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'NOT IN MY BACKYARD'

*Public Attitudes Towards Mental Illness and
People with Mental Illness Living in Sweden*

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Torbjörn Högberg

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**Karolinska
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From
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PUBLIC ATTITUDES TOWARDS
MENTAL ILLNESS AND PEOPLE WITH
MENTAL ILLNESS LIVING IN
SWEDEN

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*'It is not the thing-in-itself that terrifies the people;
it is their conception of them'*

Epictetus, Greek-Roman philosopher who lived about 55 – 135

ABSTRACT

BACKGROUND

Several studies reveal that inadequate knowledge exist regarding mental illness among the general population as well as stigmatizing attitudes towards persons suffering from a mental illness. The public's attitudes towards mental illness and people with mental illness can be summarised with the inference that the majority consider people with mental illness are in need of help and entitled to receive support; thus support the idea of social integration of individuals with mental illness. However, negative and stigmatizing attitudes towards persons with serious mental illness still present one main obstacle to overcome in order to facilitate social integration.

AIM

The overall aims of this thesis were 1) to explore, analyze and describe the public's opinions and attitudes towards mental illness in general and towards persons with a serious mental illness in particular, 2) to analyze the respondents' attitudes in relation to their socio-economic background. An additional aim was to evaluate the reliability of an existing questionnaire; Community Attitudes Towards Mental Illness (CAMI), and subsequently adapt and develop the questionnaire in accordance with Swedish conditions.

MATERIALS AND METHODS

In sub-study I, nine psychiatric nurses were interviewed. Two men and seven women participated in the study. The method of interviewing and analysis was inspired by the constant comparative method of 'grounded theory'.

In sub-study II, nine psychiatric nurses were interviewed. Two men and seven women participated in the study and a qualitative content analysis was used for the analysis.

In sub-study III, the English version of CAMI was translated into Swedish, renamed 'CAMI-S', and distributed to all nursing students who were in their second year of studies at three universities situated within large to mid-size cities in Sweden (n = 421).

In sub-study IV, the CAMI-S questionnaire was supplemented with 9 items concerning the respondents' intention to interact with a person with a mental illness and then renamed 'New CAMI-S'. 5.000 questionnaires were sent out. The population consisted of a sample of Swedish residents aged 18-85 years. The sampling frame was based on the Register of Total Population (RTP) and consisted of all registered residents in Sweden aged 18-85 years. The number of individuals within the sampling frame included 7.055 235 people. An independent random sample, consisting of 5.000 people was extracted from the sampling frame; 2.391 (47.9%) of the 5.000 distributed questionnaires, were returned and analyzed.

SUMMARY OF FINDINGS FROM EACH SUB-STUDY

In sub-study I, the process of 'behaving as a nurse or not' was identified as a core category. Four subcategories were identified: 'receiving involuntary information', 'to take action or not', 'behaving as a mediator in the neighbourhood' and 'the freedom of choice'. The findings show that psychiatric nurses with professional knowledge about mental illness have moral concerns about their role as nurses during their leisure time.

In sub-study II, the nurses perceived that personal contact between the neighbour and the mentally ill person was one essential way to reduce fear of the mentally ill person. They viewed themselves as a link between the mentally ill person and other neighbours. Without the personal contact between the mentally ill person and the neighbours, there may be a risk that integration will fail, no matter how excellent the supported dwelling is framed.

In sub-study III, a corrected inter-item-total correlation including all the 40 original statements, revealed a weak loading on 20 items and therefore was excluded. A factor analysis of the 20 items showed moderate to high loading, revealing the collected data could be adequately represented by extraction of three factors identified and labelled as; *Open-minded and Pro-Integration, Fear and Avoidance and Community Mental Health Ideology*.

In sub-study IV, a majority of the respondents displayed moderately positive attitudes. Respondents within the age group 31-50 years, appear to have increased sympathetic attitudes towards persons with mental illness. Additionally; it is worth noting, that in contrary to previous research, results showed that persons with a lower level of education, tend to be more sympathetic towards persons with mental illness than persons with a high level of education.

