss the delineations to partly similar services. A more thorough discussion of the choice of context, and why I chose these particular locations for data collection, can be found in the methods section, chapter 5.5.

#### ***3.1 The Danish schools***

##### **The folk high school system**

Denmark has a long tradition of folk high schools, and they are an established part of Danish society. The profile and purpose of Danish folk high schools is very different to Norwegian

colleges (høgskoler), and are more similar to Norwegian folk high schools (folkehøgskoler) than Norwegian colleges.

There are approx. 70 ordinary folk high schools in Denmark. All of the schools offer long courses, which students, usually young people, attend for a year. Many schools also offer shorter courses, often one to three weeks, normally during holidays. These courses have many adult participants, both working age and retired, and there are also special courses for families with children. In addition to the short and long courses, there are also medium-term courses of 1-4 months.

The mission of folk high schools is general education and enlightenment. The schooling is organized through the Danish Ministry of Education. The Danish Folk High School Act states that the folk high schools:

*"...provide teaching and companionship in courses, the primary purpose of which is life enlightenment, popular enlightenment and democratic formation. It is approved by the Minister of Education for subsidy. The education must have a broad, general character. Some subjects or groups may play a prominent role, but never at the expense of the general policy." (Act no. 1605 of 26/12/2013 (Applicable)), the Danish Folk School Act).*

According to the Act, the schools are not permitted to hold exams other than preparatory adult education. Students live in the school for the duration of the courses. They eat together, participate in common formal and informal activities, and the social community is an important part of the school offering. The duration, scope and content of the education is carefully regulated by the Folk School Act

The schools receive financial support from the state, and the students pay an additional fee. It is not allowed to withdraw surplus from the schools' operation, and any surplus should be returned to the school.

### **Day folk high schools**

In addition to the ordinary folk schools, there are a number of different day folk high schools.

These were formerly organized under the Ministry of Education and received state aid, but in 2002 the Day Folk High School Act was removed and the operations were transferred to

the municipalities. Today, the day folk high schools are municipal institutions offering education with folk enlightenment or work promoting purposes, adapted to adults.

As mentioned, the general rule (with some exceptions) of the ordinary folk high schools is that students live at the school during the course. In the case of day folk high schools (also called mini colleges), it is most common that students live at home and attend courses during the day. The courses may have a specified, limited duration, or the schools may have a more open offering, where students can participate for a longer period. There are a number of different day folk high schools, with offer services for many different student groups.

Some courses focus more on different disciplines, such as theatre, photography, IT, general studies courses, music, healthcare. Other courses deal with topics such as stress management and depression management, job seeking and résumé writing, or lifestyle/health. Other courses target specific groups, such as people with reading/writing difficulties, ADHD, immigrant women or single mothers.

There is a huge range of different courses. Compared to a Norwegian context, some courses resemble short courses (typically evening classes), others resemble postgraduate education and qualification. Some courses are reminiscent of qualification and job seeking training which, in Norway, is offered through NAV, while others have elements of psycho-education and coping with illness and may correspond to courses provided by Learning and Coping units in the health authorities. However, the day folk high schools offer all of these different course types in the same system, often in the same school.

All of the schools have tuition fees, but the prices vary greatly. In some places, you pay per course, elsewhere for a full-time programme. Depending on the type of course, the course fee may be covered by social services, e.g. students on sick leave or have been unemployed for a long time.

### **The day folk high schools in this study**

The day folk high schools (hereinafter also called schools) also includes schools specifically tailored to adults with mental illness. The services and organization of these schools vary. Some primarily offer stand-alone evening classes; others have an integrated service. Some

offer short courses, focusing on returning to work, for people with depression, sleep problems or burnout. Others have services for people with long-term and severe mental disorders and who need services of a certain duration.

For this study, I interviewed informants from two different schools that offer comprehensive programmes for people with long-term mental disorders. For reasons of confidentiality, I cannot disclose the name of the schools. Both schools have services for youths in a clarifying period, and for adults in retirement (corresponds to Norwegian disability pension).

Youths generally have their course fees covered by social services for a limited period - often six months initially, which may be extended for one to two years. After this period, the students' progress to mainstream school, work, other labour initiatives, etc. Following evaluation, some people are granted early retirement and choose to stay in school as early retirees. Some students initially participated in the youth programme, got an early retirement and choose to stay in school. Some of these may, after some time, return to mainstream education, after having been permitted to spend more time on their development.

Older students on early retirement may attend school as long as they want. The students pay a fee for the education. In one school, a fixed amount is paid per month, which includes as many subjects you want, up to five days a week. In the other school, payment is per subject for one semester at a time.

All students have a mentor or tutor who they can talk to when they wish, about things related to school as well as other subjects. In cooperation with their mentor, students put together a schedule for each semester, evaluate personal goals from the previous semester, and set up new goals for the next semester. These goals may be academic (learning decimal calculus) or personal (attending all classes, making friends, setting boundaries and saying no). If the student want, other teachers may be informed of the goals, so they know how to support the student in achieving the goals.

The schools have a fixed schedule, and each subject is taught at specific times. The students have no fixed classes, but may freely choose subjects from the issued timetable. A number of different subjects are taught, in different categories: sports (e.g. swimming, exercise in the gym, walking groups, zumba, yoga), theoretical subjects (literature, mathematics,

languages, psychology, philosophy, chemistry), subjects relevant to everyday life (e.g. cooking, IT, personal finances, news/social understanding) and arts and crafts (e.g. drawing, ceramics, fusing/glass art, woodcraft, redesign). Several courses also combine various topics, for example, “The Health Line”, which focuses on self-care, healthy cooking and the trialling of various types of physical activity, and “Nature and Environment”, with lessons in science combined with nature walks.

The schools have morning assemblies every morning. The assembly usually begins with communal singing. One of the teachers will then speak about a current topic. This might be information on a school project, or maybe about a news story, an exhibition, a book or a scientific topic (nesting habits of a bird species or how GPS works, etc.). This takes about 10-20 minutes. Information messages are then given before the assembly closes with a song.

Both schools have communal lunches, where hot food may be bought for a reasonable sum. There is also the option to buy breakfast before the morning assembly, or you can buy coffee and eat a packed breakfast.

All education is voluntary. Young students who have their education covered by the municipality make contact via their coordinator. Students on early retirement pensions can contact the school and meet with the principal/education inspector, either alone or with a friend or family member. To gain admission to the school, students must be over 18 and have a mental disorder. A statement from a doctor/psychologist or similar is not necessary, and you do not need to specify your diagnosis. However, to receive early retirement for a mental disorder, the disorder must be severe and have lasted for some time.

If a student is too affected by drugs to participate in the education in a safe manner, s/he will be asked to go home and sleep, and come back the next day. If students are too ill to attend classes for a period, the place will remain open until s/he is prepared to return. In one school, the rule is that students must call/send an SMS before a certain time if they cannot attend that day. If they do that, everything is in order, and they will be expected the next day, regardless of the reason for the absence. If they do not notify the school, the contact teacher will call them or send an SMS to ask how they are and encourage them to come in either that day or the next day. Beyond being missed, the absence has no consequences.



### **3.2 DPS and municipal mental health care in Norway**

District Psychiatric Centres (DPS) are part of the Norwegian specialist health service in mental health care. Besides the decentralized specialized health services in these community mental health centres, their mental health services consist of more specialized hospital wards and psychiatrist/psychologists in private practice. The DPS's bear the primary responsibility to provide treatment in their geographical areas, for both emergencies and referrals. The DPS's also provide advice and guidance to the municipal health services, and serve as a link between the municipalities and the more specialized hospital wards.

The DPS's have outpatient clinics, one or more inpatient wards, and most of them also have different teams, like crisis resolution team, psychosis team, rehabilitation team or ACT/FACT team.

Treatment in a DPS is largely voluntary. Patients are referred to a DPS by a doctor (usually a GP) or psychologist. The referral is processed by the DPS's admissions team and the patient is granted or rejected services after an assessment of the need and expected benefits of treatment. In the event of rejection, the patient is entitled to appeal the decision. A waiting period is normal before the treatment can be initiated. In the event of outpatient treatment, a fee is paid each time, until one has paid an amount that give the right to free services the rest of that year. There is no fee for admission to an inpatient ward.

#### **The offer of DPS inpatient wards in this study**

Two different DPS inpatient wards were included in this study. They were organized under two different hospitals, both part of the South-Eastern Norway Regional Health Authority.

All treatment in the wards was voluntary. The patients were referred in the normal way and it was assessed who got admission and who was rejected. Many of the patients in the target group for this study had been repeatedly admitted to the ward, often over several years. If the referral for admission was rejected, they could then apply again via a GP, and then either be admitted or be rejected again. Some patients had agreements for regular admissions. In one ward, some patients had an agreement about "user-controlled beds". They could then occasionally request admission for a maximum of five days. However, there was a waiting

period for when they could request a new admission after a stay, and limits on how many times per year they could take advantage of such admissions.

The majority of the patients came from home, had been referred by a GP or a therapist, and had waited until they got an admission. Others had been admitted as emergency to a hospital ward and then transferred to the DPS, either immediately or after a short waiting time.

The average length of stay on the wards was approximately 22 days, but in exceptional cases, patients could be there for two to three months. The staff wanted the stays to be short-term. Discharge dates were often determined early in the stay, sometimes before the patient arrived. This was necessary out of consideration for the next patient, who had to be notified in good time of when he/she would get his/her admission.

The treatment in the wards consisted of various components. Most patients were offered medical treatment, in collaboration with a physician. Milieu therapy, including talks with milieu therapy staff, adjustment of circadian rhythms, regular meals, and activities in the unit (e.g. card games, board games or trips outside) was a central part of the schedule at the wards for all patients.

There were also sessions with psycho-education on current topics, such as sleep hygiene and coping with anxiety. These themes were often repeated periodically. The content could therefore be a bit random in the weeks the patient attended, and more or less relevant to the individual patient. Because of the limited length of stay the patients usually only attended just a few such sessions.

Both wards offered individual consultations with a resident psychologist, and possibly also with a social worker and/or psychiatrist, depending on the assessment of the needs, utility and suitability. Some received frequent consultations (1-2 per week), others only at admission and discharge.

One ward offered several different types of groups. Some of these had a clear therapeutic focus, for example. coping groups or discussion groups. Other groups were more practical, such as physical fitness groups or interest groups. The groups generally met once or twice per week. With an average length of three weeks, patients often did not attend very many

group meetings. Some patients also needed some time in the ward to settle down, and usually only managed one or two group meetings during the stay.

Both wards had daily morning meetings, which patients and some of the milieu therapy staff attended. Physicians or psychologists did not attend. Meetings typically provided information about the day, for example, about trips, activities and other issues. Patients were also encouraged to raise issues they wished to discuss, and one of the wards had a round in which each patient was asked to say something about how he/she felt that day, and about any specific plans that day.

Both wards focused on physical activity, through morning exercise and daily and weekly walks. One ward also offered regular relaxation hours, while the other offered yoga and exercise in the gym. Both wards emphasized user participation. Patients were included in the discussion about treatment and treatment plans. In one ward, the treatment plan was made together with the patient. In the other ward the plan was prepared by the staff, and the patient could then comment on it and make suggestions. Although the patient's wishes were taken into consideration, it was the staff who made the final decisions regarding treatment, including duration of stay. If the patient did not follow the ward's programme, e.g. by not participating in communal activities, his/her stay could be shortened, and this could also be taken into account when assessing a referral for a new admission at a later date.

### **Municipal services when patients are not in the ward**

When patients are admitted to the ward, they are supposed to get treatment and support, as required, through a partnership between the specialist health service (usually the outpatient clinic at the DPS) and the municipal mental health care. In formal terms, the specialist health service is responsible for the treatment, while the municipalities are responsible for the general care, including housing. In practice, the distinction between what is treatment and what is care could vary, especially for this patient group, where interaction and practical arrangements are necessary prerequisites for treatment. The various municipalities will have different services and will organize their services differently. As a rule, however, there is a mental health team, offering conversations, support and home visits. Most municipalities and districts also have one or more municipal day centres (see below), with different organization and different services.

As regards housing, the services will vary widely, e.g. in terms of demographics and municipal finances. But most municipalities have different types of housing, with or without varying degrees of support by staff. Other municipal services such as GPs, home visits by nurses, help with household activities, physical therapy and various cultural services may also be appropriate for people with long-term and severe mental disorders. These different types of services would be appropriate for many patients in this study, whether they actively use them or need them without using the service.

### ***3.3 Demarcation in respect to other services***

In my exploration of the possible effects of services based on various settings, I chose, as mentioned, to use informants from Norwegian DPSs and Danish day folk high schools.

As far as I know, there is nothing entirely similar to the Danish folk day high schools in Norway, but there are some services with certain traits that are partly similar. I will describe these briefly below. There are also some partly similar services in other countries, for example, the recovery colleges in the UK and work training and education programmes in other countries. However, I choose to limit myself to services in Norway, and to services that are on the borderline between health care, rehabilitation, treatment, education and employment. Pure treatment services are thus not included in the list, nor is general education available to the general public.

For a critical discussion of my choice of context, see the method section.

Most municipalities have one or more day centres for people with mental disorders. Generally, it is difficult to provide any comprehensive description of the municipal day centres because the services, opening times, organization and target groups vary widely. Some centres primarily offer a meeting place, with coffee and socializing. Other centres offer a variety of activities, including various courses, physical training and cultural offerings

The Norwegian Fontenehusene are part of the international Clubhouse model, which emphasizes work as a method for rehabilitating mental disorders. The staff of the houses work together with house members to ensure the daily operation of the house, and its members work at the Fontenehuset and in internships or study programmes outside the house.

People who receive financial support from NAV will often be offered or ordered to attend various initiatives or courses. The aim of these courses is to assess, and often increase, the working capacity of the individual. The services may have different duration and content. Some offer training, either in a sheltered company or an ordinary internship. Others are courses focused on motivation, writing applications and techniques for succeeding in a job interview.

There are some secondary schools in Norway especially adapted for young people with mental health issues. The target group is young people with mental health issues who are entitled to secondary education, but have difficulties completing the education because of their mental disorders. The schools have regular curricula, examinations and grades, but the teaching is adapted to the target group.

The coping units of the health authorities, specific wards and units, as well as many municipalities, organize various types of *psycho-educational* courses for different patient groups. This is not limited to mental health, but applies to all kinds of illnesses, and includes, for example, heart courses, courses for stroke patients, diabetes courses, etc. An independent life is a common course for people with schizophrenia, the “KID course” for people with depression, the “Sleep School” for people with sleep problems and the “Dementia School” for relatives of people with dementia. The purpose of the courses is to provide information on the relevant illness or condition, and how best to live with the illness.

There are several different *education programs* designed to support people with user experience to use their expertise in specific positions in healthcare. Such positions may include employees with user experience (MB's), experience consultants, experience teacher or co-researchers.

Several of the *ordinary folk schools* in Norway have specific courses for people with mental disabilities. These are ordinary folk school annual courses, where students live in the school. Although this is a custom folk school offering, it is not an offering for the target group in this study, but rather adapted for people with mental retardation as their primary diagnosis.

## **4 Aim and research questions**

This study consists of three sub-studies. The primary objective of the study as a whole is to explore whether, and if so to what extent, different environmental conditions influenced the experience of everyday life, the sense of self and the opportunities for personal and social development of people with severe and prolonged mental illness.

The main study has the following research questions, explored in the different sub-studies:

1. How do students and patients describe their environmental conditions, and their possibility to engage in and affect these environments?
2. How do students and patients describe themselves, and their personal and relational development?
3. How do teachers and mental health professionals describe their daily work, relations and attitudes?

### ***4.1 Paper 1***

Informants in the first paper were students and patients, and the aim was to explore the experiences of persons with similar diagnoses and backgrounds both in psychiatric treatment and in schools for adults with mental disorders. We had the following research questions for this sub-study:

1. What kind of environmental conditions, including relationships, are the patients and students describing?
2. How do patients and students describe themselves and their participation in these environments?

### ***4.2 Paper 2***

The second paper was also based on information from students and patients. The aim of this paper was to identify and examine possible differences in descriptions of self and of personal development related to a focus on education compared to a focus on symptomatic treatment of mental illness.

We addressed the following three research questions:

1. How do patients and students describe development of their relationships and interactions?
2. How do patients and students describe themselves, their motivations, and their actions?
3. How do patients and students describe their own personal development?

### **4.3 Paper 3**

For the third paper, mental health professionals and teachers were informants. The aim was to explore how the two groups of informants described their work and its contextual and normative framing, and how this might affect the potential for students and patients to develop personal growth. To achieve this aim, we formulated three specific research questions, as follows:

1. How do teachers and mental health professionals describe their daily work and tasks, and the impact of norms and framing?
2. How do teachers and mental health professionals describe their relationships with their colleagues and with their students/patients?
3. How do teachers and mental health professionals describe their attitudes and values?

## **5 Design and method**

In the following I will describe and discuss the design and methodology. It would have been possible to only provide a description here, and compile all of the discussion in chapter 7. However, a critical reflection of the practical and methodological choices is an important part of the process leading to the decisions on methods described in this chapter (Vaglum, 2010). I have therefore chosen to integrate description and a critical discussion of the design and methodology in this chapter (Vaglum, 2010), and reserved chapter 7 for a discussion of the findings and interpretations.