CONCLUSIONS

A summary interpretation of the main findings contained within this thesis, reinforces the assumption that negative attitudes towards people with mental illness living in Sweden exists. This suggests that persons with mental illness frequently encounter stigmatizing attitudes in their surroundings as well as from mental health professionals. The present thesis also demonstrates that additional knowledge is not the only way to eliminate prejudices against mental illness and mentally ill people. Mental health professionals with knowledge also display stigmatizing attitudes, which implies that they, as well as other citizens, must examine their own moral attitudes, improve their ability to interact with persons with mental illness and become more tolerant in order to prevent alienation.

Key words: attitudes, CAMI, mental illness, public views.

LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals (I-IV)

- I** **Högberg T.**, Magnusson A. & Lützén K. (2005) To Be a Nurse or a Neighbour? A moral concern for psychiatric nurses living next door to individuals with a mental illness. *Nursing Ethics* **12**, (5), 468-478.
- II** **Högberg T.**, Magnusson A. & Lützén K. (2006) Living by themselves? Psychiatric nurses' views on supported housing for persons with severe and persistent mental illness. *Journal of Psychiatric and Mental Health Nursing*, **13**, (5), 735-741.
- III** **Högberg T.**, Magnusson A., Ewertzon M. & Lützén K. (2008) Attitudes towards mental illness in Sweden: Adaptation and development of the Community Attitudes towards Mental Illness Questionnaire. *International Journal of Mental Health Nursing*, **17**, (5), 302-310.
- IV** **Högberg T.**, Magnusson A. & Lützén K. (2010)
Public's Views and Attitudes Towards Mental Illness:
A Swedish Survey.
Resubmitted.

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GLOSSARY

English

County Council

Government Bill

Institute of Occupational Health

Mental Health

Mental Ill Health

Municipality

Swedish Association of Local Authorities

Social services

Social Services Act

Swedish Code of Statutes

Swedish public reports; SOU, 1992:73. Final report from the committee on psychiatric care. Welfare and freedom of choice – service, support and care for the mentally ill

The 1995 Psychiatric care reform /
The Psychiatric care reform

- the concepts are used synonymously in this thesis

The Act of Compulsory Psychiatric Treatment

The Federation of County Councils

The Institute of Public Health

The National Board of Health and Welfare

The National Board of Health and Welfare monitors and evaluates; SoS 1999:1. Welfare and freedom of choice? The final report of the evaluation of the 1995 psychiatric care reform

The National Co-ordination of Psychiatric Care

The Swedish Parliament

Swedish

Landsting

Regeringens proposition

Arbetshälsoinstitutet

Psykisk hälsa

Psykisk ohälsa

Kommun

Svenska Kommunförbundet

Socialtjänst

Socialtjänstlagen

Svensk författningssamling

Statens offentliga utredningar; SOU, 1992:73. Slutbetänkande av psykiatrireformen. Valfärd och Valfrihet – service, stöd och vård för psykiskt sjuka

1995 års psykiatrireform /
Psykiatrireformen

- begreppen används synonymt i denna avhandling

Lagen om psykiatrisk tvångsvård

Landstingsförbundet

Statens Folkhälsoinstitut

Socialstyrelsen

Socialstyrelsen följer upp och utvärderar; SoS 1999:1. Valfärd och valfrihet? Slutrapport från utvärderingen av 1995 års psykiatrireform

Nationell psykiatrisamordning

Sveriges Riksdag

1 PREFACE AND INTRODUCTION

As a high school student in the autumn of 1982 I set foot for the first time in a mental ward. I was young, only seventeen years old, naive and inexperienced. My knowledge regarding mental illnesses was relatively limited. However, the little information I had was obtained during a short course at High School; a two-year nursing degree that led to an assistant degree in nursing. My experience with people who suffered from a mental illness was non-existent. My childhood was a calm environment, consisting of a core family with a mother, father and a brother, three years my junior – it was at a time when my greatest problem was quarrelling with my brother. I had not been exposed to any greater challenges during the hard school of life, in other words my experiences of life were limited which meant that I was unaware of the suffering that life sometimes imposes on people.