### **5.1 Design**

This is a qualitative study, with a descriptive and explorative design. Qualitative methods are generally well suited to exploring areas where there is little previous research, and which were therefore considered highly suitable for this study, since there is little research on how patients participating in various services perceive themselves and their personal development. The data collection was inspired by the Life Form Interview (“Livsformsintervjuet”, Haavind, 1987), but the interview was adapted for this study (see descriptions of the interview in chapter 5.6). The analysis was based on the hermeneutical principles of pre-understanding understanding, and whole, partial and empirical theory. The interview design provides ample opportunity for insight into how the various informants describe themselves, their daily lives, environment, norms, relationships and development, which was essential to this study. It was also desirable to not only explore *what* they described, but *how* they described it, and the narratives they used spontaneously. This was also addressed by the selected method, and could easily have been lost by using of a more structured, quantitative method.

### **5.2 Discussion of the selected design**

The study has a qualitative, exploratory and descriptive design, while the informants belong to four different groups.

This provides a unique opportunity to explore the similarities and differences in the subjective descriptions of everyday life, commitment, self-experience, participation,



relationships and development. It is important to emphasize that although the informants belong to various groups, this is still a qualitative, not quantitative, study. The informants in the student and patient groups have much in common, but the samples were not matched case-by-case (e.g. in relation to age, diagnosis, gender, etc.). It is important to note this when comparing the descriptions of the various groups. Due to the study's design, observed differences may be attributed to coincidences in the sample, and this must be considered when assessing the findings and interpretations. It is essential that the findings and interpretations that emerge are qualitative, and that this study is followed up by further qualitative and quantitative research. No structured measurements have been used for self-perception in this study (e.g. EASE).

It would of course have been possible to choose other designs, including mixed methods, to obtain quantitative information. This study emphasized the exploration of phenomena thoroughly using qualitative interviews and with perspectives from four groups of informants.

Together with the information from students and patients, the employees' descriptions of the frameworks for the services provide a holistic and comprehensive picture.

Overall, it appears that, also in retrospect, the selected design was reasonable.

The informants (students and patients) are asked to describe themselves and their everyday lives. When they do so, they also provide good descriptions of their relationships, their own interpretations of what is happening, the narratives they use, self-perception, experienced development and descriptions of personal involvement.

These descriptions are spontaneous, and provide useful information about which areas are perceived as important, but it is not a structured measurement of sense of self.

It could have been useful to include a structured measurement, for example, through pre- and post- testing with an instrument suitable for the task; preferably EASE. This would, however, have been difficult to implement in practice within the time framework of a PhD. One must assume that self-perception develops over time, and that there should be a minimum of two to three years between the first and second tests with EASE so that some effect could be expected. This assumption is supported by the information from the student informants, who confirm that they have experienced personal and social development, but

that it took several years. Pre- and post- testing of larger groups, with a minimum interval of three years, is unfortunately not possible to achieve within a PhD.

### ***5.3 Informants and inclusion***

The study included four different groups of informants: patients, students, teachers and health care professionals.

#### **Patients and students**

##### *Inclusion criteria for patients and students*

- Present and/or previous psychiatric disorder (with or without concurrent substance abuse) that needed treatment and led to considerable difficulty in functioning in daily life. These difficulties might involve:
  - Not being able to follow up ordinary employment/education, or significant difficulties in doing so.
  - Relational problems that have affected family life, friends or other network.
  - Problems with, or being unable to, participate in extracurricular and/or social activities
  - Have/have needed treatment for mental health problems, either from primary care or specialized health services or from both (regardless of the informant has received relevant treatment or not).
- These difficulties should have lasted at least two years.
- The informant should be able to participate in the interview, without too much difficulties (for instant not being in an acute psychotic state).
- The informant must be able to participate in an interview in Norwegian/Danish, without need for translation.

##### *Recruitment, informants and data collection*

At the wards, nurses invited patients they considered to meet the criteria to participate. At the schools, teachers asked some students directly, and I attended a morning gathering and

provided information about the study. Lists were available to sign for any student meeting the criteria and wishing to participate.

Each interview had about 60 – 80 minutes' average duration. No formal testing was done during the interviews, but as a clinical psychologist, I used the interviews to informally check if the inclusion criteria were met (by asking patients about their history of illness, or about diagnosis, if they wanted to share). For one of the patients, it was uncertain if the criteria were met. She has had problem functioning for about two years, and had also got a diagnosis of paranoia. However, her problems seemed to be more related to a conflict at work than to severe mental illnesses. Her interview was included in the analyses, but marked in a different colour, so I knew when working with the analysis that this informant might not meet inclusions criteria. No citations from her are referred. All other informants seemed to meet the inclusion criteria.

14 patients were included, from two different community mental health centres (DPS) in Norway. Nine patients were interviewed twice (6–12 months apart) and five were interviewed once, totalling 23 interviews. All patients consented to participate in the second interview, however five of them were unavailable at that time.

Initial interviews were conducted when the patients were admitted to a short-term open ward. At the time of the second interview, most patients were living at home after discharge from the ward. All admission at the wards were voluntary, and most patients had to wait several weeks from referral to admission. The patients were therefore not in a very acute stage at the first interview, and even less in the second interview.

15 students were included, from two different Danish schools for adults with mental illnesses. Since these kinds of schools do not exist in Norway, I had to visit Danish schools for the interviews. All interviews were conducted at the schools; Six students were interviewed once and nine students were interviewed twice (6–12 months apart), for a total of 24 interviews. The second school were included late in the process, and the five students from this school were therefore only interviewed once, for practical reasons. There was also one student at the first school, that not were able to participate in the first interview, but wanted to participate in the second interview, and therefore also were interviewed only once. For details about the background of patients and students, see Table 1.

**Table 1. Background of patients and students**

<b>Background information</b>	<b>Patient (N=14)</b>	<b>Students (N=15)</b>
<b>Diagnoses *</b>		
Anxiety/depression	8	5
Bipolar disorder	0	1
Schizophrenia, other psychotic disorders	6	7
Personality disorder	4	8
ADHD, learning disorders, autism spectrum disorders	2	3
Dependency (alcohol, drugs)	8	3
Other	1	0
<b>Age</b>		
18–29	7	7
30–49	5	5
50 or older	2	3
<b>Gender</b>		
Male	9	7
Female	6	8
<b>Duration of problems</b>		
2–5 years	1	
6–10		
11–20	1	
Since childhood/adolescence	12	15

\* Many informants reported more than one diagnosis.

All information is from the informants' own descriptions. Many informants had received several different diagnoses, and some were unsure which diagnoses were still considered valid. Sometimes they also needed some help remembering the exact name of their diagnosis (PTSD could be expressed as “all that letters meaning you had traumas”, etc.)

## **Teachers and health care professionals**

### *Inclusion criteria for teachers and health care professionals*

- Must have been working at the ward/school for minimum six months.
- Must work directly with patients/students.
- Informants could have different education and profession, as long as they work with patients/students. At the wards, this includes nurses, assistant nurses, doctors, psychologist, and other relevant staff. At the schools, this includes headmasters, teachers and assistants.

All informants met these criteria, and most of them had been working at the same place for several years.

### *Recruitment, informants and data collection*

14 informants were staff at two different Danish schools for adults with mental diseases. All interviews were conducted at the schools. The informants included both headmasters (who also worked as teachers), teachers and one assistant.

At one school, I asked the teachers about participation when I attended one of their meetings and presented my work. At the other school, the headmaster forwarded an e-mail from me to the teachers before I arrived, and asked them to participate. Teachers then volunteered to participate.

14 informants were included from two different District Psychiatric Centres in Norway. Informants included two clinical psychologists, one head nurse, nurses, and assistant nurses. All worked at open, short time wards, where patients were admitted voluntarily. Patients typically stayed at the wards for 2-6 weeks, with 3 weeks as average. At both wards, the head nurses asked specific members of the staff about participation. For details about teachers and health care professionals, see Table 2.

**Table 2. Information about teachers and health care professionals**

Schools/wards and positions	Gender		
	Number	Male	Female
<b>Schools</b>	<b>14</b>	<b>9</b>	<b>8</b>
Headmasters	2	2	0
Teachers	11	7	7
Assistant	1	0	1
<b>Wards</b>	<b>14</b>	<b>5</b>	<b>9</b>
Psychologist	2	1	1
Head nurse	1	0	1
Nurse and assistant nurses:	11	4	7

#### ***5.4 Discussion of sample and inclusion***

##### **The inclusion criteria do not specify diagnoses**

As mentioned in section 2, I wanted to use a clinical description of a patient group which, across diagnoses, is recognizable to most clinicians. Many of these patients will have multiple diagnoses simultaneously, others will receive different diagnoses over time, and it was therefore important to me to focus on function instead of diagnosis. This was also practical because the schools do not use diagnoses, and it would not be possible or desirable to ask to speak with students with a particular diagnosis.

It probably would have been possible to ask to speak with students who had experience of psychosis, but this was not done. Partly because we considered that the duration of the condition, along with the degree of functional decline, was more important than the diagnosis, and also because such categorization would be inaccurate. Most of the patients and the students said they had received several diagnoses, so there was great overlapping between different diagnosis types. Meanwhile, there were many participants who did not remember their past diagnoses, or knew which diagnosis was valid now (Paper 1, Paper 2). This confirms the impression that it would have been difficult, in practice, to recruit specific diagnostic groups, that we would probably have ended up with roughly the same

informants, and that the diagnostic accuracy would not, in practice, necessarily become greater, even though it might give that impression.

All information on diagnoses is based on the patients' own descriptions, and some of these were obviously inaccurate - informants themselves said that they did not remember their last diagnosis, or that they were unsure. It is also possible that some diagnoses were not reported because the informants forgot them, did not want to disclose them, or did not believe them relevant. There is a described bias in the sample associated with concurrent substance abuse (higher for patients than for students), and I am unsure whether this is real or related to differences in reporting. This confusion could have been avoided if all informants had been diagnosed as a part of their participation, or if the diagnostic information had been obtained from the health care system. To diagnose the informants in an ethical way, would have taken a lot of time, and most likely would require several meetings. These diagnoses could also be in conflict with the diagnosis they already had, and could have given confusion. It was also important for me to trust my informants, and to ask for diagnostic information from the health care system would have been difficult, especially regarding the Danish students, since many of them had little contact with the health care system now. Both of these alternatives were therefore considered to be of such disadvantage to the interview situation that they were deemed irrelevant.

In addition to the challenges related to the uncertainty of which diagnoses the patients had, there are also problems related to the inclusion of different diagnoses. Changes to the sense of self are much more prevalent in people with psychotic disorders than with other mental disorders (Henriksen, Nordgaard, 2014, Parnas et al, 2005), and there are thus possible challenges in including different diagnoses in this study. Changes to self-perception have been identified in patients with other disorders, especially severe personality disorders (particularly BPD), although these are probably of a different type to those in patients with psychotic disorders (Nelson et al., 2013, Beeney et al 2016). A clearer range of informants with a specific diagnosis could have perhaps provided more precise information about subjective experiences and opportunities for development, and this should be considered in any follow-up studies, particularly quantitative studies.

On the other hand, findings and interpretations from the interviews (paper 1, paper 2) show that nothing in this sample group suggests that patients with different diagnoses have

different backgrounds, generally different descriptions of their situations, or different development. The two factors that stand out in this range are age (the youngest participants generally described more development than older participants who have been ill for more than 15 years), and the services they receive (students generally described more development than patients).

### **Sample in relation to the inclusion criteria**

The inclusion criteria for patients and students specified that informants must have a severe mental illness (with or without concomitant substance abuse) which had led to changes in daily functioning. The difficulties should have lasted at least two years. With one possible exception (discussed previously), all of the informants satisfied these criteria. Most informants described how they had experienced severe function impairment due to mental disorders for much longer than the two years specified in the inclusion criteria. Five, ten and thirty years were common descriptions for both patients and students. Even though no specific questions were asked about this, the majority spoke of problems that had begun in childhood/early adolescence.

All informants describe different types of function impairment that were specified in the inclusion criteria. All of them had been out of employment/study for a long time. Many received disability benefits. Each one disclosed that they were experiencing, or had experienced, significant relationship problems, and trouble completing daily tasks and participating in social contexts. Each one also described that they were undergoing, or had previously undergone, extensive psychiatric treatment. The only obvious difference between the groups was that the patients primarily described how these were ailments they still had, while many students said that the situation had changed and that they were now either coping with the situation better, had fewer ailments or no ailments at all.

The informants were not asked specifically whether they had experienced childhood trauma. But the majority of informants, both students and patients, spontaneously said they had experienced childhood trauma. This is not surprising. A clear correlation between childhood trauma and severe mental illness has been identified, both in terms of psychosis and severe personality disorders, especially BPD (Cotter et al. 2015, Varese et al, 2012, Moskowitz et al. (ed) 2008, Read et al. 2006). The fact that this correlation also exists in the informants in this



study was expected and only confirms that the informants, both patients and students, are in the target group. It is also natural that not all of the informants spoke of childhood trauma. There may be different reasons for this (Ormhaug et al 2012, Sampson, Read, 2016). Experienced anomalies in sense of self were not explicitly described in the inclusion criteria, but is closely associated with severe mental illness. Both students and patients spoke about a number of anomalous self-experiences, either in the present, past, or both. They described different phenomenon such as thought chaos, difficulty making decisions, difficulty relating to other people, extreme passivity and apathy, a sense of being different to others, not belonging to the world, hallucinations (voices), etc. All of these are phenomena which can be a part of anomalies in sense of self, as described in e.g. EASE (Parnas et al 2005). This indicates that the informants in the study are representative of the group of patients with severe and prolonged mental illness.

### **Method for the recruitment and inclusion**

As mentioned above, I recruited the staff of the schools as informants by attending meetings and informed them of the study (school 1) and through the principal distributing mails and information (school 2). Those who wanted to participate, then made contact with me. Some students were asked by their teachers if they wanted to participate (schools 1 and 2), others enrolled personally after I had informed them at an open meeting (school 1).

In the wards, relevant employees were asked by their managers if they wanted to participate, and the staff of the wards asked the patients if they wished to participate in the study (based on inclusion criteria).

I have no information to suggest that the managers or employees of the wards had their own criteria, in addition to my inclusion criteria, for whom to ask to participate, and I do not suspect that this happened. Nor is there anything in the interviews to suggest that I have been talking with patients who were particularly healthy or happy, or employees who promoted a particular view. Nevertheless, it can never be completely excluded, based on how the inclusion was done, that some selectivity may have occurred.

## **Informants from two countries**

Half of the informants are from Norway, and the other half from Denmark. There is therefore the possibility that the differences that emerge may be a result of differences in nationality and culture. However, the Scandinavian countries share many similarities, and are generally regarded as comparable.

One possible difference between the countries is that it is popularly said that Danes are "happier" and more "relaxed" than Norwegians. If that is correct, it could possibly be relevant to the findings showing that teachers and students speak more about happiness than do the patients and health care professionals. I did not, however, succeed in finding any scientific references suggesting real differences in temperament, beyond the popular perception. The students' descriptions of past experiences with the mental health services in Denmark are also consistent with patient's description of mental health care in Norway. Teachers' descriptions of the cooperation with the health and social sector in Denmark coincide with the descriptions from Norway. All in all, there is much evidence to suggest that the biggest differences are between different systems, and not between countries.

## **The context's influence on the sample**

It could be argued that the patients were in a more severe phase than the students, or were generally more severe ill than the patients as they had been admitted recently when the first interview was conducted, while the students had been attending school for a longer time. The interviews were, however, not conducted in acute psychiatric wards. Most patients came from home and had been waiting for a scheduled admission, and were not experiencing acute crisis. All admissions were voluntary, and the patients had chosen and wanted to be admitted. Most informants also described a chronic condition, constantly switching between admission, discharge and new admission. The differences between the initial interviews (when they were admitted) and the second interviews (when they were at home), were mainly contextual. Most informants actually appeared as if they felt better and were healthier during the initial interview than during the second interview. The majority of students also described similar stories to the patients from before they started school, i.e. switching between admissions and discharges.

It is more relevant that students actively opted to start school, and also to continue over time. Some of them described, however, that they had not wanted schooling in the beginning, or that they had been absent a lot at the beginning. So even here, it does not seem that this is an extraordinarily motivated group, but rather that, over time, they perceived a service they could benefit from. Teachers also explained that although some students left school prematurely, it was not common, and some of these would return later, with better results.

## ***5.5 Discussion of selected context***

In this exploration of the participants' experience of services with different academic foundations, I have chosen to select informants who have been offered DPS day school places, and in the Danish day schools for people with mental disorders. This is a choice, and I will discuss some of the reasons for this choice in this section.

### **DPS is the most common specialist health services for the target group**

The purpose of this study is to explore whether, and if so to what extent, different normative, practical and narrative environmental conditions impact the experience of everyday life, the sense of self and the opportunities for personal and social development of people with long-term and severe mental disorders. I am specifically interested in exploring the importance of services rooted in medical and non-medical frameworks of understanding. It is therefore appropriate that one of the services included should be one that is considered a standard, common treatment for this target group. And DPS is central to this.

By definition, municipalities should not offer treatment, while third line services (hospitals) must primarily deal with specialized issues. As one of my research questions was to examine the informant's descriptions of themselves and their own development, I wanted a service that was both clearly within the health professional model and offered treatment aimed at change. It was also important to me that the service had a certain level of competence, and was a central and common part of the services to the target group. From the appropriate available services, I assessed that DPS is the mental health service that best meets these requirements.

It could, however, be an opportunity to use informants who used outpatient clinics in DPS, rather than inpatient wards. My assessment was that more people in that target group would use inpatient wards rather than outpatient services. This was confirmed as only a few informants explained that they had consultations at outpatient clinics, and that these consultations often only took place over a limited period of time.

### **Necessary refinements in the interests of the scope of the study**

Most patient informants had services from both DPS and the municipalities, and it could, therefore, be appropriate and useful to also interview key people in municipal psychiatry in the different municipalities, and include them as a separate informant group. Many student informants were being, or had been, monitored by the Danish social psychiatry service, and it could, therefore, have been useful and necessary, for equality's sake, to also include such key people as a separate informant group.

Employees of Norwegian municipalities could not, however, act as substitutes for informants from DPS, as that would not provide enough information about a measure aimed at treatment and development.

And the informants from Danish social psychiatry could definitely not act as substitutes for informants from the schools because they might belong to the more traditional social psychiatric understanding model, and a comparison between Norwegian and Danish social psychiatry would become a completely different study, and probably far less relevant.

### **There is little research on the Danish day schools**

In Denmark, various day folk high schools have provided services to adults with mental disabilities for more than 20 years. Despite this, they are not very well known in Norway and, as far as I know, it has not been assessed whether this would be a useful service in Norway.

In Denmark, the schools are not well researched and the existing research is characterized more by smaller evaluation projects than actual research. Meanwhile, the evaluation that has been carried out is positive, and the students disclose anecdotes of very good experiences with the schools.

When this type of schools also is a financially reasonable service, locally based, voluntary and with high satisfaction levels among users with low drop-out levels, it is, in itself, useful to explore these services thoroughly.

### **The Danish day schools have an exceptional position in cultivating of clear framework and a professional foundation**

It is, of course, a research challenge to have informants from two different countries. As I still chose this, it was primarily about cultivating the academic bases. It was a basic prerequisite for this project that I wanted informants from services with two different professional models of understanding.

If we compare the overview of the Norwegian services on the borders between treatment and education/employment (3.3), with the description of the Danish day folk high schools, it is clear that the schools differ from the other services in terms of objectives. With the exception of the municipal day centres, all of the services mentioned in chapter 3.3 either had an objective of recovery/improved function (e.g. able to work), or to live with and accept the illness. This is quite unlike the day schools' focus on personal development as a value in itself, regardless of the result.

This focus on self-development is particularly relevant in terms of the research mentioned in chapter 2.2 about possible connections between anomalies in sense of self, childhood trauma and severe mental illness. It is, however, important to emphasise that, although the schools I've visited focus on personal development, it is not a common feature of all day schools.

There are day schools with a much clearer focus on results and job training, and which are similar to ordinary Norwegian labour initiatives organized by NAV. And there are also schools that are more characterized by psycho-education. These services were deliberately not included in the study for the same reason that the Norwegian labour market initiatives and psycho-educational courses were not included.

The Norwegian day care centres are fairly similar to the Danish schools considering that the focus is on the services provided, not to either provide information about illness or increased levels of functioning. However, the day care centres generally have less expertise than the schools, and are often more focused on socializing than on education, although this will vary

widely between different day centres. In Denmark, there are "places to be" ("væresteder") which correspond to the Norwegian day care centres.

These "places to be" focus much less on academic activities than the schools, and work much like Norwegian day care centres, and the users of the centres often focus more on illness. This is different from the schools. Since the focus of the subjects is so evident in the schools, it is natural that people talk about the subjects during breaks, like whether there are trips that they have taken or will take, the ceramic project they are doing or topics from the social sciences or philosophy teaching. In the "places to be", the primary common experience is illness, and therefore illness is often a theme in conversations.

This is also recognizable in the Norwegian day care centres. In recent years, there has been significant development of the day care centres, and more centres are now moving away from the traditional model. They rename, and they focus more on courses and activities. A natural follow-up to this study may be to study the development of such day care centres and their effects on different target groups. In this study, however, I chose to include informants from the schools because the academic foundation was much clearer there.

### **The two settings should represent different models of understanding, yet have some relevant similarities**

It was important for this study that the services should be clear and typical representatives of different models of understanding. It was also desirable that the two services had some similarities, particularly in regards to frames and exterior designs. Despite all of the differences, the schools and DPS wards had several such similarities in terms of volunteering, target groups, service design and degree of specialization. There were of course also many differences, including the need for referrals and the duration of the service.

That there were some similarities, was nevertheless relevant. One example is that in both schools and inpatient wards, the educators/treatment providers and students/patients spent a lot of time together during the day. This is significantly different from other services which could have been included, such as weekly outpatient therapy sessions.

The interviews with informants showed, however, that even if the framework for interaction were fairly similar, the contents and their personal descriptions of the interactions were very

different. This is important, and would hardly have been as obvious if the informants had been in situations that were significantly different, e.g. individual therapy versus education.

## ***5.6 Interview and adaptation of the interview***

All informants were interviewed with qualitative interviews, inspired by the “Form of Living Interview” (Haavind, 1987). This interview was chosen because it is an excellent method to get people's description of their life, and their own narratives in a structured way, without asking leading questions.

However, it has not been used very much, and mainly in families with small children. The interview was therefore adapted, so it would fit for the purpose of the study and the different groups of informants.

### **Interview, adapted for students and patients**

The interview was opened by telling the informant that I had few specific questions, my main interest was to learn more about how their normal day was. I then asked them if they could describe what they did yesterday. If the informant seemed insecure, I said something like – “Let's start with the morning, when did you wake up?” I wanted a detailed description, but not too detailed, - if they said something like “I live alone, I woke up at 8, got up, ate and took the bus to school,” that was detailed enough. Some added more information, other less. If the information were too general, I would ask for more details with statements like “can you please tell me a little more about that?”

In addition to their descriptions of their day, I also asked for their own *assessment* of what they described. If they said something like “When I arrived at school, I attended to the morning gathering”, I would first ask them to describe this more closely, and, when they did so, ask them: “What do you think of morning gathering?” If they said they liked it/not liked it, I asked “why, what is good/bad about it?” This adaptation of the interview was made to explore the informants' own thoughts and assessments of their everyday life. In this study we were not only interested in *what* the informants described, but also in *how* they described their situation, and in their personal narratives and “ownership” of their everyday life.

Many informants mentioned change, saying things like “Now I can...” “Earlier I used to ...” If they said something like that, I would ask them to describe the changes. This could be both positive and negative changes.

All questions were open, I never asked “do you like it?”, But “what you think about that?” “How is that?”. I also used phrases such as “can you say more about that?”, “can you please tell me what that means for you?”, etc.

For the students, every school day differed, according to the timetable. After they had described yesterday, we therefore went through last week, with even lower level of details, and I asked them only to describe things that were different from the first day, for instance other subjects, or other appointments. After they had described the whole week, I asked if they experienced this as a “typical” or “normal” week, and if not, why. We wanted to explore if there were any specific exceptions, such that they used to have music on Wednesdays, but this week the teacher had been sick, etc. I also used the same technique for patients, although their days both were more similar to each other, and at the same time more randomly different.

Most informants, both students and patients, spontaneously mentioned illness or diagnosis. If they talked about disease, without mentioning the diagnosis, I asked something like: “It is totally up to you what you want to talk about, or tell me, but I’m wondering if you’re ever gotten a diagnosis of your problems?” Those who had not mentioned the diagnosis spontaneously replied without hesitation and named their diagnoses – or those they could remember.

We also added some specific questions to all patient and student interviews. Order could vary, depending on the structure of each interview, but all of these informants got the following questions:

1. “(Norwegian) newspapers has often, especially in summer, interviews with celebrities who are asked to draw a line describing his life, with ups and downs. Like this:”

I then demonstrated by drawing a line, and said things like “An athlete, for instance, could say that “I had a good childhood, so here the line is high, then I struggled a bit as a teenager, and then the line went down, and here won the World Cup, so here the line is at top notch.”



After drawing the line, I continued: “Now I’m wondering if you could draw such a line of your life?”

All informants drew the line, without problems. The drawing themselves were of little importance, and are destroyed, but their descriptions of ups and downs gave an easy and quick overview of their history, without burdening the informants with detailed, and possible leading, questions.

2. “If you should present yourself to a person you had never met before, what would you say?”
3. “What do you think is best with this school / this ward?”
4. “Is there something that is not so good here, or that you would like to have changed?”
5. “I wonder if you have any thoughts about the future, what do you think your life will be like in for instance one, or five, years?”
6. “We will finish this interview very soon, but before we do so, is it something I forgot to ask about, or that you would like to add?”

### **Interview, adapted for health care professionals and teachers**

The structure and opening of the interview with teachers and health care professionals was similar to the interview with patients and students. However, for these groups of informants, we limited the period of interest to the time they were at work. So, I opened the interview by asking informants to describe what they did last time they were at work. If they were insecure, I said something like – “Did you work yesterday? When did you arrive? What was the first thing you did?”. Even if I did not need all tiny details, I still wanted a detailed description of their day, and if their descriptions were too general, I would ask them to “please, tell me more about that”.

Also for these groups of informants, I wanted their assessment of their descriptions, and more information were retrieved by open, not leading, questions.

Teachers had different timetable every day. Nurses and nurse assistants sometimes worked at daytime, sometimes in the evening, and their tasks would vary according to shifts, and to the patients’ situation. After they had described the last time they worked, we therefore went through last week, with less details, focusing on differences and new situations. After

they had described a whole week, I asked if they experienced this as a “typical” or “normal” week, to explore if there were any specific exceptions in the described period, that could affect the answers.

Also for these groups we also added some specific questions to all interviews, most often at the end of the interview:

1. “What do you think is best with this school / this ward?”
2. “Is there something that is not so good here, or that you would like to have changed?”
3. “We will finish this interview very soon, but before we do so, is it something I forgot to ask about, or that you would like to add?”

### ***5.7 Discussion of the interview and interview situation***

The chosen interview method had several advantages. It was structured enough to maintain focus and give the informants a framework within which to speak, while not posing any leading questions, and the informants were free to describe their reality the way they wanted.

The disadvantage of this was of course that not every topic was covered by all of the informants. They were, as mentioned, asked some key questions, but there were not so many, and they were fairly open. No direct questions were asked about experiences related to anomalies in the sense of self. Nor were they asked about other subjects, such as experienced trauma, relationships with family, and cooperation between different agencies. Many informants spoke spontaneously about such topics, but it is quite possible that other informants had similar experiences, which were never disclosed because they were not asked explicitly.

The presence of childhood trauma and cooperation between agencies or others were not topics for this study. Sense of self was a topic, but to include direct questions about this would probably have demanded the use of a structured study (e.g. EASE), because these experiences are typically diverse, personal, and difficult to elicit with direct questions.

Many informants described such phenomena, spontaneously, and included descriptions of their everyday lives. Sense of self is a clinical term, but it is very reminiscent of the

phenomenological concept of life-world, which deals with precisely these immediate and automatic experiences.

An exploratory method which asks the informants for their own descriptions of how they experience their daily lives, is therefore well suited to obtaining this type of information. I conducted all of the interviews. I have specialization in clinical community psychology, and I found, with some of the patients, that it was tempting to take on a clinical role as a treatment provider. These were patients who had a lot of experience with therapy and psychologist conversations, and I knew that these patients, who "could talk to a psychologist," could tempt me to leave the researcher role for the role of a therapist. The structure of the interviews was, however, so clear that I quickly noticed this when it happened, and went back to the researcher role.

On several occasions the researcher role seemed unnatural, so I chose to put this into words for the informants, by saying something like this:

*"Yes, I'm a psychologist, and you've talked with many psychologists before and know how that may be. However, I am here today as a researcher, so it will be a little different. I will make sure that we stick to the framework of a research interview. Is that okay for you?"*

This clarified the situation, and we could continue the interview. However, I do see this as an interesting finding in itself, and as a confirmation of how well integrated the patient role was in some patients.

I also have previous experience as a patient with a psychiatric diagnosis (this is discussed in the section below on pre-understanding), and in that regard I have written books, lectured and given interviews. This means that some people in Norway know about my background. A few of the patients knew about this, and mentioned it after the interview was over. I asked them how they felt about that, and they said spontaneously that they thought it was fine and that it was easier to talk to someone with patient experience. This compares well to the experiences of "user asks user research". Some employees also knew of my dual experience, and mentioned it after the interviews. On the same question, about how they felt about it, they replied that they "thought it was fine." It is of course possible that some of the informants, especially the employees, may have moderated their statements and made them more "politically correct" in meetings with me.

However, there is little in the findings to suggest this. The employees were very open, even on difficult and ethically controversial topics. It was considered whether it would be appropriate to inform all the informants about my background, both as a former patient and psychologist. The advantage of this would be that the topic would be open and that everyone would have the same information. I chose not to do this as saying something like that at the beginning of the interview could have provided guidance in the conversation, and also provide a focus for me as a person, which I found had very little purpose.

Most Danish interviewees knew little about my background, but some had heard of me (the books have been translated into Danish, and I have also lectured in Denmark).

The reaction to the teachers and students who knew who I was, did match the reactions from the Norwegian informants. Some said it towards the end of the conversation, and said that this was either unproblematic or beneficial.

I am Norwegian, and Norwegian is my mother tongue, while half of the informants were Danish speakers. The form of the interview, in which I asked them to talk freely, and only asked follow-up questions, was a clear advantage in this context, as I was not dependent on being able to trust that they understood all of the nuances of my questions as exactly as the Norwegian informants. If I had specific questions, this could have been a bigger problem. It was unproblematic because the important thing was that they spoke freely, not that they understood every word I said exactly. I also have a good understanding of Danish, after many visits, and had no difficulty in understanding the informants. If there was a word I was unsure of, I just asked.

## ***5.8 Recording and transcription***

The interviews were audio recorded. Norwegian interviews were transcribed by medical secretaries with Norwegian as their native language, while the Danish interviews were transcribed by medical secretaries with Danish as their native language. The secretaries were asked to transcribe the interviews exactly as they appeared, with incomplete sentences, stuttering and natural mistakes. Sounds, hesitation and pauses were written in the transcription in italic (for instance: *coughing, short pause, laughing, ect.*).

Citations used in the papers, and in this thesis, were translated into English by me. At the same time, the citations were gently adapted, by removing sounds, hesitations, and repetitions that are a normal part of oral language, but is disturbing in written language. The reason for this small revision were mainly a wish for more clarity. However, there were also an ethical consideration – oral language is usually different from written language, and to use oral citations in a written text can make the informants seem less competent than they really are.

The written transcriptions were stored in a less secure file than the audiotapes. For security reasons, the secretaries were therefore asked to omit names, both of persons and places from the transcriptions, together with sensitive information or information that could identify persons.

### ***5.9 Discussion of recording and transcription***

One of the participants did not want me to use recorder in the second interview. He said that it had gone well last time, but he did not want it this time, - and this was of course respected. During this interview I took detailed notes and everything was written up in detail immediately afterwards. These notes were then marked with a different colour and quotes from the interview were not used in the article. The analysis took into account that the citation was not literal and exact. Beyond that one person, none of the interviewees objected to the use of a recorder, they spoke freely and it did not seem like they cared very much that it was there. It would have been an advantage if I had transcribed the interviews myself, but since the material was so extensive, I couldn't manage it. I also considered that since Norwegian is my native language, and half of the interviews were in Danish, it was more appropriate that all interviews were transcribed by someone fluent in Danish and Norwegian. However, since I did all the interviews myself, I remembered them when I read the transcript and also used the tapes as support in the process of analysis.

### ***5.10 Qualitative data analysis***

The analysis of the material was made based on the transcripts of the interviews. The recordings were used as support in this analysis, along with a handwritten log book. Since I myself had conducted all the interviews, I also memorized them extensively and brought

that with me into the analysis. N-VIVO software was used in the analytical work. The analysis of the interviews was inspired by the hermeneutical spiral and the hermeneutical principles of content analysis: pre-understanding - understanding, whole – part, theory - empirical (Kvaale, Brinkmann, 2009 Malterud, 2011). Since the study included four informant groups, and several informants were interviewed twice, the material consisted of 75 transcribed interviews; and each interview lasted between 60 and 90 minutes. Altogether it is an extensive data set. Because all of the analysis was done in N-Vivo, I have no total page count for the transcribed material. However, each interview was typically 25-35 pages long and total number of pages was estimated to be between 2000 and 2500.

To make it more manageable and transparent, the analysis of interviews was therefore divided into two separate processes. First, interviews with students and patients were analysed, and then the same process was repeated with teachers and health workers.

Both analytical processes (students / patients and teachers / health workers) were completed in the same way:

I started by reading through all the interviews several times, while I took notes and listened through parts of the recordings. This resulted in a comprehensive understanding and correlation of the interviews and the transcriptions.

After this I created separate projects in N-Vivo for each group of informants. In the first process, one for students, one for patients, in the second process, one for teachers and one for health workers. First and second interviews with students and patients were in the same group, but the interviews were marked, so I knew which type of interview I was reading.

I then went through all the interviews, one at a time, identified meaningful units (sentence, paragraph), and grouped them into different sub-categories. The first and immediate categories were then condensed several times into new sub-categories. Sub-categories were then abstracted to major categories. The main categories of the two groups of informants in each assay process was now seen in context.

To ensure consistency and to minimize subjective bias, the relevant units, sub-categories and main categories were discussed with supervisors. This was an extensive process, involving recapitulation and thorough discussions, until it was agreed that each sub-category and main category was significant, consistent and had a precise and descriptive definition.

The findings and interpretations from the first analytical process was subsequently separated into two thematic groups. Main categories both from student interviews and patient interviews (which described environmental conditions) were presented in article one, while main categories from both the patient and student interviews (which described personal development) was presented in article two. All findings and interpretations from the second analytical process (health professionals and educators) was presented in article three.