My encounter with mental health care opened my eyes and sparked an interest in a group of people within society whom I had never met before. I wish I could say that after my completed practice it was solely my newfound interest in psychiatric care and people with mental illnesses that instigated the acceptance of an offer to commence working as a care provider in a psychiatric clinic, but there were other attractions. The truth is, I found the working environment and the fellowship within mental care very pleasant and open hearted; to such extent that it was a strong contributing factor towards the commencement of my career within the field of psychiatric care, which I am still active in. After a few years working as a care provider within acute mental care, combined with studies to become a nurse, I chose a specialized course within mental health care and started to work at a treatment home for eight people with the diagnose schizophrenia. This experience was towards the end of the 80's when the clinic where I was employed had, in the spirit of the sectorisation of the psychiatric care, decided to 'take home' the long-term, so called chronics from the big psychiatric asylum ten miles away. 'Take home' meant that the patients now were placed in the municipality where they originally were registered, in smaller home-like dwellings.

At this point it was the first time I came in contact with the general population's attitudes towards people with mental illnesses. Their aversion to these people was revealed in such a way that neighbours close to the treatment home, which was located in a little suburban neighbourhood, felt upset that the patients behaved differently from others.

Their negative reactions were at times warranted, as it could have to do with a patient entering into a neighbour's garden to pick all of the tulips to decorate their own room, but it also had to do with verbal expressions that seemed to be irrational. For example, – a patient had been seen talking to him/herself; something the neighbour argued that this was not good for the children in the neighbourhood to witness.

A few years later, during the mid -90's, I sat as a member of the committee in a housing-co-operative. Some of the members together with neighbours were very upset about the fact that one of the blocks nearby had leased out a whole 'stairwell' to the local community council who had established housing for people with a mental illness. This was viewed as a consequence of the psychiatric reform. What was going to happen in the safe, little neighbourhood? Could the new neighbours be trusted? Were they dangerous? Many questions were raised that received different answers. A few of the committee members argued with conviction that the value of housing in the area would decline, along with the fact that children could not play freely without supervision. Others kept their distance with their comments. However, the majority had reserved feelings towards the new neighbours.

At the same time the National Board of Health and Welfare argued that the negative attitudes the local people had towards people with a mental illness could be 'educated away', which would then lead to a more welcoming society. If this was the case, it should mean that other professionals – including myself; with several years of

experience of psychiatric care and working with people with a mental illness would willingly be prepared to live next to people with a mental illness. When I asked myself this question, I could not with absolute certainty provide a positive answer. What made me hesitate? I didn't recognize my neighbours' way of reasoning; I was not worried about the children or the value of property declining. Instead, I was annoyed with the fact that the new neighbours: were smoking in my stairwell. It smelt bad and it was a fire hazard. I also thought about my experiences during my time as a nurse at the treatment home. One of the people who lived there would frequently set fire to his curtains, which naturally resulted in a lot of anxiety for patients and personnel. What if he did it in the middle of the night when everyone was sleeping? I also had on many occasions, experienced patients who in different ways and for varying reasons caused blockage in the sewerage pipes, resulting in flooding and water damage. Similar experiences contributed to my hesitant attitude towards the new neighbours. In addition, questions that I asked myself were raised:

- How do the public's negative attitudes appear to people with mental illness?
- Are the public awareness campaigns regarding mental illness really effective?
- Is it really possible to 'educate away' negative attitudes towards people with mental illness?

My initial, specified research questions were now established, the questions that have led to more questions raised. Questions that I have tried to find an answer for and is the reason why I am now writing an introduction to this doctor's thesis.

During the years since I began my postgraduate studies, the problem with the public's negative attitude towards people with mental illnesses has been increasingly acknowledged. Mental illness is still put under taboo. People with mental illness are still not admitted into various social contexts. The knowledge regarding mental illness has increased over the past years, but there is still considerable work to be done before the general public and responsible citizens gain a sensible view on mental illness, free of judgment and ignorance.

My expectation is that this thesis will expose the lack of knowledge amongst the general public regarding mental illness and, by extension, contribute to the change in mindset of people with negative attitudes towards people with mental illness in order to welcome them into society and give them the opportunity to become more involved within the community.

2 BACKGROUND

2.1 THE DEVELOPMENT OF PSYCHIATRIC CARE IN SWEDEN SINCE THE 1800'

Swedish psychiatric care has, like psychiatric care in most western countries, been centralized to the large mental hospitals, also known as the Mental Asylum, that started to be built in the beginning of the 1800's (Qvarsell, 1991, Hansson, 1993, Markström, 2003; Ottosson, 2004). The first mental hospitals in Sweden were established in Vadstena in Östergötland and Danviken outside of Stockholm after a decision by the Swedish Parliament in 1823. The treatment periods there were long, sometime life-long (Qvarsell, 1991). At that time, people with various kinds of mental illnesses was referred to as 'lunatics'. People that we would classify today, as having a serious mental illness¹ were kept inside and monitored by the large mental asylums, often located outside the city.

The localization was due to the fact that it was considered morally correct to hide these people away from the rest of society. In this way, society was protected from them and in turn, they were protected from society with the motivation that 'the maniacs' should be separated from inappropriate outside influences' (Foucault, 1992; Brunt, 2002; Svedberg, 2002; Magnusson, 2003; Ottosson, 2004; Riving, 2008; Sanner, 2009). This, apparently, humane way of treating the mentally ill, according to Foucault, (1992) was in actual fact a subtle way of exercising power. In the developing, industrial society, Foucault maintained that it had become important to distinguish the ill from the normal, which in a sense was used to mould and discipline other citizens of society.

A large proportion of the people who were treated for mental illness suffered from dementia and other chronic diseases of psychiatric nature. Some of them were suffering from psychosis and were subsequently diagnosed with schizophrenia (Häfner, 1987; Belfrage, 1994; Cullberg, 2005). However, the care 'provided' was often of less quality; the wards were full, the availability of physicians was low and it was difficult to recruit staff with satisfactory education, if any at all (Qvarsell, 1991, Bengtson-Tops, 2001). Costa (2006) maintained that the large mental hospitals in the outskirts of the cities served as final stations for all people suffering from various diseases that were difficult to handle in the patient's home environment. Furthermore, Costa along with Foucault (1992) meant that the purpose of building the asylums in the first place was based on socio-political reasons and not primarily for the needs of people with mental illness.

The old mental asylums were predominately self-sufficient. The reason for this was partly socio-economical, but it was also noted that if the patients were active and occupied, they were often much calmer and more secured to reality. Therefore, activities such as weaving, gardening and other occupations within the mental hospital area were available – the commonality for all chores was that they were driven by the patients themselves. However, it was not about any goal-orientated rehabilitation, it was more a way to get days to go as smoothly and quietly as possible (Ahlgren & Wilhelmsson, 1994).

The resistance against the big mental asylums was already escalating in that time and voices were raised to replace them with smaller, more homelike establishments.

¹ Here and onwards in the frame story, the concept 'person / persons with serious mental illness' refer to that the person has 'a mental illness of a serious nature, so serious that the person is disabled as long as the illness progress' (SOU 2006:100, p. 67). 'A person has a mental disability if he or she has significant difficulties in carrying out activities in important areas of life. These difficulties are consequences of a mental disorder and have been or would be likely to persist for a long time' (SOU 2006:5, p. 6). The concepts 'person with serious mental illness' and 'people with mental disabilities' are used interchangeable in this frame story.

However, until the 1960's, institution based care dominated within Sweden and during the period between 1860 and 1960 the number of beds within the mental asylums increased; in Sweden from 971 to 33.752, which was a result of a general institutional trend.

From a historical perspective, society's attempts to overcome the problems of mental ill health, has varied in terms of the explanations of its emergence. Measures have also been affected by the spirit of the time and the current strategies to solve problems within society in order to build up a functional society (Qvarsell, 1991; Foucault, 1992; Hydén, 1995; Markström, 2003). With the assistance of various institutions, society would become better and stronger. The needs of citizens would be met with a humane and organised manner. The expansion of mental hospitals was at its strongest during the 1930's; at a time when the psychiatric clinics within the somatic hospitals were also starting to establish (Qvarsell, 1991; Sjöström 1992; SOU 2006:100).

Psychiatric care within Sweden has, similarly to other parts of the western world, experienced major changes with a move from institutional care to care within the patient's home with support from professional care providers. A discussion regarding the closure of the larger mental asylums commenced in Sweden in the 1960's (Nyström, 1999, 2003). It was now apparent that the asylums were being closed off from society from both organisational and physical perspectives. Despite this, four new mental asylums were established as late as the 1960's (Ottosson, 2004). In order to integrate psychiatric care with the County Councils activities as well as to create a holistic responsibility for all healthcare; the management of 23 mental hospitals with approximately 20.000 beds transitioned, with a few exceptions, from the State to the County Councils in 1967 (SOU 1992:4; Markström, 2003; The National Board of Health and Welfare, 2003a).