### ***5.11 Discussion of data analysis***

The data in this study was very comprehensive and it was a challenge to deal with it in a structured manner. I tried to do the analysis manually, but found evaluating such large amounts of data impractical. I concluded therefore that it was more efficient too use N-Vivo. Through the use of this program, and by dividing up the material into various categories, I was able to accurately analyse all the information I had. It should also be noted that N-vivo was exclusively used for practical matters - to organize and manage the material- and that the analysis itself was carried out manually.

In the actual analysis work I cooperated closely with two supervisors. Only I read and identified meaningful units in the more than two thousand pages of transcribed text, but meaningful units were submitted to the supervisors. We then discussed the various sub-categories, which units belonged to which respective category, which sub-categories were synthesized together, which sub-categories were abstracted into main categories, and also the terms of the sub and main categories. In this process with rigorous and repeated discussions, a number of changes and clarifications was done, and consensus was achieved. It was a transparent process; my reviews were regularly and continuously shared and discussed with others, which I think is essential for the outcome.

### ***5.12 Preconceptions***

It is not possible for someone to be completely neutral and objective, and it would be very dangerous to believe that one could be. Within qualitative methodology it is therefore important to be conscious of preconceptions, so you can deal with them in the most appropriate way.

My expertise, before I started this project, is complex, and includes both experience as a patient and expertise as a clinical psychologist. Over the period of several years, I was treated in mental health units for a severe disorder (Lauveng, 2005 Lauveng, 2008). After I recovered, I was educated and trained to become a psychologist, and since then I've worked as a clinical psychologist, specializing in clinical community psychology.

The role of the clinician is of course completely different to that of a researcher, and this was something I had to bear in mind during research interviews, especially in situations where my training as a clinician diverged from my role as a researcher. In cooperation with a supervisor I therefore developed procedures for how to conduct ethical evaluations during interviews (see paragraph 5.13). Once these were in place, it was unproblematic to maintain focus on the role of the researcher in the interview situation.

Throughout the project, I wrote a log book (handwritten notebook). In this book, I accounted for my preconceptions after the project had started, but before the interviews and data collection began. My preconceptions at that time were that I believed that schools would have a positive effect, at least on some students. Specifically, I expected that:

- Students would have less severe problems than patients (selection).
- Students would show obviously greater improvement than patients and progress more quickly in their job / studies.
- That the *content* of the subjects, especially practical knowledge, would have great significance.
- That patients - at least some of them - would feel uncomfortable on the wards (built on many stories about patients who complain about Norwegian psychiatric care).
- That therapy and treatment would be important for patients.

In retrospect, I see that I had few, if any, expectations directly related to teachers and health workers.

A thorough review of what I found can be located in the chapter: "The findings and interpretations of the three articles." Here I just want to underscore that some of my expectations turned out to be correct, others were less so or were part of a larger picture, and some were erroneous. I also encountered a number of topics that I had not thought of



or been aware of in advance, but that became apparent during the analysis of the material. My expectations about what I would find was therefore in no way identical to what I actually did find, which I see as positive and reassuring. Meanwhile, there was of course some overlap, which must be regarded as natural, since I was familiar with the field already.

To make sure that my preconceptions not would influence the results too much (to avoid all influence is probably impossible) I made several efforts:

Firstly, I wrote down my preconceptions in advance in a handwritten document, a log book. I brought this log book with me to the interviews and wrote my reflections in it after each interview. This made me constantly aware and conscious of my own preconceptions, so I could acknowledge these and actively reflected on them. The fact that I used the logbook regularly during the work, ensured that I remained conscious of my own reactions. In this way, I also was able to detect and remedy for any patterns or imbalances. During the interviews, I stuck to a framework, focusing on what the informant had done that day / week. Beyond this, I followed the informant's own choice of theme and asked exclusively neutral monitoring questions, without specific guidelines.

In the analysis, I chose to deliberately cooperate with supervisors regarding content and headings of the sub and main categories. I know it's easy to get stuck on a specific viewpoint, and through an open and transparent process, with constant discussions with others, I wanted to reduce the impact of preconceptions and subjectivity.

### ***5.13 Ethical Considerations***

The Regional Research Ethics Committee (REC) and the Privacy Ombudsman at Akershus University Hospital approved the study. The data was collected and stored according to their regulations. The Danish Ethical Committee for Research notified me that no approval from themselves were required. Participation was voluntary, all informants received verbal and written information about the study and signed a statement of informed consent.

Participation in the study was not related to permission to continue in treatment or education, and there were no consequences for informants regardless of whether they chose to participate or not. All informants were told that they could end the interview at any time without any reason, but no one did. All informants were also notified that they could contact me in a period for up to six months after their final interview, if they had any

questions or reactions regarding the project or the interview, but none of them used this opportunity.

To secure confidentiality, quotes in the papers do not specify age or gender, and information about which schools and DPS I visited have not been made public.

No information from single interviews with health professionals or teachers was shared with management at DPS or schools in any way which could identify the informant. The same was true for patients and students, and no information was shared with therapists or teachers in a recognizable way unless the patients specifically asked for it to be shared. Most interviews were conducted at the wards and schools, but confidently and in private.

All interviews were conducted by me. I am a clinical psychologist and have experience of therapeutic conversations with patients. This was beneficial because I had experience in managing patients with severe mental illness and was confident that I could manage any potentially challenging situations (should they occur), but there were no such incidents. However, the situation was also challenging, as many of the informants in the patient groups described very difficult situations, especially at home between inpatient stays. For me, with my therapeutic experience, it was problematic to hear about patients in such challenging, and sometimes unethical or dangerous situations, without making any interventions. At the same time, I knew it was crucial for the research that I was able to observe without intervening. To find a good balance, I made the following guidelines in cooperation with my supervisors:

I would only give up the objective position of a researcher and actively intervene if any of the following situations should occur:

1. The patient had an acute stress reaction during the interview. In that case I would of course end the interview and take care of the patient.
2. I got information about a situation where peoples life or health were in danger.
3. An informant (patient / student) asked me for help in a difficult situation.
4. The situation was assessed as being severe and it was likely that my intervention would change the situation for the better.

Using these guidelines, I experienced the following situations:

- No informant got an acute stress reactions during any interview. No informant asked me to intervene in any way.
- Several times I considered patients living conditions to be unacceptable, but not life threatening. In these situations, however, all authorities were well informed of the patient's situation and I could not see that further intervention from me would have any positive effect for the patient. So, my focus was on documenting the situation through research.
- One time a patient told me about plans which included both suicide and violence toward others. The patient notified me that the ward had not been informed about this, because they (the ward) had not asked. When I asked the patient, I immediately got permission to inform the ward, and this was done in cooperation with the informant.

As reported in paper 3, some of the mental health professionals made statements in the interviews which could seem moralistic or judgmental regarding patients. Some informants also described situations which, based on their descriptions, seemed to be ethically problematic and could possibly threaten human rights. We followed the same ethical guidelines as above for these situations. All described incidents had happened some time ago, and it was not possible at the time of the interview to change the outcome. We agreed that all statements should be met in the same neutral way, with an emphasis on "please tell us more about that", in a non-confrontational way. The rationale for this was to collect all information in a neutral, non-judgmental way, analyse it later, try to understand the context of the statements, and possibly contribute to make some similar future situations better for those concerned.

## **6 Findings and interpretations from the three papers**

In this chapter I will briefly go through each of the three articles to summarise the findings from the interviews with the various informants. For more detailed information, please refer to the articles.

### ***6.1 Paper 1: Same diagnosis, different lives: A qualitative study of adults with severe mental illness in treatment and in education.***

This paper focused on how the students and patients perceived their lives, their environmental conditions, their relations and their own engagement in these relations.

#### **Method and analysis**

This paper had 14 patients and 15 students as informants. As mentioned previously, main categories from the analysis of the interview with students and patients were divided into two groups. The first group of categories (findings related to environmental conditions and quality of life) was presented in this paper. A total of seven sub-categories were included in this group. These were abstracted into four main categories, two for students and two for patients.

#### **Research questions**

For this paper, we had the following research questions

- 1) What kinds of environmental conditions, including relationships, are the patients and students describing?
- 2) How do Patients and students describe themselves and their participation in these environments?

#### **Findings and interpretations**

*Students: A nurturing environment*

*Well-being*

Students described how various aspects of schooling altogether gave them a better quality of life. Structure was important for many, as they had something to go to every day. Several also mentioned that they had developed a healthier lifestyle with more exercise, fresh air and regular meals at school. All stressed the importance of having fun and that school gave them many good experiences.

#### *Learning and reflecting*

Most students stressed the importance of learning new skills. They described that it was important to learn things they could use in their everyday lives, and that could give them new opportunities. Furthermore, they described the actual process of learning something new as important, and as something which contributed to mastering.

#### *Students: Supporting the unique individual*

##### *Relations*

All students described the good social environment at school as one of the most important things. They described good, safe, stable and reciprocal relationships with teachers and experienced that teachers cared about them as individuals. They also described the importance of friendship and fellowship with other students, including laughing together and supporting each other. Some perceived the school as a family. Several students also described an attachment to the school itself as a separate phenomenon, in addition to the relations to the students and teachers.

##### *Individual customization*

All students described that they experienced person centred leaning and support in school, and that their individual needs were met in a way adjusted to them. All also described that this element was very important to them, that the teachers knew them as individuals, and that the teaching was tailored to their wishes and interests.

#### *Patients: discontinuity*

##### *Good care at wards and no care at home*

Patients described chronic experiences of discontinuity, with a constant alternation between support at the wards and loneliness at home. The stay on the wards was described by most

as good and safe, and they stressed in particular the importance of social support and conversations with the staff. Their domestic situation was generally described as extremely difficult, with much loneliness and many severe symptoms. There were variations in the amount of treatment patients received at home, but most described this as little or fragmented treatment, and/or that they were not able to follow-up the services they were offered.

#### *Lack of lasting relationships*

With the exception of one or possibly two, all patients described extreme loneliness and few or no stable relations. Most relations were described as professional, and these relations were characterized by minimal contact with staff. Patients felt that they had little influence on these relations, that the relations were often of short duration, and that they constantly were given new contact persons and therapists.

#### *Patients: Little support adapted to individual needs*

#### *Adjusting to the system*

Patients described care as standardized and not accustomed to the individual. -They described that they had to adapt to the system, whilst the system to a very little extent adapted to them and their needs. They also described that they had to adapt to many rules, and that they had to attend many mandatory activities which they felt were not relevant to them.

#### *Not taken seriously*

Most patients told that they felt they were not taken seriously when they described their problems and needs, and that they received less help than they needed. They said that they might receive good help, but they themselves had little influence on this.

### **Summary across informants in this article**

The two groups of informants in this study had comparable diagnoses, symptoms, background and medical history. However, they described that they lived completely different lives, and their descriptions of daily life and relations were very different.

Their participation was also described as different. Patients described being encouraged to become independent, while at the same time feeling that they were not taken seriously and had little control over their own lives. Students' descriptions were the opposite. They described receiving much support over a long time, and at the same time experiencing much influence and control over their own situation. They felt they were taken seriously and participated in a system of mutual cooperation.

Few or no patients described neither clinical or personal recovery, while all students described either clinical recovery, personal recovery, or both.

Overall the findings and interpretations suggest that the most important thing for these patient groups may not be their diagnosis, background or individual symptoms, but rather what environmental conditions they are offered. Stable and mutual relations, individual adaption, good experiences and enough time seems to be particularly important in this context.

## ***6.2 Paper 2: Treating symptoms or assisting personal development: Can different environmental conditions effect personal development for patients with severe mental illness? A qualitative study***

This second article explores how the different environments (schools and mental health services) may affect patients' and students' experience of their relations, own engagement and personal development.

### **Methods**

Data was collected through qualitative interviews. Participants included 14 patients in psychiatric treatment and 15 students at schools for adults with mental illness. Most informants were interviewed on two occasions 6-8 months apart, altogether 47 interviews. All had been diagnosed with a severe mental illness which had had a profound impact on daily functioning (most often psychoses or personality disorders) for a minimum of two years.

## **Research questions**

1. How do patients and students describe the development of their relationships and interactions?
2. How do patients and students describe themselves, their motivations, and their actions?
3. How do patients and students describe their own personal development?

## **Findings and interpretations**

### *Patients: Lack of lasting and meaningful relationships*

#### *Loneliness*

Most patients described an overwhelming loneliness when they were at home. Many had few or no stable relations apart from relationships with healthcare professionals. Although these relationships could be good, patients had limited time with the healthcare professionals. Many described having contact with others for only a few hours per week. The rest of the time they were alone.

#### *Humans as tools*

Patients mostly met other patients at the wards, and then only for a short period. Many described this as useful and important, since they could learn from the experience of others, or practice learning social skills. No one described fellow patients as friends, and their descriptions focused primarily on utility for themselves, not on the joy of companionship.

### *Patients: Sense of self and personal narrative*

#### *Self-presentation and identity as a patient*

All informants were asked how they would present themselves to someone they did not know. For most patients, this was a difficult question, and they were struggling how to answer. Most ended up saying that they would tell their name and nothing else. Some would also say they were ill, or what diagnosis they had. No one described any other information which they wanted to share. For most patients, the descriptions of their lives and themselves intertwined with their identity as a patient. Medication was also important for



most, and both medication and disease were often described as explanations for actions or feelings.

#### *Being a spectator in one's own life and contradictions*

Many students used passive or objectifying statements about themselves, describing how others described them, or what others said about their needs. There were also many contradictory statements, where patients first described something and then said something directly in contrast to this, without even seeming to notice or be affected by these contradictions.

#### *Patients: Stagnation and discontinuity*

##### *No or non-specific experience of development*

With one, possibly two exceptions, none of the patients described permanent improvement or lasting personal development. In the first interview, on the ward, some patients said they had experienced improvement, that they had plans for life at home and that things would be better now. In the second interview, they talked about a rapid relapse, new admissions and that they had failed to follow the plans they had made.

##### *Hopelessness*

With one, possibly two exceptions, all patients described an overwhelming hopelessness and lack of faith in the future. Many said that they had no hope, or that they had no future.

#### *Students: Relationships*

##### *Development of quantity and quality of friendships*

All students reported that they had more friends now and were less lonely than before they started school. For some, friendships were closely linked to the school and the school environment. Others described a positive effect that stretched beyond the school and said they generally had more friends now, and that they were also a better friend to others.

##### *Development of personal relationships*

Several students described changes in personal relationships. Some had married, others divorced. Some had more contact with their family of origin, others less contact, or a different type of contact than before. Regardless of the type of change, all students

described the changes as positive and as something they themselves had chosen and were happy with.

### *Students: Sense of self and personal narrative*

#### *Self-presentation and self-acceptance*

Students were also asked how they would present themselves to someone they did not know. Most responded spontaneously and quickly, and it seemed like they thought the task was simple. Most would say their name and then include other topics such as family relations ( "I am the mother"), interests ( "I love sports"), origin ( "I'm from ...") or something else. Most students described either directly, indirectly, or both, that they accepted themselves more than before, and had better self-esteem.

#### *Personal engagement and integrity*

Many students described that they had more willpower than before, or that they had always been strong-willed, but that this willpower had been absent for a period and was now back again. They described themselves as active participants in their everyday lives, and they described both that they had choices, made choices and experienced control over their own lives.

### *Students: Development*

#### *Changes in symptoms and strategies for coping*

Most students had received much psychiatric treatment before they started school, and they described symptoms of severe mental illness, including various types of disturbances in sense of self.

The students described two different forms of development. Some, especially older students who had been ill for more than 10 years, described a development that corresponds to personal recovery. They said that they were better, had milder symptoms or better ways of coping with symptoms, and better quality of life. At the same time, they described that they had some need for treatment or support outside school, but less extensively than before.

Others, especially younger students, described a development that corresponds to clinical recovery. They described that they were better off, had little or no symptoms, needed

minimal or no treatment, had stopped taking medication and had entered mainstream education or work.

In this sample, I could not see any differences between students based on diagnoses, only on age and duration of disease.

#### *Personal growth, happiness and hopes for the future*

All students described that they had a better life now, that they were happier, more stable, and had experienced a personal development. Many also described specific examples of this development, things they mastered now that they had struggled with earlier. In the second interview, many described positive, stable changes since the first interview. All students also described hopes and plans for the future. These plans varied depending on age and personal circumstances, but all described a sense of optimism about the future.

#### **Summary across informants in this article**

Students and patients described significant differences in how they felt about themselves, their relationships and their own development. Students described positive and sustained development, stable relationships, less loneliness, more pleasure, better functioning, less symptoms, more active choices and much hope for the future.

Patients, however, described a greater focus on treatment. At the same time, they described little or no development, much loneliness, much symptoms and little hope for the future.

Findings and interpretations support the hypothesis of sense of self as a core problem in severe mental illness. For these patients, it is likely that their difficulties are closely linked to the development of self-experience. It may therefore be more effective to provide an enduring and supportive environment contributing to the development of a safe sense of self, than to focus solely on repeated short-term treatments of symptoms.

### ***6.3 Paper 3: How can context affect teachers' and healthcare professionals' interactions with adults with mental illness?***

This article focuses on how the health care professionals at the wards and the teachers at the schools describe their everyday work, their attitudes, relationships with colleagues and patients/students, their duties and the frames they work within.