During the 1970's the de-institutionalization² gradually started to gain momentum. However, Bülow (2004) questions whether or not a 'real' de-institutionalisation had been accomplished, depending on how the term 'institution' was defined. He maintains that if group dwellings are regarded as an institution, then a de-institutionalisation had not occurred based on the fact that the number of people with serious mental illnesses who live in group dwellings has escalated substantially, rather than decreased since the psychiatric care reform. On the other hand, according to Lamb & Bachrach (2001) definition, a 'real' de-institutionalisation can be considered has taken place since they claim that a 'real' de-institutionalisation occurs in three steps – similar the one that occurred in Sweden:

1. Patients are discharged from the mental hospitals
2. Admittance to hospitals are prevented and re-directed to psychiatric out-patient clinics
3. The development of community-based care has been established; combining social and psychiatric services

The alternative to the big institutions were regarded as an area-based care organisation; holistic views, easily accessible, non-institutional care, provided participative and preventative measures were guiding principles (SOU 2006:100). The development of day care and increased open care with highly professional teams became to a high degree advocated (Hansson, 1989; Szecsödy, 1990; Hydén, 1995; Markström, 2003;

² The concept of de-institutionalisation refers to 'the phase-out of a healthcare system dominated by institution-based solutions, and the attempts to replace them with psychiatric out-patient clinics and community-based care combined with an extensive support in the community' (SOU 2006:100, p. 84). The de-institutionalisation of the psychiatric care in the Western world has been going on since the 1960's, but the content and speed of development varies by country. 'A bit simplified, the process in Sweden can be divided into two phases. The first phase was the sectorisation of the psychiatry that began in the mid-1970's and the second phase was the psychiatric care reform which came into force on 1 January 1995' (Bülow, 2004, p. 83).

Ottosson, 2004). One of the ways of thinking was that the patient should meet the same care provider within in-patient- as well as out-patient clinics and thus be guaranteed a continuous and inclusive disposition before, during and post potential admittance to a psychiatric clinic. The overarching aim was declared to change and improve the quality of psychiatric care. The new ideas were known as 'sectorised psychiatric care', and could be regarded as a consequence of the gradual drop in numbers of hospital beds for psychiatric patients, initially in the mental hospitals but also in the future within the psychiatric clinics.

'The sectorised psychiatric care' meant that 'the psychiatric care organization' was responsible for all of the psychiatric care provided to the citizens within a geographical area. 'The sectorised psychiatric care' was an international phenomenon that could be compared to the English 'community psychiatry' or 'community mental health care' (Cullberg, 2003). A psychiatric clinic was provided with total responsibility, involving both open and closed care within in a geographical area, meaning a responsibility to offer psychiatric care to all citizens in the area that were in need (Markström, 2003; Ottosson, 2004).

In order to alleviate co-operation with municipalities and other neighbouring care providers, geographic division was often in agreement with the division of primary councils and city areas. Closed psychiatric care, with long treatment periods provided at the big mental hospitals had now decreased significantly to the benefit of closed psychiatric short-term care, which frequently managed within psychiatric clinics in conjunction with somatic hospitals. Sub-specialised care that is, special clinics for people with a mental illness also started to emerge (Hydén, 1995; Markström, 2003; Ottosson, 2004; Costa 2006; Sanner, 2009).

The individual's position within society changed drastically during the 1900's. The process of democratisation, with its individualized self determination – autonomy – as the underlying principle, gained momentum and the individual's position was strengthened through the establishment of various rights within different areas of school, employment and health care. This process also included people with serious mental illness (Hydén, 1995; SOU 2006:100). This turnaround in society at large, in addition to the changed perception of mental illness, its cause, origin and treatment, gradually provided people with a serious mental illness a stronger position within society through organised adjustment, new policy and change within health care. Nevertheless, the national co-ordination of psychiatric care, points out that the rights of this specific group was secured both later and to a lesser degree compared to other groups in need of society's contributions (SOU 2006:100).

The perspective shifted from custodial care within the big mental hospitals to closed short-term care at a psychiatric clinic and by extension to general psychiatric out-patient clinics. Later on sub-specialised care in the form of specific out-patient clinics for people with psychosis were built up; where they, besides medical treatment, also were offered a more community based care that focused on how it was to live with a serious mental illness within society on a more everyday basis. This form of psychiatric care was now known as 'social psychiatric care'³ (Hydén, 1995; SoS 1998:4).

According to Cullberg (2005), 'social psychiatric care' was previously referred to as the component of psychiatric treatment that involved the patient's social conditions. Today, Cullberg (2005) consider that the term 'social psychiatric care' encompasses the

³ The concept of 'social psychiatric care' has multiple and overlapping meanings.

Priebe & Finzen (2002) gives it three meanings:

- a) an ideological movement with bases in the settlement of in-patient institutions and the development of out-patient and community-based integrated care
- b) an applied mental health care, which includes open care
- c) one of three areas of science in psychiatric research in which the other two areas are on one hand biological research and on the other hand psychological / psychotherapeutic research.

social output and activities that lie outside the scope of ‘affiliated hospital psychiatrics’ and is almost completely separated from the clinical and medically dominated psychiatric care. Costa (2006) claims that the continuation of sectorisation led to a form of ‘cultural revolution’ within the field of psychiatric care since the placement of patients away from the mental hospitals to their residential / or catchment areas, together with the development of new working methods, the sectors/psychiatric clinics could offer better support within the specialised out-patient clinics to all of its patients; especially for persons with serious mental illness.

2.2 THE 1995 PSYCHIATRIC CARE REFORM

During the last few decades, psychiatric care has subsequently experienced a range of radical and significant alterations. The changed view that we have experienced has developed owing to both human and economic forces (SOU 1992:73). The new psychiatric care within Sweden today, similar to the current view of mental illness and towards people with mental illness, is founded on a range of factors. Hydén (1995), particularly elevates the *‘de-institutionalisation, the ideology, normalisation and integration, policy, legal rights policy and coercion as well as municipalisation’* as important comprehensive changes that have had long-term consequences with regards to how ordinary people perceive, experience, define and are disposed to mental illness and to people with a mental illness. The previous direction, which was characterized by permanent custodial confinement of persons with a mental illness *‘has been replaced with the expressed goal that the service provided and the care of them should be developed in a way that it provides them with the opportunity to live an independent life, integrated into society within their home district’* (The Government bill, 1993/94:218).

The place where people with mental illness were cared for has consequently shifted, from predominately closed institutions to care within society (Nyström, 1999; Brunt, 2002; Bülow, 2004). Nevertheless, criticism was also directed towards community based psychiatric care. The final report from the committee on psychiatric care (SOU 1992:73) revealed that people with a serious mental illness were still poorly integrated into the rest of society in comparison to other marginalised groups. The report also demonstrated that people with various forms of physical disabilities had a better quality of life compared to people with mental disabilities. In addition, living conditions for people with mental disabilities was far below normal of the average Swedish population (The Government bill, 1993/94:218; Ottosson, 2004).

Therefore, in June 1994, the Swedish Parliament decided on a policy change that meant a clarification of the municipal responsibilities for people with serious mental illness. The policy change resulted in a division into two separate organisations; one with the mission to provide medical care and the other organisation with the responsibility to provide social support including contact initiatives, planning and collaboration as well as housing and meaningful activities.

Consequently in 1995, the municipalities were provided with increased responsibility for people with a serious mental illness by the Swedish Parliament. At the same time, the municipalities were given a funding responsibility for patients, who had been cared for continuously more than three months within 24-hour psychiatric care and who had been determined by a psychiatric specialist that treatment had been completed (SOU 1992:73). Thus, the county council was given the responsibility of medical examination and diagnosing people with serious mental illness as well as medical and psychological treatment and follow-up post diagnosis. The municipalities were commissioned to mainly have responsibility for contributions involving living and housing support, but also for other support within everyday life (The National Board of Health and Welfare, 2010). The municipalities were thus given incitement to launch supportive activities suited for people with serious mental illness. In connection with the change, there was also an exchange of taxation established between the County Councils and the municipalities, resulting in an average of 15 per cent of the psychiatric resources and

activities were transferred to the municipalities. It was thought that the care of people with serious mental illness would to a larger extent take place in society (SOU 1992:73).