## **Method and informants**

Informants for this article were 14 health workers from two open DPS inpatient wards and 14 staff members from two different schools for adults with mental health issues. Eleven of the health care workers were nurses or assistant nurses, and three were psychologists. The staff members from the schools were two principals (who also worked as teachers), a mercantile staff member and 11 teachers. The method was individual, qualitative interviews, and all informants were interviewed at their workplace during working hours. Each person was interviewed once.

## **Research questions**

For this paper, we had the following research questions:

1. How do teachers and healthcare professionals describe their daily work and tasks, and the impact of norms and framing?
2. How do teachers and healthcare professionals describe their relationships with their colleagues and with their student/patients?
3. How do teachers and healthcare professionals describe their attitudes and values?

## **Findings and interpretations**

*Teachers: Bottom-up accommodation of teaching and support*

*Teaching subjects*

The teachers' main task was to teach the students. They also described a sincere commitment to the subjects and spent a lot of time on preparation and on the teaching itself. In addition to that they all stressed that the subjects themselves were important, most also described how they could use the educational environment in different ways to support students with personal growth and maturation.

*Care and help*

The teachers described that giving students care and support, both practically and emotionally, was an important part of their job. In addition to the individual support tailored to each student's specific needs, the schools also offered inexpensive breakfast and dinner

every day, holiday trips and social gatherings in the evenings. Schools were also focused on offering safety, predictability and flexible solutions for both students and teachers.

### *Teachers: Mutual and respectful relations*

#### *Sense of community*

All informants described the school as a community and a fellowship, and they emphasised the good social environment. Teachers and students had obviously different tasks and different responsibilities, but they also had much in common. No doors were closed and no rooms were only for teachers or just for students. They ate together and they worked together. The informants described the work environment as good and with minimal hierarchical structure. They had much flexibility and influence over their own work, and both teachers and the principal attended the morning gathering with students.

#### *Teachers as humans*

Most teachers described that they were aware of how they themselves as humans could affect relationships with students, both positively and negatively. They described how their personal preferences were important for the work they do, and that their own interest in a subject or topic was important to be able to motivate and engage students. They also described how they actively organised their days to ensure that their own limitations would not affect students negatively.

#### *Relationships with students and students as humans*

The students attended school several days a week over a long period, often several years. Students and teachers therefore spent much time together in many different situations and came to know each other well. The relationships were described as mutual and based on cooperation. The teachers were aware of the students' difficulties, often knew they also knew individual diagnoses, but diagnoses and diseases were not used to describe students. When teachers spoke about specific situations that had arisen, they never used illness as an explanatory model, but focused on other causes such as personality, interests or various contextual factors.

### *Teachers: Acknowledging the individual*

#### *Acceptance and development*

Older students can attend school as long as they want, so no one are in a hurry. Teachers teach students, but neither require or expect rapid changes in their functioning or situation, and generally express a great deal of acceptance and patience. Teachers also described that they observe noticeable progress in students, on many different levels. The development and progress comes, but it comes naturally and is not pushed.

#### *The value of happiness*

It was important for teachers that students were happy, that they were happy at school and wanted to continue. They spent a lot of time in preparation and planning to make the teaching fun and interesting, and joy was seen as an independent value. The school also organized parties, excursions and other things so that students could have good experiences. This was seen as an important part of the school.

#### *Flexibility and limitations*

The teachers described how they in many ways adapted their teaching to the students' needs and desires. The starting point was always based on conversations with the students, so that their needs was in the centre. This was important for all teachers, but they also described the challenges involved in teaching students from different backgrounds and with different interests. The principals described challenges associated with an increasingly tighter budget, and how they regarded it as their task to minimize the effect this might have for teachers and students.

#### *Health care professionals: Top-down application of treatment*

##### *Organisational demands*

Healthcare workers described how a great deal of their daily work was related to running the ward. This included practical work, distribution of responsibilities and tasks among staff, and participation in many different meetings. They also told that they spent much time on paperwork, both reading and writing reports, journals and more.

### *Observations, discussions, and conclusions*

The healthcare workers also described that they spent a lot of time observing patients, conveying these observations to colleagues, receiving observations from colleagues and discussing observations as a team.

### *Treatment according to guidelines*

The ward offered various forms of treatment, including medication, group therapy, individual therapy, physical activity, psycho-education and milieu therapy. All treatment was based on the patients' diagnosis and on national guidelines for the treatment of the particular disease. The patients always had input on what they thought of their treatment plans, but it was the health professionals who made the final decisions.

### *Health care professionals: Professional relationships and distinctions between groups*

#### *Diversity and hierarchy*

All interviewees said they enjoyed the job, liked their colleagues and had a good working relationship with them. They described a good environment, but also an environment with a clear hierarchical structure and delineation between different groups. Patients and staff did not eat together or smoke together, and patients were not permitted to go wherever they chose in the ward. The specialists (doctors and psychologists) did not participate in morning gathering with patients, did not participate much in the milieu at the ward, and did not eat together with the milieu therapists at the ward.

#### *Cooperation and networking*

All informants emphasised that collaboration with other health care workers, particularly primary care health workers, was very important. Some described this cooperation as good, others described several challenges, and most were concerned over what level of support patients received at home. Many said they knew patients were very lonely at home and had only a small social network.

#### *Milieu therapy as relationship*

Good relations with patients was cited as important for all informants, particularly among the milieu therapy staff. They described safety, support, being together and conversation as

important elements in the treatment. When they were asked to describe their day, most described that they spent much time "in the milieu" or "in milieu therapy." This could include informal conversations with patients, participation in various activities (such as playing cards or games), but also sitting in the living room and reading the newspaper, or observing patients and intervening to regulate behaviour if necessary.

### *Health care professionals: Independence as a goal*

#### *Short-term Admissions and re-hospitalisation*

Patient stays at the ward were time limited. The average hospital stay was 3 - 4 weeks, although some were longer. Some informants thought that was too short, while others thought it was an appropriate amount of time. Several mentioned that the short time could lead to rapid re- admissions, especially for some types of patients. Many thought that the ward was best suited to patients with mild anxiety disorders and mild to moderate depression, - patient groups who could be helped in a few weeks. For patients with more complex and enduring difficulties, such short stays were less suitable and led to frequent re-admissions.

#### *Effects of treatment and demand on patients*

It was important for all informants that the treatment should have an effect, which meant that patients would become more independent and be able to manage at home. This was described as hard work, and it was important that patients were self -motivated, worked hard and not only were there to relax and have fun. The healthcare workers distinguished clearly between patients who according to the healthcare workers' experience worked well and became more independent, and patients they described as less motivated, childish or attention-seeking. The last group was described as un-motivated and not ideally suited for treatment.

#### *Service user involvement*

Both wards emphasised service user participation and, although there were small differences in how practice was carried out, both wards had routines to ensure service user participation. However, in both wards it was the staff who took all final decisions regarding the treatment, after the patients had been consulted. Several of the staff described that it



was rare patients' input led to significant changes. Many of the activities on the ward were mandatory and much treatment was standardised. If patients did not participate in the planned activities, this was often interpreted as resistance or lack of motivation or cooperation.

### **Summary across informants in this article**

Both the healthcare workers and the teachers described that they were genuinely interested in patients'/students' welfare. At the same time, they described that they were working under very different environmental conditions. These environmental conditions seemed to influence both their actions, attitudes, which social norms that were allowed to develop, and which professional relationships there was room for. There will certainly be a need for more research, but findings and interpretations from this study suggest that standard psychiatric health services are best suited to patients with short-term and limited mental health problems. For patients with enduring and complex disorders, often combined with childhood trauma and disturbances in sense of self, there is a need for other services. Central elements in such services will be much time, stable relationships and more focus on personal development than on treatment of symptoms.

## **7 Discussion of findings and interpretations**

In this section I will discuss the findings and interpretations across the three articles and the informant groups. Based on the exploratory research questions, several major themes have been identified through thorough analysis. I have found some common issues regarding the concerns of participants, but also discrepancies between the various groups' descriptions of the same themes.

I will review the primary issues which I have found, discuss the relationship between how the four informant groups experience and describes each topic, and discuss each topic and differences in the descriptions in relation to the research summarised in chapter 2. I will also discuss what implications the methodological decisions discussed in chapter 5 and the implementations of these may have for the main findings. Finally, I will give my assessment of which findings I think are most important, and what implications these should have for services to persons with severe mental disorders and for further research.

### ***7.1 Relationships between health professionals and patients and between teachers and students***

Both patients and students describe relationships with health professionals and teachers as very important and vital for recovery and development. Both patients and students described that they have limited social networks and few stable relationships. For students, this anyway was the case before they started at the school, although this has been changing for a proportion of them. Many also disclosed that they have had problems in childhood, and a large proportion described various types of neglect and abuse.

Bearing this in mind, it makes sense that it is precisely relationships to contact persons which is described as crucial, above descriptions of specific therapies, training or interventions. It also fits well with theories of psychological development that highlights contact with a primary care giver as crucial for the development of a stable self experience (Fairbairn, 1952 Winnicott, 1971 Winnicott, 1986, Stern, 1985, Bronfenbrenner, 1979, Bronfenbrenner, 2005). This also fits well with trauma research mentioned above, which highlights stable relationships as critical to developing or repairing regulatory systems that has not been successfully developed. (Bath, 2008, 2015, Ludy-Dobson and Perry, 2010, Siegel, 2012). And

it fits well with the recovery and psychotherapy research (Slade, 2009, Ljungberg et al, 2015 Topor et al, 2015).

The differences in how patients and students describe their own development is attributable to many factors. It can be understood in terms of how the various informants describe the content of and framework for relations with contact persons. For although both students and patients describe relationships with their contact persons as important and also generally good, the descriptions of relationships and interactive frameworks differ on several important points, and I will discuss some of these below.

### **Duration of relations**

Students described stable, sustained, lasting relationships, that they know the teachers and that teachers get to know them well. Patients, however, mainly describe a number of short-term relationships and a situation characterised by continuous discontinuity. Several of the psychological developmental theories point out that it is precisely stability over time which is crucial for development, (Fairbairn, 1952 Winnicott, 1971 Winnicott, 1986, Stern, 1985, Bronfenbrenner, 1979, 2005), and that the child has the opportunity to experience themselves through stable, predictable relationships with others (Fairbairn, 1952 Winnicott, 1971 Winnicott, 1986, Stern, 1985, Bronfenbrenner, 1979, 2005). This is described in Winnicott's theory of "holding" and "mirroring" (Winnicott 1971 Winnicott, 1986), and also in Fairbairn's object relations theory (Fairbairn, 1952), which describes how the influence of a stable loving care giver is required to form good self-representations in the child.

Recent research, based on neuropsychological theories about how the brain is shaped by use, highlights the same issues (in different terminology), namely that stable relationships are essential for the development of healthy neurological functioning (Bath, 2008, 2015, Ludy-Dobson and Perry, 2010, Siegel, 2012). Patients may feel better after a few weeks' stay in the ward with secure relationships providing a sense of wellbeing. However, since they quickly are discharged to solitude again, it is also natural according to this comprehension framework, that the development does not persist, and that momentary improvement does not lead to stable and lasting changes. To achieve lasting changes, there is a need for long term relations, like those described by the students.

## **Intensity of relations**

Students described their relations with teachers as intensive. Most patients, on the other hand, described no relationships that were both stable and intensive. They described intensive follow-up once they were inside the ward, but this contact was brief and also divided between several people. Outside the ward, most experienced far less contact. Those with most frequent contact had typically a 45 minute session per week, and often in a limited period. It is likely that this is too low intensity to have any real effect for this group, where the relationship itself is as important as the content of the conversation (Bath, 2015). Topor and Denhovd (2012) found in a study of 58 people with severe mental disorders that time was a critical factor for a good working alliance, which in turn made recovery more likely. Patients described that it was important to meet regularly, have a good time when you met, and to be undisturbed during meetings. While it is debatable what is meant by "undisturbed" in different settings (teaching vs. treatment), there is no doubt that the students spent much more time with their teachers and that this may have contributed to their development.

## **Reciprocity and quality of relationships**

Students and teachers described their relationships as reciprocal. Students said they collaborated on various tasks, that the content of the interaction was based on their needs and that they themselves could initiate contact if they wished. The teachers described that they had a bottom-up approach to work, and that students' needs were the base for what they did. They further described that their work situation gave them room to develop flexible approaches and much care.

This reciprocity was lacking in descriptions from patients and health workers. Several of the patients described that they often experienced not being listened to, were not taken seriously, and did not get the help they felt they needed. Health workers described a top-down approach to work, with restrictive guidelines and frameworks dictating what help they could give each patient. Not only the scope, but also the contents of the treatment was guided by external factors through extensive use of diagnostic-based guidelines. As there are external factors that govern much of the treatment, it is reasonable that patients do not

experience relationships as reciprocal. They cannot be reciprocal, because neither clinicians nor patients have complete control over the framework for the treatment.

This lack of reciprocity may again have consequences for the relationship. The descriptions of the relationships between health professionals and patients corresponds to what is described as distant relationships (Slade 2009). This is a common relationship type within mental health care, and it can work in certain contexts. But with the unequal distribution of power real development and recovery becomes difficult to achieve. As this model implies that the health worker knows best what interventions the patient needs, it will also be difficult to achieve the immediate and personal experience of "I am, I sense, I know what is good for me" - simply because the model dictates that there is someone else who knows better than the patient what their needs are. This also fits in well with the patients' descriptions of not being heard. It is also consistent with their descriptions of self-objectification, where they instead of describing their own needs, describe how others describe their needs.

Bronfenbrenner's theory of proximal processes (Bronfenbrenner, 2005) claims that for development to take place, the person must participate in an activity that takes place regularly over a period of time and which involves more people. According to Bronfenbrenner, however, it is not just the duration that is important, but also that the relationship is mutual and characterized by cooperation. Ljungberg et.al. (2015) did a meta-analysis of 21 studies to explore what patients experienced as helpful and useful in relation to health workers. Their findings show that what patients emphasised as useful was spending a lot of time with health workers, that they got access to resources and support, and that the relationship was characterised by mutual cooperation (Ljungberg et al, 2015). It is therefore possible that the difference between reciprocity and control in relationships may have contributed to differences in development for patients and students.

### **Relation as "base" and "safe haven"**

Students had the opportunity to be students at the school for a long time, for older students as long as they themselves wanted. Patients, however, were discharged when health workers felt they were better and no longer needed the support. This provides a special framework for relationships. On the one hand it is a prerequisite for a relationship that it will

"work", e.g. lead to improvement for the patient. This is underlined by all health care professionals - patients should not be on the ward only to "enjoy themselves", but in order to receive treatment. At the same time, according to national guidelines, the usefulness of the treatment should be assessed against the treatment cost (Nord, 2002). If the relationship is good enough so that the patient is experiencing improvement, that the treatment has been "useful" and results have been achieved, it will be ended, often against the patient's will. This could have been unproblematic if the patient had other secure relationships such as family or other networks, but becomes more challenging when the patient is discharged to loneliness (paper 2).

Attachment theory (Ainsworth et al, 1971, Ainsworth et al, 1978 Bowlby, 1969), emphasises that children need both a safe base to explore the world from and a safe haven to return to after exploration, when they are tired, scared or frustrated (Hoffmann et al, 2006). Although these theories dealing with infant development are the fundamental factors in the model - a safe base to explore from, and a safe haven to return to, they coincide with the students' descriptions. Patients, however, have partly safe havens - they can be admitted when they get ill. However, since they often experience rejection when they want to be admitted, this haven isn't really safe. The base is also only partly present and for a very limited time - both patients and clinicians describe that patients are encouraged to quickly cope and become able to be discharged. However, when coping and managing on their own is achieved, it leads to a break in the relationship. The base will therefore seldom be perceived as safe, because it is temporary. This is confirmed by research on 'user-controlled beds', where the patients have the opportunity to return to a "safe haven" for a few days at their own request. This seems to be an important prerequisite for coping and autonomy, and contributes to the documented reduction in the use of total bed days by patient with contract of "user-controlled beds" (Heskestad, Tytlandsvik, 2008).

### **Systemic constraints**

There is nothing in this material indicating that health care workers have less ability than teachers to develop stable and good relationships, or that there are characteristics of the Norwegian patients which makes it difficult to develop such relationships. Although patients describe a number of challenges related to relationships (lack of reciprocity, not being taken

seriously, lack of intensity and stability), they also describe relationships as good, saying that it is the social contact in the ward with safety and conversations, which is important to them and that they want more of. Nor is there anything in the material which would indicate that healthcare professionals have an unwillingness to develop relationships. Many told that relationships with patients are the most important to them, and several mentioned that they would like to have more time, especially with some patient groups. It is therefore not the characteristics of patients or health professionals which appears to preclude the creation of the relationships that are necessary for self-development, but rather the limits, norms and general guidelines of the system, which imposes limitations for both healthcare professionals and patients.

## ***7.2 Social fellowship and reciprocity***

In the student interviews, there was much reminding of the model of a family structure, where the teachers had a role as "parents", and appeared to be role models, support workers and caregivers, and where fellow students not only had the role of friends and classmates, but also of siblings. The activities, consisting of basic care, food, physical activity, learning and development with a gradual adaptation to an increased workload and more responsibility, reinforced this impression of the family. The relationship with teachers was important and eventually also the interaction and relationship with schoolmates, students also even used words like "family" and "siblings", although the most common term for classmate was "friend". They described that they looked forward to coming to school and meeting friends, and they described the typical pleasures of friendship like discussing problems, doing things together, talking, laughing, sharing experiences and having a good time together.