The aim of the 1995 psychiatric care reform was to assure that people with a serious mental illness would receive better support, so that they as much as possible could participate in society on equal terms as everybody else. For example, this would be done by stimulation of the local expansion of housing for the target group, as well as to establish day centres in order secure meaningful activities. The psychiatric reform was typified by ideological phrases such as welfare, freedom of choice and social integration. These guidelines, founded on the view of people with serious mental illness as autonomous individuals, were aimed to increase their welfare and strengthen their freedom of choice. The psychiatric care reform meant in other words an attempt to improve the condition of living for these people out in society (SOU 1992:73; SoS 1999:1; Nyström, 1999; Arvidsson, 2004). Through increased participation, better care and social support, the standards of living and conditions of life would improve and therefore make it easier to access a normal life. Through providing entry to the situations of life that are in general with regards to housing, employment and service, it was intended that people with mental illness would be re-united to the social life they had for so long been excluded from (Palmlad & Cullberg, 1993, Nyström, 1999).

The resolution was therefore, that a person with a serious mental illness would live in his/her own home, collectively or independently while still having access to meaningful activities during the day. The common aim was and remains that as many people as possible should be supported to live within their own homes. Those who were assessed not to be capable of that need were offered to live in a sheltered accommodation or group dwellings with varying levels of care (Nyström, 1999; Markström, 2003; Cullberg, 2005).

The structural change that has occurred in psychiatric care with a focus on out-patient clinics and community-based care has subsequently resulted in significant change for the individual (Palmlad, 1992; Palmlad & Cullberg, 1993; SoS 1999:1; Nyström, 2003; SOU 2006:100). In-patient care, also referred to as psychiatric 24-hour care, of people with mental illness, within institutions and psychiatric clinics has now decreased and treatment within psychiatric out-patient care has increased. In 2001, the total number of psychiatric beds amounted to approximately 5.200. The number of patients treated with the support of the Act of Compulsory Psychiatric Treatment, a given day in 2001 amounted to barely 1.200. In 2005, the total number of psychiatric beds had decreased further to 4.384. Of today's accessible beds, a fourth is utilized for forensic psychiatric care, a little more than a fourth for compulsory care according to the Act of Compulsory Psychiatric Treatment and the remaining beds for patients receiving voluntary care (SOU 2006:100).

The length of stay when receiving psychiatric in-patient-care should be kept short to amongst other things, counteract hospitalization. In order to be admitted to 24-hour psychiatric care today, it is almost necessary that the person is a danger to him-herself or/and to others. The goals of treatment is that the person with a mental illness, as soon as possible, should return to his/her everyday situation and continue treatment in out-patient care with a starting point in their own home (Socialstyrelsen, 2003; Ottosson, 2004; Ottosson *et al.* 2004).

2.3 HOUSING FOR PEOPLE WITH MENTAL ILLNESS

One of the goals of the psychiatric care reform was to improve the housing conditions and quality of life for people with mental disabilities. The de-institutionalisation of psychiatric care created the expectation to develop a more humane and open health-care system within society for people with disabilities as a result of a serious mental illness (Brunt, 2002).

The principle that all people are of equal worth and have equal rights forms the basis for Swedish handicap policy. People with disabilities should have a good life and be assured economic and social security (The Government bill, 1999/2000:79). The responsibility of this is divided between the municipalities and the County Councils. Independent living is therefore a basic right (SFS, 2001:453). According to the Swedish Code of Statutes (SFS, 2001:453), the ability to access independent living increases a person's opportunity to live an independent and dignified life. Moreover, the municipalities have the ultimate responsibility for those who live in the community to receive the support and help they require. Additionally, it is established that the municipality has the responsibility to provide all people the ability to live in a way that corresponds to their needs and should therefore install housing with particular service for people, who due to physical, psychological or other reasons, encounter significant difficulty with living.

Brunt (2002), considers the independent living, i.e. their own home to be a necessary pre-condition in order for people to recover from a period of mental illness. He argues that availability of different types of housing for people with mental disabilities '*must be flexible, with the possibility of living together with other people in a sheltered housing alternative within independent living with a comprehensive network of support from personnel from both the county council and the community care*' (Brunt, 2002, p. 63). Brunt (2002) interviewed people with a mental disability with the aim to gain knowledge regarding how they wanted a sheltered housing to be developed in order to satisfy their healthcare needs and support, ultimately to improve their quality of life. He found that the interviewees specifically emphasised the opportunity of social interaction as an important component to experiencing quality of life. In addition, they underscored the right to self-determination, integrity and individually adjusted support as central elements in order to experience a desirable psycho-social environment.