These descriptions fit in well with several of the aforementioned theories of normal identity development. For infants and toddlers, the connection to the primary caregiver is most important, and this was also important for students and patients, as described previously. As the child grows, mutual cooperation and participation in a community of equals is important for development (Bronfenbrenner, 2005, Stern, 1985). Bronfenbrenner's proximal processes means that learning and development is done in collaboration with others, whether through dyadic processes or other interactions. Mead, as a key representative of symbolic

interactionism, highlights that when we talk to others, we ourselves are also recipients of our own message, while also creating our own self through interaction with others - so that the self is a social self (Mead, 1913, Mead, 1936). Our "self" interacts with other "selves", such as when students speak empathically to and about other students with similar needs, and hears others do the same. This provides signals to the student himself, both in relation to the person he is, and how he expects others to relate to his problems.

### **Friendship and usefulness**

Patients also described the relationship with their fellow patients as important, but they described it in other ways. None of the patients used the word friend and they highlighted primarily usefulness of the other patients in their descriptions. This included that contact with other patients were perceived as an arena for training in social skills, - but also that by hearing about the experiences of others, they could learn from them and possibly use the same methods themselves. Some also mentioned that by hearing how unwell others were, they were able to feel better because they considered themselves as healthier than that person. These kinds of statements are in stark contrast to statements of students, who emphasise that although the social environment and contacts with friends is among the most important in school, it can be stressful and painful to see that these friends at times are very sick and suffer. The interpretation of similar experiences were therefore described quite different – what the patients perceive as something which strengthens them, was perceived as a burden by the students.

A part of the explanation for this is possibly the patients' strong emphasis on usefulness of fellow patients. Where students had developed a friendship and natural empathy that made them sad when others were in pain, patients focused more on the personal usefulness to themselves of the others' descriptions. This is probably not due to insensitivity but rather the social norm that the purpose of the treatment was personal benefit and improvement of their own health. Several of the patients said that they were encouraged by therapists and support workers to use "the milieu" (i.e. the other patients) to "work with their social anxiety." Others described how they were told that they should work on getting a larger social network, since relationships can be beneficial for mental well-being. This focus was further confirmed through interviews with health professionals, where they repeatedly



emphasised that the patients were on the ward to get better, not to "just have a good time." Ringer (2013) found in a study of patients in a psychiatric ward that patients often adapted their attitudes, statements and actions so that these matched what they perceived as acceptable social norms of the ward, and it is likely that such processes may have occurred here.

Social relations are a crucial factor for recovery in patients with severe mental disorders (Schon et.al, 2009). It does not mean, however, that having this type of extrinsic motivation to create a friendship is necessarily a good strategy. (Ojanen et al 2010) showed in a study of healthy young people that with extrinsic motivation one may easier get many friends, but they are more volatile and less lasting than when intrinsic motivation is the basis for interaction. These results suggest that establishing friendship based on intrinsic motivation is more demanding, but in return leads to more lasting relationships.

Although the study by Ojanen focused on children and youth, it is still interesting in this context, since it says something about how the motivation to relationships affects the development of friendship over time. As the patients focused on usefulness, and also were encouraged to do so by the staff, it is possible that it will be harder for them to develop friendships that will last over time, both in friendship to fellow patients and also to people outside treatment settings. Friendship is often considered to have a value in itself, and this focus on "usefulness" may also violate the social norms in the society of what friendship should be.

Since social relations are so crucial for recovery (Schon et al., 2009) it will be particularly unfortunate if patients are encouraged to use less appropriate strategies to understand what friendship is and how it can be created, fostered and nurtured. It is possible that it would have been more appropriate if staff used other strategies rather than referring to extrinsic motivation when encouraging patients to establish relationships. However, more research on this is needed to provide more certain conclusions about what would be most appropriate.

However, not only the motivation for friendship, but also the time perspective is very important here. Students attended school for a long time and had therefore plenty of time to get to know their fellow students and develop friendships. Most also described that over time they had got more friends, were less lonely, and that they felt that they themselves

were a better friend now. Patients, however, met other patients usually only for a short time in the ward, and although some said they had tried to maintain contact outside the ward, this was usually not very successful. They described no development in terms of relationships, they were as lonely as before, and no one said that they had developed their role in social relations. This fits in well with the findings of Ojanen (2010), which states that friendships need time to be developed and maintained, and that being a friend also requires skills that must be learned and developed over time.

It is known that severe mental illness will affect the ability to enter into reciprocal and stable social relations, and it is not surprising that patients are lonely and struggle to establish stable friendship (Harley et al 2012, Rocha, Queiros, 2013). What is more interesting is that students with similar diagnoses say that they have had the same problems before, but that they don't anymore. As relational difficulties are common in people with severe mental illness, especially psychosis, special training is available for correcting cognitive bias and to improve relational abilities (Rocha, Queiros, 2013). While these programs appear to be effective in some areas, the overall effect appears to be somewhat limited (Rocha, Queiros, 2013). Students in this study, however, has not received any systematic training or correction of cognitive style. They have however been given the opportunity to participate in social relationships with fellow students, and with teachers as active participants and role models in this social interaction several hours daily and several times a week over a long period of time. It is therefore possible that this intensive and long-lasting social training in a natural environment gives better results. If so, this would be consistent with modern principles of learning, such as those adopted for work. Earlier one often chose to train people with special needs in a special environment, and then hoped that they learned the skills needed and be able to apply these in ordinary jobs. This was in practice often inefficient and has been replaced by methods such as Individual Placement Support (IPS) (Bond and Drake, 2014). With this method training takes place directly in the job, without the need to first learn skills in one location and then transfer them. This method has had far better results than previous methods based on transfer of learned skills (Bond and Drake, 2014). It is thus possible that the same principles are valid also for social learning, and that this might explain why the students have such good relational development without specific training. This is probably also highly complex processes also involving other factors.

### **7.3 Coherence across life domains**

One of the most striking things in patient interviews was the continuous discontinuity described by the patients and the apparent lack of connection between different life domains. Connection between different life domains is central to Bronfenbrenner ecological model. His second system, “the mesosystem”, deals with precisely these relationships between the systems that the child belongs to, how they mutually influence each other, and the importance of interaction between the systems (Bronfenbrenner, 1979).

The importance of coherence between different life domains is not only central within developmental psychology, but is considered particularly important when it comes to treatment of complex and prolonged disease, and is among other basis for the establishment of the Norwegian coordination reform. Already in 2001 it was therefore determined that "citizens who need long-term coordinated services under the health and care services law, the specialist health services law and the mental health services law have the right to have an individual care plan" (Prop. 91 L, 2010-2011, Law on Municipal health services, etc.). Enactment of an individual care plan has several purposes, including ensuring that patients receive comprehensive, coordinated and individually adjusted services, ensuring real service user involvement, and ensuring collaboration between the patient (and possibly relatives) and service providers, and collaboration between service providers.

All patient in this study had a need for long-term, coordinated services according the relevant laws, and they were thus in the target group for individual care plans. However, they were not asked directly if they had an individual care plan or not, so I don't know how many of them actually had such a plan. What is known, however, is that none of the patients mentioned this spontaneously in the interviews. One patient mentioned a single coordinating meeting at the ward before discharge, but he didn't say if he had experienced this as helpful, or if concrete plans had been drawn up, his description focused on the fact that he was terrified before the meeting, and happy afterwards, that he had “survived”. None of the other patients mentioned plans, collaboration or coordinating meetings when they were asked what they had done, what their daily life was like, how the treatment was or how they envisioned the future. It is of course possible that some (or all) had an individual care plan, but anyway it had no prominent place in their daily lives or consciousness. All patients also described the services they received as fragmented, random and without any

coherent plan for rehabilitation or treatment. This is very unfortunate, since a great deal of research, including regarding ACT teams, has shown that multifactorial, coherent and long-term treatment is essential to achieve improvement in severe mental illness (Caslyn et al, 2004, Dieterich et al, 2010, Aagaard, Muller-Nielsen, 2011). There are also strong indications that recovery processes in severe mental illness are largely relative to factors outside treatment such as economic conditions, social support, access to good housing and meaningful day activities (Topor et al, 2011). Many patients will need various forms of assistance to achieve good quality of life within these life domains, and cooperation between support staff is important.

As far as I know, there are no equivalent to the Norwegian individual care plan in Denmark, and none of the students mentioned something like these plans. However, many of the students described a similar situation as the patients, with little coordination, but these descriptions were of their past. They described how they earlier had received help from various support systems, how they continuously had to relate to new case officers and helpers, and that assistance was both entirely dependent on who they got help from, and also poorly coordinated. In contradiction to these descriptions of the past, most of them described that they now saw the school as a co-ordinating unit. Each student made plans with their supervisor every semester, with personal goals for what they were going to work on for the next six months. This could be purely personal goals, professional goals, or a combination of the two. In addition, they described that it was important to them that they could discuss all kinds of problems, also purely practical, with teachers, and possibly also with fellow students. The teachers confirmed this by describing that practical help, care and support in a variety of areas was an important part of their working day, and something they considered as crucial for students to develop and get a better life. Teachers could also participate in meetings with local authorities and other aid agencies, which were described by the students as very useful and important. Most students described that they needed less help than before, but those who still needed help from agencies outside the school described that it was now better and more individualised, and that they behaved more actively in relation to this help now, and said what they needed and how they wanted to use the help. These descriptions are in agreement with research which underlines the

importance of coordinated and practical help to support recovery processes (Topor et al, 2011, Caslyn et al, 2004, Dieterich et al, 2010, Aagaard, Muller-Nielsen, 2011).

### **Dependence and independence**

It is also interesting that the teachers did not express any concerns related to offering the students a lot of support. This was in clear contrast to the descriptions from the health personnel, who were concerned that the patients, to the greatest extent possible, should become independent and take care of themselves. Paradoxically, the descriptions from the students and patients indicate that the students who received a lot of support, became far more independent than the patients who received limited support and were encouraged to be independent. However, these seemingly paradoxical descriptions become meaningful, if one looks at the importance of knowing that help is available when necessary. As mentioned previously, easy access to admissions for patients with schizophrenia led to a slight increase in admissions, but at the same time, taking everything into account, fewer days in hospital (Heskestad & Tytlandsvik, 2008). Rusner et al. (2010) found that various forms of dependency could be positive and necessary for improvement for patients with bipolar disorder. This dependency included that others were dependent on the patient and trusted him/her (similar to the students' descriptions that is important for them to go to school because the other students are waiting for them) and that they themselves have a dependency relationship to others and know they can get help, support and care when they need it (Rusner et al., 2010).

### **Psychotherapy**

Even though the students described that they experienced a lot of support and profited from this, the access to long-term psychotherapy is still severely limited in Denmark. This was something that several students mentioned that they missed. Some had previously received this periodically. They believed that a holistic provision that also included therapy as an integral part (for example, of a school programme) would be very useful for them. The few Norwegian patients who had the provision of long-term psychotherapy also experienced this as being predominantly helpful, but at the same time insufficient. There were usually just 1–4 hours per month, which was of too low intensity considering that the rest of the week/month was fairly empty of content. However, recent research indicates that

psychotherapy, including relational psychotherapy, can be effective in severe mental illness (Brus et al., 2012, Guthrie, Moghavemi, 2013, Gardfield, Steinman, 2015). Thus, based on the descriptions from both students and patients, it would be relevant and interesting to see if a holistic service provision, consisting of both psychotherapy and social support, would be even more effective than just the social support alone. However, such a provision would need to be given carefully attention. It would also be very crucial that any therapy that was implemented should follow the principles that otherwise applied for the school programme.

#### ***7.4 Development takes place over time***

The importance of time and the duration of interventions have already been discussed several times. The crucial difference between the students' and patients' descriptions is that while the students have had the opportunity for a cohesive, coherent and stable provision over a long period of time, the patients describe a situation characterised by chronic discontinuity, with constant shifts between the security at the ward and the loneliness outside. By definition, time is the core of development, and also within learning processes that are developed gradually over time. As mentioned previously, all developmental psychology theories have time as a key factor, where development within one area provides the possibility for further development in other areas (Fairbairn, 1952; Winnicott, 1971, 1986; Stern, 1985; Bronfenbrenner, 1979, 2005). Constant repetition of routines and stable relationships over time are also essential for developing regulatory systems, or if necessary, for repairing any missing ones (Bath, 2008, Ludy-Dobson & Perry, 2010; Siegel, 2012). The time factor is also important for developing stable and secure relationships over time.

Research on recovery and the course of severe mental disorder supports this assumption (Topor & Denhovd, 2012; Slade, 2009; Landheim, 2016). Strauss et al., (1985) describe eight different longitudinal processes in schizophrenia. These include a non-linear development, as well as identification of different phases in the development. Strauss et al. describe how the development can periodically appear to halt, but what really happens is that the patient needs time to consolidate what has already been achieved before he is ready to move on to a new level (Strauss, 2009).

Because time is so crucial for the development of self-experience, regulatory systems, relationships and skills, it is likely that there is a connection between the described

differences in development and the described differences in time and continuity. This is, of course, related also to other factors. Even if the patients' time in psychiatry is comparable to the students' time at school, the big difference is that the students' provisions have been coherent and holistic, while the patients' provisions have been fragmented, marked by discontinuity and constant disruption. Thus, the patients' situation has not provided the same possibility for development over time.

### **Time limitation's impact on the staff's attitudes**

Completely different approaches to the meaning of time can be found in the descriptions given by the teachers and health workers. Although both teachers and health workers expressed that they were concerned with students/patients and wanted to help them, some of the health workers expressed, in part, moralistic and negative attitudes. This was partly expressed directly in interviews, as well as by health workers and patients who reported about other health care workers who had negative and/or moralistic attitudes to patients. Sometimes there were descriptions of actions (both actions of the informant and actions of others), which can be characterised as aggressive and somewhat unprofessional. No such descriptions were given of teachers, either directly or as descriptions by other teachers. Again, it is possible that this can be due to variation in the sample and characteristics of the individuals. However, it is possible that this may also be due to other structural factors, including time.

The teachers' main task was to teach subjects to the students. The framework allowed them to use a lot of time on the relationship and to exercise a high degree of flexibility. This is a task that the teachers largely had control over themselves. and the task is certainly possible to carry out. The health workers' task, however, was to cure the patient's mental disorder, focusing on symptom changes and behavioural changes. They should do this in a very short time, optimally within three weeks, the average length of inpatient stays.

The target group for this study was patients with severe and long-term mental disorders, and all student and patient informants were within the target group. The teachers worked mainly with students within the same target group. However, at the district psychiatric centres in Norway, there are patients with various disorders. When the health personnel described their working days, they described their work with *all* of the patients, including the

patients with milder and more short-term mental illness, such as a single episode of depression or short-term and specific anxiety disorders. In contrast to the patients in this study, the patients with short-term and limited disorders usually had an acceptable home situation. Many of them had family, friends, work and leisure interests. Some of them would have difficulties in some areas, such as recently experienced divorce or work conflict. However, usually they would mostly function satisfactorily. For many of these patients with limited and short-term problems and a comparatively good home situation that motivated them for discharge, the goal of symptom change in the course of three weeks was realistic. For patients with a short-term depression, treatment consisting of rest, sleep, medication, cognitive therapy, psychoeducation, physical activity and support can give good results within a few weeks (Norwegian Directorate for Health/Helsedirektoratet, 2009). This was also described by health workers in this study. They reported that these patients could benefit from a stay on the ward, and they said that it was nice to see deeply depressed patients get better in a short time. For health personnel, of course, this is the optimal process: severe ill patients are admitted, receive prescribed treatment, become well after a few weeks, want to be discharged, and are not readmitted to the ward.

However, for the patients in the study, it is more complicated. As mentioned previously, most of them had been ill for many years, and many had had difficulties since childhood. Although some patients (especially psychotic patients) can experience a slight short-term improvement, and/or get through a crisis with the help of medication, usually in combination with rest and sleep, this will usually not result in any lasting improvement or recovery. Patients will usually be referred again later. For the group of patients as a whole (including patients with severe personality disorders), it will be practically impossible to offer effective treatment with the aim of lasting improvement or change in their situation over the course of three weeks (Alanen et al., 2009; Huprich, 2015). The health personnel's commission is thus impossible — in any case, within the given time period.

In addition, one of the main tasks of the health personnel is to motivate patients to change behaviour. This could mean achieving a better day rhythm (getting up in the morning), stopping self-harm, becoming more independent and autonomous, and desiring to be discharged from the ward. However, for these patients, improvement would mean that they would have to leave the ward and go home to a situation that most of them described as



being characterised by severe illness, high symptom pressure and extreme loneliness (Paper 1). It is always difficult, usually impossible, to get others to change if they do not want to do so. In many cases, when the patients had limited motivation for changes that would lead to rapid discharge, the task of the health personnel became very difficult, and in practice often impossible. This sense of hopelessness was also described by the health workers, especially when they described the resentment they could feel when they had worked with a patient and had him/her ready to be discharged from the ward, only to find that the patient had returned with a new crisis and new referral after a few weeks.

It is possible that precisely this feeling of inadequacy can explain some of the judgemental attitudes, in that health personnel experienced the need to put the responsibility on someone else or something else other than themselves (e.g. the patients' lack of motivation or aptitude) when they experienced "not succeeding" with the impossible task.

Being forced to perform tasks that require you to do something, at the same time that you have little control over the result, can lead to stress, burnout and irritation (Karasek, 1979; Premeau, 2014). Even though these are probably complex processes, where individual and contextual factors contribute (Premeau, 2014), the requirement of action, combined with the degree of control would be able to predict the level of stress and irritation in the staff. It has also been shown that different types of stress, combined with personal factors, can lead to compassion fatigue, burnout and lack of empathy in health workers (Adams et al., 2006; Harrison & Westwood, 2009). Reynolds and Scott (2000) found that nurses often had limited empathy with the patients and that this had negative impact on the patients (Reynolds & Scott, 2000). However, there was no indication in the findings and interpretations in this study that indicated that the health workers I interviewed were burnt out or lacked empathy with the patients. On the contrary, even if someone reported about some conditions they were unhappy with, all informants expressed great satisfaction with their work and said that they were happy on the ward, with their work and with their colleagues. They also expressed a lot of empathy with the patients in general. The statements that were less empathetic, or moralistic and/or judgemental were solely related to patients with long-term and complex difficulties. It is known that it can be stressful for health personnel to work with patients who have severe psychiatric problems, and who may also have experienced trauma. It is therefore possible that the lack of empathy for the patients in this group can be explained by

secondary traumatisation (Newell & MacNeil, 2010) and/or transference reactions. If this was the case, however, it would be natural that also the teachers who worked with the same patient group would describe some of the same attitudes, but none of them did so. Of course, this may be due to coincidence. However, it is likely that the differences, at least in part, may be explained by differences between the tasks of the teachers and the health workers. The teachers' task is to teach students with no time pressure, which is certainly possible, while the health workers' task is not possible and creates frustration which is then taken out on the patients.

### ***7.5 Everyday care, joy and activity***

Both students and patients described that regular care and support in everyday life was important to them. For the students, in addition to their relationship to teachers and fellow students, this was especially about the importance of structure, that they knew that they had something to go to every day. In addition, they described that it was important to them that the school served good and inexpensive food and that they could eat with others, and that they were offered several different types of adapted physical activities, including outdoor activities. The same factors were also described by the patients. They appreciated and benefited from their relationship with the staff, regular meals, excursions, activities, support and care. Of course, the difference between the groups was that the patients experienced this support on a 24-hour basis for a few weeks at a time, while the students had access to support and daily care mainly during the day (9 a.m.–4 p.m.), five days a week, for a long period of time.

In developmental psychology, stable, flexible and accommodated care is considered to be quite central. First, it is necessary for the infant to actually be able to survive. However, as previously mentioned, Winnicott's term "holding" (1965, 1971) can be understood in a purely concrete sense, as well as in a figurative sense. Through the concrete care given that is necessary for the survival of the child, the child is also given nonverbal signals that it is desired, welcome, seen, and taken care of. Winnicott emphasises the importance of that care being flexible and adapted to the child (1965). When the child (or the adult students in this study) experiences the provision and the care they receive as being individually adapted to their needs, they experience being seen, acknowledged and desired as individuals.

According to Winnicott's theories and the students' descriptions, this is important for the development of a secure, subjective self. This is also confirmed by other research (Slade, 2009, Topor et al 2011, Topor et al., 2014, Landheim, 2016) that show that material conditions and practical support have great significance for recovery and personal development.

Patients' descriptions also confirm this, when they describe that their stay on the ward actually helps them and ensures that they get better. Several of the patients, however, react negatively to the number of rules and norms and to the top-down approach to treatment, as described by health personnel. This corresponds well with the emphasis of the importance of individually adapted care. It is likely that this lack of flexibility, combined with the short time that the patients are at the ward and the loneliness they experience at home, may explain why the improvement they experience is not lasting. The care is good enough to provide an effect, but not lasting enough to give a long-term and stable development.

### **Joy and play-based activities**

The different groups of informants also gave very different descriptions of concepts such as "happiness", "pleasure" and "well-being". The students talked a lot about joy, that they were happy, were feeling good, were doing well, that the school gave them a number of good experiences and that this had contributed positively to their development. These descriptions were supported by the teachers' descriptions. The teachers viewed this as one of their important tasks to help ensure that students felt secure, felt good, had good experiences (especially since many of them had bad experiences and little joy in the past), that they were happy in school and wanted to attend classes. This focus is reflected in their attitudes, in practical arrangements and in the prioritisation of everyday life. It was important that students were happy in school, felt good and wanted to continue school.

Several developmental psychology theories emphasise that play is a necessary and important part of child development (Winnicott, 1971, 1986; Stern, 1985; Bronfenbrenner, 2005). Winnicott describes people as basically creative. He claims that children—and adults—who have experienced secure enough relationships, automatically use various forms of play to create individual representations of reality. He calls these representations "potential room", that is, opportunities to deal with facts in a playful, creative and

innovative way. In doing so, events that have happened are processed, and space is created for further development. For adults, such play-based activities include art, experiences in nature, various physical activities, and other forms of playful or creative outlet. This also corresponds well with the research on trauma theory (Perroni, 2014; Panksepp & Biven, 2012), claiming that the traumatised brain heals faster when it is in a state of playfulness and security.

It is interesting that security is a central starting point for play for both developmental psychologists and trauma researchers. First, the child (or the adults) must experience feelings of security, stability and care, before they can begin to play. This makes good sense when one reads the descriptions from the students and teachers. Both groups of informants emphasise how the students' relationship to the teachers, the safe setting at school, care and support are essential prerequisites for enabling the students, gradually and slowly, and over time, to let themselves go in creative activities. They increasingly experience joy, which in turn gives them new developmental opportunities. The students gave concrete descriptions of the various creative ways they use school subjects to work with themselves and their own challenges. This corresponds well with Winnicott's descriptions of potential rooms and with trauma theory's emphasis on the importance of play for the development of more flexible regulatory mechanisms and for overcoming previous trauma.

### **Attitudes to joy and well-being**

However, the students' and teachers' descriptions of joy are clearly different from the descriptions given by patients and health personnel. The patients said they liked to stay at the ward, but spoke little about joy. They emphasised several times that being there was "hard work". When the patients were at home, most of them described an everyday life with loneliness, pain and illness. They said they suffered through the days. Descriptions of joy were totally absent in the home situation. Health personnel also emphasised that it was important that the patients should not enjoy themselves too much at the ward. Several of them emphasised that the patients were at the ward to work and not to enjoy themselves. If they enjoyed themselves too much, it could be difficult to motivate them to leave the ward. Here we see that health personnel and teachers have completely different motivation. The teachers want students to feel comfortable and to want to continue attending school, while

the health personnel want to get patients out of the ward as soon as possible. First and foremost, these differences are due to different contextual and systemic conditions, as well as the fundamental differences in the health workers' and teachers' concept of learning. Such epistemological differences can greatly affect what we see, how we interpret what we see, and what measures we deem necessary (Ekeland, 2014). It is natural that teachers want students to be happy at school. For teachers in general, regardless of where they teach, one goal is to prevent dropout and motivate the students to complete their education. The framework is different in these schools, in that there is no exam. Even so, it is likely that the usual norms and the normal epistemological foundation for teachers (that students should be happy and want to attend school) is active also in this context. However, for health personnel, the situation is completely different. They have a medical epistemology, focusing on getting patients better, off the ward, and home to continue with their life. There are also regulations imposed by the authorities and managers to maintain a limited length of inpatient stays and to follow treatment guidelines. In addition, the wards also have waiting lists with other patients that need a place as soon as there is a free bed.

These practical and epistemological conditions are in addition to more specific professional considerations. Many patients in this group want frequent and long-term admissions, which also was expressed by several of the patients in this study. They would like to be hospitalised more often, quite willingly for a longer stay each time. Even if this is the wish of the patients, it is not always appropriate. Long-term admissions on inpatient wards can have unfortunate side effects for all patients. It is considered as particularly unfortunate for patients with severe personality disorders because it usually leads to patients quickly becoming more ill (Bateman & Fonagy, 1999; Paris, 2004; Mehlum & Jensen, 2006; Paris, 2011; Biskin & Paris, 2012,). Therefore, it is often recommended that these patients should not be offered admission. In the exceptional case that they are offered admission, the inpatient stay should be of very short duration and limited to the acute crisis situation. (Bateman & Fonagy, 1999; Paris, 2011; Biskin & Paris, 2012). This is also reflected in the Norwegian guidelines for the prevention of suicide in mental health care (Norwegian Directorate for Health and Social Affairs, 2008), as well as in international guidelines for the treatment of borderline personality disorder (National Institute for Health and Clinical Excellence, 2009).

As mentioned previously, however, regular outpatient treatment is often not intensive enough to be effective for this group of patients. The students' descriptions of the school programme as a safe, stable and lasting provision, with a framework that does not encourage regression, is interesting as a possible alternative to inpatient treatment. This is also supported by studies showing that day treatment in an institution may have good results for many of these patients (Bateman & Fonagy, 1999; Paris, 2004). It would be especially interesting for further studies to explore whether such an adapted school provision, with its less demanding and long-term approach, may be an appropriate alternative for patients who do not benefit from more structured, demanding and time-restricted day-treatment provisions, such as an outpatient day clinic.

At the same time, several students mentioned that they missed psychotherapy. Those who had received psychotherapy previously, believed that an integrated provision, where the school's teaching and social environment was combined with therapy, would be optimal. This is supported by studies showing that a multifactorial approach is appropriate in severe and complex mental disorders (Topor et al, 2011, Caslyn et al, 2004, Dieterich et al, 2010, Aagaard, Muller-Nielsen, 2011). This would therefore be relevant to explore further in future studies.

### **Attendance at schools vs day centres and gathering places**

Several of the Norwegian patients reported that they have or have had provisions to use municipal day centres in the periods they were living at home. However, they had either never attended the day centre or had only used it for a short period before they quit going there. This corresponds with the students' descriptions. The majority of them also said that it had been difficult for them to attend school in the beginning. The differences were that the students reported that it now was much better and that they actually attended school regularly without major difficulties.

There can be many reasons for these differences. An obvious possible explanation lies in selection and recruitment. Since I recruited students at the schools, I of course got to talk with students who actually took advantage of the provision of schooling. This does not prove that there are not students who drop out from school. In the interviews the teachers also described that some students stopped attending school, even if they still had a need for the

provision. However, this concerned relatively few students. Moreover, the teachers reported that several of those who quit returned to school at a later time. However, this did not apply to all of them, of course. It is not possible from this study to say anything for sure about whether there are more or fewer students that quit schools compared to patients that quit the municipal day centres. This must eventually be explored further. At the same time, several students reported that they had previously tried to use the Danish “gathering places”, which are similar to the Norwegian day centres, but they had stopped going because it did not function for them. This may indicate that there may also be other reasons, independent of selection, which may explain any differences in attendance.

What is known is how students and patients describe their own attendance at schools and day centres, respectively. The students described that it was difficult in the beginning, but that it was important to them that the teachers phoned them every day, without rebuking them, but only to tell them that they were missed and that they were welcome the next day. This was important to them, both knowing that they were remembered and missed, and being assured that no one was angry, that they had not “burnt their bridges” by not showing up and that they were welcome back. This corresponds with the patients’ descriptions, that when they had first been away one or more days, they felt it was difficult to come back. This also corresponds with the research that says that the personal relationship is extremely important for self-experience (Fairbairn, 1952; Winnicott, 1971, 1986; Stern, 1985; Bronfenbrenner, 1979, 2005), combined with that fact that someone is waiting for you and wanting you to come.

### **The importance of school subjects**

The students described that one of the differences between schools and gathering places was that it felt easier to go to school because it was less demanding. This may seem paradoxical since gathering places do not require anything, while schools focus on teaching. However, for people who are very anxious and socially insecure, it may be easier to sit in a structured classroom situation (where a teacher teaches a topic) than to deal with an unstructured social situation with small talk. This is confirmed by the fact that many of the most ill students reported that they mainly took theoretical subjects, where they could only sit and listen, because the practical subjects were too complex for them. Many students also

stressed that they experienced security and well-being when they were at school and learned something, without being forced to tell their personal story, share symptoms, traumas or anything else. Both learning something new and not focusing on their own troubles were described as easier. This can be a possible explanation, along with other conditions, for why going to school is perceived as being easier.

As mentioned earlier, there are many similarities between the Danish schools and the provisions that can be found in Norway, such as the Norwegian Labour and Welfare Administration courses and day centres. However, one of the major differences is precisely that the school's goal is to offer students new knowledge and new experiences rather than encouraging the participants to talk about their own life/own problems and/or participate in work/work training. This is confirmed by the patients' descriptions. None of my patient informants participated in work training. They described a weekday that primarily focused on their disease and their own problems. When they were asked to describe their daily life, most of them described few or no interests or activities that were not related to disease and/or treatment. Some said that they would like to learn something, get activities or friends, but that this had to wait until after they had become healthy. This may be an appropriate strategy for short-term disease progression and for acute injuries. However, it is a riskier strategy when the person, like my informants, had been sick for very many years.

The students had been ill an equally long time, but they used a different strategy, by being engaged in activities, even before they were healthy. They described that within the adapted framework of school, they learn new things, rather than talk a lot about their own disease. This was experienced as being positive and meaningful. They also told that the focus on academic subjects resulted in less disease talk during the breaks, which they perceived as positive. It is also possible that collaboration on joint projects, beyond disease, has had a positive effect on the students. This is expressed in several theories (Winnicott, 1971, 1986; Stern, 1985; Bronfenbrenner, 1979). As the child grows and after the person has become an adult, an important part of the development of the self is that one can share interests and activities in mutual fellowships. Therefore, it is possible that it is not just the "not talking about disease" that is in operation, but also the sharing of interests with others who are occupied with the same thing as themselves, both fellow students and teachers.



All the students described that learning something, no matter what, was important to them. It gave them a sense that they were able to master something, learn something new; they had the possibility for development. Their descriptions were a lot about development, mastering, change and personal growth, all factors that are key elements of concepts such as flourishing. They are closely related to personal growth and well-being (Keyes, 2007). They described also that learning new skills gave them new possibilities, including social ones. If you can cook, you can invite a friend to dinner. If you can discuss poetry, you can attend a poetry festival. This corresponds with research that shows that improved social functioning and the possibility to participate in positive and meaningful activities are closely linked to better self-esteem and mastering in patients with severe mental illness (Shahar & Davidson, 2003).

Having knowledge and being able to participate in new social contexts can also have consequences for the development of identity and self-experience. When the students and patients were asked to introduce themselves, the patients focused mainly on disease, while the students mostly mentioned interests or skills, in addition to relationships and other things.

Many students also mentioned specifically that the theoretical and philosophical topics were important to them. Some said that it was easier for them to participate in the common social situations and conversations when they were up to date on current topics and thus were able to discuss news and other things. This corresponds with the knowledge that improved social functioning is useful for this group of patients (Shahar & Davidson, 2003). Other students described that the subjects themselves (especially psychology, philosophy, history and literature) were important for gaining a better understanding of oneself and others, along with a more reflective attitude on life. Dorwrik et al. (2012), found that participation in literature groups was important for patients with depression. It was also the content of what was read, not only the social situation, that was relevant (Dorwrik et al., 2012). Other studies have also found that reading groups can have a positive effect on cognitive and psychosocial functioning in patients with psychosis (Volpe et al., 2015). However, there is currently relatively little research on the effect of teaching in philosophical and psychological topics, including the reading of fiction, on this patient group. Other findings and interpretations from this study (such as the importance of relationships and the importance of development

over time) are supported by much other research, but in this area there is far less relevant research. However, the findings from this study and their interpretation, combined with the little research that is available, indicate that this is an important area that should be explored more closely.

## ***7.6 Health, recovery and empowerment***

There was a big difference between the students' and the patients' descriptions of personal development, improvement and recovery. Most of the informants from both groups described long-term illness, severe symptoms, along with specific examples they had experienced of self-disorders. Although the descriptions of the phenomena are fairly similar, there is a clear distinction between the two groups. The patients pretty much described these phenomena in the present tense, as something still going on, while the students described this as something that either belonged to the past or that they had now mastered in a different way than previously.

Of all the patient informants, there was one patient who described a personal growth and development much like what Slade (2009) describes as personal recovery, with hope, mastering and belief in the future. This patient also described some factors that indicate a process of medical recovery with improvement of symptoms and functioning, even though this was still in an early stage of development. Another patient described some uncertain and preliminary signs of personal development, but it was unclear how stable this development was. None of the other patients described any signs of personal or medical recovery. Most of them expressed little or no hope of improvement in the future.

In contrast to this, all students described that they had experienced personal development and that they had hope for the future. While the patients' descriptions, with the one exception, were fairly similar, the students' descriptions appear to be divided into two different groups.

Some students (especially older students, who had been sick for a very many years) described a development that was similar to what Slade (2009) describes as a personal recovery. They reported increased well-being, better social and practical functioning, hope for the future, and meaningful activities and interests. At the same time, they also described that they still had some symptoms of their mental disorder and needed some treatment.

However, several described that they now needed less treatment and less intrusive treatment. They were also more active participants in their own treatment. These are important elements within both a recovery-oriented treatment (Slade, 2009) and a process of empowerment. There is no contradiction in needing treatment and being empowered. On the contrary, the important thing is that the person themselves experiences having control over and being involved in their own care.

Other students, especially the younger ones, who had not been ill for so long, described a development which corresponds to medical recovery. They described fewer symptoms and less need for treatment (including fewer or no admissions and less or no medication). Furthermore, they described a marked increase in functioning which often included that they had begun ordinary work or studies. These students also described conditions that are included in personal recovery, such as meaning, mastering, well-being and personal growth. These factors were in addition to the signs of medical recovery.

In this sample, I found no connection between the diagnosis the patients said they had been given and how they described medical and/or personal recovery. As mentioned previously, the only differences were related to age and how long they had been ill, as well as what services they received. It is natural that age is a factor, as practical, personal and social conditions including iatrogenic effects and secondary effects of the disease, makes it more difficult to achieve full medical recovery when one has been ill for several decades. In addition, this group may also have been more ill in the first place. However, it is interesting that the findings and interpretations do not show any differences related to the diagnosis in the younger patients. As mentioned previously, self-disorders in psychosis are believed to be more severe and fundamental than in other conditions, including personality disorders. It would therefore be natural to assume that recovery can be more difficult to achieve in psychoses than in the other. However, this is not reflected in the findings and interpretations from this study. Again, this may be due to many different factors, including coincidences related to the selection. However, it is an interesting finding that might indicate the possibility that self-disorders (regardless of their type and severity) can be improved through long-term and close relations and interaction, combined with other previously discussed factors. This corresponds with other studies, which find that recovery is quite possible even for severe mental disorders, such as schizophrenia (Bentall, 1990; Topor, 2004).

## **Reduction in the use of psychotropic medication**

Several of the students reported that during the time they have been in school, their use of medication had been sharply reduced or completely stopped. They describe this as a controlled and secure process of reduction, and with stable and positive results. Some said that they had been given the expectation of life-long medication therapy, but now they did not need the medication anymore. They had replaced medication with other mastering strategies, such as physical training or social support. These are interesting findings and interpretations, especially seen in the context of the ongoing debate about medication-free treatment within the mental health services. The Minister of Health, through the Ministry of Health and Care Services, has recently required all health authorities to establish medication-free treatment options. (Ministry of Health and Care Services, 2015). This order has been debated, and there have been many contributions in the public debate. Many people (both patients, relatives and professionals) welcome this freedom of choice for patients. Others, especially professionals, are more sceptical, referring to the lack of research on the effectiveness and safety of medication-free treatment for patients with psychotic disorders. Yet others are positive to the principle of testing medication-free treatment. However, they are uncertain about whether establishing separate inpatient wards is the best way to implement such treatment. It is therefore very relevant to examine the students' descriptions, which in addition to describing a generally positive development, also describe the reduction in the use of medication. The students' descriptions also shed light on interesting challenges that have been discussed in the current debate about medication-free treatment. The students have received services which not only are medication-free but which also are based on completely different principles than medical ones. The schools are outside the dichotomy medication/not medication because they are based on a completely different epistemology and a different set of norms. This might solve some of the problems associated with integrating medication-free treatment on ordinary wards, including the risk of medically-educated staff having too little knowledge about alternative approaches, that the staff would follow old habits and continue medication because that is what they are used to, and that health professionals and patients habitually relate to medical epistemology.

At the same time, for students that take advantage of the provision of schooling, there are no requirements about either use of medication or freedom from medication. The provision of schooling can thus also solve some of the challenges of establishing separate medication-free services, such as whether this treatment is only offered to the healthiest patients who can manage a medication-free treatment from the start, whether there may be too sharp distinction between medication treatment and medication-free treatment with little focus on reduction as an important result, and whether the duration of the treatment may be too limited in time if it cannot be followed up when the patient is discharged to their home.

Of course, the findings and interpretations from this study are too limited to draw any conclusions regarding medication-free treatment, and we have not aimed to get detailed information on types and amounts of medication used by the informants. Still, the findings and interpretations from the study indicate that this type of long-term schools based on a non-medical epistemology may be an important alternative to pure medication or medication-free treatment. It is therefore relevant with further studies in this area. Some of the students reported that they missed a psychotherapy at school. On that basis, it may be appropriate to explore the possible positive and negative impacts of some form of school health service that could offer both therapy and medication for a longer time, including possibility of reducing medication according to need and desire.

## **Physical health**

Health concerns not only mental health but also physical health. An overwhelming majority of the patients described various somatic ailments and pain. Many of them reported about various side effects of medication. Some also said that they were now or had previously been dependent on various medications. Most said they appreciated that during their stay at the ward they were encouraged to regular meals, rest and physical activity, but that was difficult to maintain this when they came home. The majority described the unwholesome living conditions when they were at home, with isolation and inactivity. Several described sleep problems or problems with maintaining a normal day rhythm. Some ate little or nothing at home. Others had a random food intake, with a lot of ready-made meals or unhealthy food. Many of them smoked. In addition, some patients reported about substance abuse in the home periods, with alcohol, illegal drugs, or a combination of the two.

It is known that the mortality rate in patients with severe mental illness is at a very high level (Bouza et al, 2012). Some of this is due to the elevated risk of accidents and suicide. But there is also an elevated risk of death by natural causes, especially cardiovascular and respiratory disorders (Bouza et al., 2012). This can have complex causes, but side effects of drug therapy, combined with lifestyle factors (smoking, diet, inactivity) play a central role. It is known that neuroleptics have side effects, such as weight gain and lack of satiety, which can increase the risk of cardiovascular disorders (Rasmussen et al., 2014). Nicotine also acts as an antagonist for neuroleptics (Tsuda et al., 2014), which can cause the patients to smoke more because they find that smoking decreases the side effects. This can lead to the dose being increased (because the effects diminish and blood tests show low concentration of neuroleptics), which in turn can lead to the patient smoking even more to lessen the new side effects. Life expectancy is also related to psychosocial conditions, such as finances, education and networking. This will be relevant since many in this group have little education, a small network and low finances. Childhood trauma can also have negative effects on physical health and life expectancy (Solis et al., 2015). This is also relevant to many of the patients in this group. Several of the patients and the students will thus be exposed to several different factors that are known to cause physical ailments and/or shortened life expectancy. These different factors can also reinforce each other in various forms of negative interaction. Prevention and health promotion measures are therefore very relevant. However, these must have a form that makes them useful for the target group.

The teachers in this study describe that cooking courses and physical activities have been effective for some patients, in that they can maintain a better diet and exercise at home. However, this will not work for all students. Some students will not be able to make dinner or work out at home, even after receiving instruction at school. The teachers describe that especially for the older patients (who experience personal, but not medical recovery), it is essential to have a stable provision of healthy food and physical activity at school. It cannot be expected that everyone in this group is able to follow up on lifestyle changes in private. Even so, they can still have significant health benefits of being in a social environment that offers regular meals and organised activities. Several of the students reported that meals and training were both very important to them. Some students also spontaneously stated that they smoked somewhat less when they were at school and were only allowed to smoke

during breaks. At home, they would be sitting inside and be smoking all day. It can seem that the provision of schooling in itself can have positive effects on the health of students, including the group that cannot manage by themselves to maintain lifestyle changes at home. This is important information that should be explored further, also in view of the cost-benefit of this type of measures.

### **Empowerment, personal commitment and subjectivity**

User participation was an important principle for health personnel on both wards. Both wards had routines to ensure that patients were consulted and allowed to give suggestions about their own treatment. At the same time, the health personnel reported that the patients' input often had limited effect, since the treatment was based on the diagnoses the patient received, on guidelines for the treatment of that diagnosis, and on the overall guidelines for the ward. This was confirmed by the patients, who told about good treatment, but also that they had often experienced not being listened to or taken seriously. Health personnel described that they tried to take into account the individual needs of the patients. Sometimes they were able to do so, while other times it was difficult to implement in practice, because of structural and practical conditions on the ward.

These descriptions differed from the descriptions of the teachers and students. The teachers described a large degree of control over their own work situation and much room for flexibility. They based their work on the different and varying needs of the students. This was confirmed by the students, who described the importance of flexible and individual adaptation in many different areas. They experienced that they were seen and taken seriously at school.

These descriptions are interesting because they shed light on the importance of the staff's empowerment in achieving empowerment of the patients. It is relevant here to distinguish between individual and structural empowerment (Bradbury-Jones et al., 2007; Wagner et al., 2010). Studies show that the structural conditions of the wards affect the nurses' scope of action (Bradbury-Jones et al., 2007; Wagner et al., 2010). Structural empowerment thus becomes decisive in determining which choices they can make. This will again effect the patient's health and safety, as well as the possibility for individual adaptation to the patient's needs. When empowerment in mental health care is discussed, the focus is often on the

patients' individual empowerment, and that it becomes hindered by the staff's attitudes. However, the relationship between attitudes and actions is complicated (Bem, 1967; Maio & Haddock, 2009). Attitudes can influence actions, but actions can also effect attitudes (Bem, 1967; Maio & Haddock, 2009). This is especially relevant when it concerns actions that a person does over time, who thus concludes that "I wouldn't do this if I didn't mean it". This corresponds with the health workers' descriptions in this study. They want to focus on user participation, but in practice, they are prevented from doing this. This, in turn, may have influenced their statements in more moralising direction. Some of them also express attitudes that give little power to the patients, such as that they must attend meetings to get to know how the patient has slept, rather than asking the patient. However, when they are asked to explain this further, most of them reflected quickly that this was pointless: they could have just asked the patient. Still, some of them maintained that they would not have got any reliable information from the patient, as a reason for why they had to ask others. Although it is not possible to draw reliable conclusions from these statements, it is possible that they reflect a conflict between the desire to base their work on empowerment principles, while structural conditions restrict the staff's own empowerment. This situation prevents them from giving more power to the patients, and at the same time, affects the health personnel's attitude concerning what is possible, often explained on the basis of patient characteristics.

Another effect of the different structural organisation (top-down vs bottom-up) was different opinions about agreements and predictability. The teachers, and especially the principals, described that they placed great emphasis on predictability and regularity because they knew how crucial this was for the students' security. The health workers talked less about this. However, some of them described how, in the practical planning of the day, appointments often had to be moved, due to organisational considerations. However, this was experienced as being of little importance, since the patients were on the ward anyway. The patients, on their side, usually described first the original appointment, as if this was the actual one. It was only by using specific questions that it was possible to find out how it really had been. The patients also described a much greater degree of passivity and resignation than the students did. Most students described how they had previously been



rather passive in their own lives, but how they had now regained willpower and personal commitment.

The classic “Marshmallow Study” (Shoda et al., 1990) explored variations in preschool children’s ability to wait to satisfy needs (eat a marshmallow) to achieve a greater advantage (two marshmallows) later. The variations were seen as variations in willpower. Long-term follow-up of children as adults showed that those who had exhibited more willpower as a child, had achieved more and had a better life (Shoda et al., 1990). However, a recent replication of this study (Kidd et al., 2013) found that children's ability to wait, in large part, was related to how much they experienced that the adults in the study were reliable, and whether the adults kept their promises. Children who first had been promised that they would get the nicer drawing materials if they waited a bit, and then received them, were far more willing later to wait to eat a marshmallow to get two of them, than children who had been promised finer drawing materials if they waited, but did not receive them (Kidd et al., 2013). The degree of willpower was thus largely connected with predictability and trust. It is therefore possible that this may explain how the students, who over time are in an environment where all agreements are kept, experience that they regained their willpower. More precisely, they experience the rationality and appropriateness of their own initiatives because agreements are kept, their contributions are heard, and the choices they take have a real impact on their daily life. On the other hand, the patients describe a situation where they are given promises that get changed later, or turn out to be not quite right. They experience also that they are not taken seriously or their wishes cannot be met. As in the case of the children in the experiment (Kidd et al., 2013), it is thus less relevant for the patient to show initiative, because the environment is not perceived as reliable, and the choices are perceived as having little real impact on what actually happens.

Most patients, but none of the students, also had a large degree of self-objectification, where they described what others said that they needed and how others described how they were. Many of the patients also made contradictory statements. This makes sense, viewed in the context of the staff’s descriptions of the application of top-down processes. The essence of the top-down perception is that one does not start with what can be immediately perceived, but rather with what one cognitively expects to find. There are probably different possible explanations of these phenomena (Paper 3). However, one

possible factor that may help to maintain this self-objectification can be found precisely in the structural factors that make empowerment difficult for both health professionals and patients. This also prevent both parties from seeing the actual conditions, because the focus is on what they expect to find. This is a very unfortunate process, because immediate perception and recognition of one's own needs and perceptions are key elements for self-experience (Parnas et al., 2005). Because this is assumed to be impaired for many patients in this group (Parnas et al., 2005), it is essential to have conditions that facilitate the strengthening of self experiences, not weaken them.

This is thus a theme that will be very relevant to explore further. It is especially relevant in the current debate about providing more structure in the health care service. It will be important to explore how such structures affect the health workers' structural empowerment, as well as finding out the specific effects they have on the patient's experience of personal empowerment, their right of disposition over their own life, and the development of subjectivity and immediate perception.

### ***7.7 The validity of the findings discussed in relation to method***

In this study, a qualitative explorative method is used to explore the informants' own descriptions of the possibility for personal development. Four different informant groups were interviewed. They were asked to describe their daily lives without any other guidance than to confine their descriptions to the framework of a day, a week and any encountered exceptions.

The findings and interpretation show that the informants' descriptions from the different groups support and complement each other in several different ways: The same themes appear in most of the interviews. There are natural and important individual differences in the interviews, and everyone has their personal point of view. Even so, there are some important themes that reoccur in the interviews, regardless of the informant group. In different ways and with different descriptions, both students, teachers, patients and health personnel talked about themes such as the importance of relationships, time, individual consideration, and the dichotomy of work/pleasure. This suggests that the method has given the opportunity to bring up themes that are genuine and important to many informants, and to explore the various aspects of these themes. Some of the findings that emerged were

unexpected compared to my preconceptions. The descriptions of the student informants turned out to fall into two different groups concerning descriptions of development. This suggests that there was room for descriptions that were not expected.

The descriptions from patients and health workers and from students and teachers complement each other and together provide a logical, coherent description of the whole. The patients' descriptions of not being heard correspond with health personnel's descriptions of having to follow a structured treatment programme and not always being able to accommodate for all individual needs. The students' descriptions of their receiving a lot of individual support is complemented by the teachers' descriptions of a flexible working day with a lot of focus on individual adaptation. These overall and logical connections indicate again that the themes that are described are valid and relevant across the informant groups.

The findings and interpretations not only show a consistency across the informant groups, but also across the themes and between the informant groups. The differences described between the services that the students and patients receive are not linked just to one theme, but recur in the descriptions of the various themes. The fundamental differences between the services are described in terms of time, relationships, activities and individual adaptation. This may indicate that the differences that are described are genuine. They describe basic differences between the services, not coincidentally related to individuals or individual situations.

The themes that are described and the manner in which they are described are also consistent with other research and with relevant theoretical perspectives, such as in the field of developmental psychology and sense of self.

In summary, the descriptions accumulated through open interviews and without leading questions thus show high consistency across themes, across different informant groups and between the findings of this study and previous research. At the same time, there were personal variations and findings that were not expected, compared to my preconceptions. This indicates that the findings and interpretations are valid. The method has been suitable for producing findings and interpretations that are valid and relevant.

## 8 Conclusions and implications

The purpose of this study was to explore whether, and if so how, different environmental conditions during treatment and education might influence the quality of life, sense of self and possibilities for personal and social development in people with long-term and severe mental illness.

The findings and interpretations provide clear indications that improvement and growth may be achieved through active participation in a safe environment that offers stable and lasting relationships and mutual interaction. The importance of time (both the intensity and duration) appears to be particularly crucial for the achievement of growth, together with the importance of stable relationships. Several informants also emphasised the importance of therapy as being very significant, however in combination with other factors, as part of a holistic progression. Traditional psychotherapy with one hour per week, without being connected with other treatment, was described as being less effective. Also other conditions which are known to strengthen self-development, such as play-based activities, learning, joy and care are stressed as being relevant. These conditions should be followed up with further research.

The findings and interpretations from the study also indicate the importance of structural conditions and views about knowledge. Today's organisation of health services for this group of patients may at least for some be an impediment to personal development, empowerment and recovery. Focus on short-term, repeated treatments of symptoms appears to have little significance for the development of these patients. The lack of holistic, intensive and lasting provisions and the consequences of this situation on the possibility to develop stable relationships is critical. Lack of focus on good and positive experiences, including lasting adaptations of basic conditions such as structure, healthy nutrition and physical activity are also unfortunate and may be a hindrance for positive development for this group. Also other deficiencies, such as little focus on mastering and learning and a lack of reciprocal relationships with peers, can contribute negatively to the possibility of personal development. In addition, it appears that basic inequalities in views about knowledge can affect the provisions, both directly and indirectly.

The findings and interpretations also indicate that some of the challenges related to health personnel's attitudes towards patients with mental disorders may be a consequence of the structural and organisational conditions. Examples of such conditions can be the lack of structural empowerment for health personnel that prevents them from offering flexible and individually adapted support. Impossible demands of rapid improvement in complex conditions can also have a negative impact on the attitudes of health personnel. Such negative attitudes could in turn have harmful effects on patients, increasing the likelihood of offensive incidents and decreasing the possibility for development. Thus, it is important to be aware of the significance of structural empowerment for health personnel's attitudes when future provisions are to be developed. This is especially crucial for provisions with a high degree of external structure that gives health workers little freedom to adapt according to the patients' needs.

The findings and interpretations in this study should be followed up with further research, using different methodologies and approaches, to provide more thorough illumination of the themes. If the findings and interpretations are confirmed through further research, this should have consequences for the design and organisation of services for this group. It is possible that it will be more appropriate to concentrate on special provisions for this group of patients, separate from the time-limited treatment of symptoms that is offered to patients with the short-term disorders and without self-disorders. It is also likely that services that are designed to develop basic self-experience over time will be more relevant, better for the patients and more socio-economically practical than short-term provisions with constantly repeated crisis management and symptom treatment. However, the findings and interpretations suggest that such provisions must be holistic and of good quality to have effect. To pick out single factors mentioned in this study and believe that they alone will have effect, will probably have little or no effect, unless attention is given to the totality, including relationships, intensity and duration.

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