Magnusson (2003) maintains that the home has a symbolical meaning in our lives as it reflects how people view themselves and how they wish to appear in the eyes of other people. Similarly, she comments that the home satisfies our need for a private life and seclusion, as well as our need for security as the home provides stability and protection. The fact that people with mental disabilities valued their own homes highly in terms of getting better and their general wellbeing was something that Erdner (2006) found when she interviewed people with mental disabilities in a study about what aspects of the daily life people with mental disabilities considered important.

Within an evaluation concerning types of housing for people with mental disabilities, the National Board of Health and Welfare (2003b) found that municipal housing for people with mental disabilities has since 1997 increased by approximately 20 per cent. During the beginning of 2002, there were approximately 850 municipal housing for approximately 8.000 people with mental disabilities. The National Board of Health and Welfare found that re-distribution of housing from 24-hour psychiatric care to municipal housing had to a certain degree occurred. Despite this, the National Board of Health and Welfare (2003b) concluded that the municipalities had at this time, seven years after the psychiatric reform, not sufficiently invested in planning, in order to supply with appropriate living and provide for adequate care and social support for persons with mental disabilities within their home community. Another observation was that the environment within many supported housing projects was similar to the institutions that existed before the implementation of the psychiatric care reform of 1995. Rooms and toilet and bathroom facilities were shared with other people and the daily life was passive without rehabilitative features. Therefore, it was suggested to establish more individualised, alternative types of supported housing to counteract new, institutionalised forms of care.

Efforts that provide support to housing are quantitatively very comprehensive within the social support network. In order to achieve stability within housing, there are currently a number of different alternatives of housing for people with mental disabilities who for varying reasons can not live in their own homes. In simple terms,

the Social services can be divided into ‘support of ordinary living’ and ‘housing with special services’. ‘Support of ordinary living’ can involve everything from help with maintenance of the home to efforts similar the method of Case management⁴

Housing with special services, often involves a more comprehensive effort which could involve a house where a number of people with special needs live. It is common that supported housing is supervised by carers, part of or the whole day, and that the people who live there have access to common areas, for example for common meals and other activities along with support with everyday life (The National Board of Health and Welfare, 2010). The National Board of Health and Welfare (2010) has also found that stability in terms of housing for people with schizophrenia and schizophrenia type conditions appears to decrease the number of admissions to a psychiatric care unit.

2.4 THE PSYCHIATRIC CARE REFORM’S TARGET GROUP

The target group of the psychiatric care reform consisted predominately of people with long-term and serious mental illness with disabilities, who have difficulties in managing everyday life and therefore are in need of care and support. The target group of the psychiatric care reform can be perceived as homogeneous, but on the contrary this group is quite heterogeneous (SoS 1999:1). The primary target group; people suffering from psychosis are particularly vulnerable since the illness affects their social ability in a negative way. The outcome is that their ability to live their lives in the society as everyone else deteriorates, with the risk of social isolation as a consequence (SOU 2006:100). The National Board of Health and Welfare (SoS 1998:4) states that that this does not mean that all people suffering from psychosis or all people diagnosed with schizophrenia belong to the care-reform’s target group.

Mental illness is a condition that is defined mainly based on the symptoms and signs of deviation from normal mental behaviour. The interval of what is considered to be ‘normal’ is reasonably wide and is based partly on a person’s cultural and social situations (Sachs, 1983; Hydén, 1995). There are several different mental conditions that have elements of psychotic symptoms; for some of them, the cause could be related to an organic brain disease, drug abuse or extreme stress. Schizophrenia is one of the so called psychotic disorders that differ from other psychosis-like illnesses due to the poor prognosis and in many cases pronounced decrease in functionality. It should also be mentioned that schizophrenia is equally common among women as among men. On an annual basis 1.500 to 2.000 people become ill in a psychosis-like illness in Sweden; barely half of them are eventually diagnosed with schizophrenia since the lifetime risk to become ill with schizophrenia is about 0.8 per cent (Socialstyrelsen, 2003b; Ottosson, 2004; Ottosson *et al.* 2004, SOU 2006:100). Co-morbidity is common with schizophrenia or schizophrenia-type illnesses. This is also in terms of certain somatic illnesses, other mental illnesses, especially depression, anxiety, drug abuse or dependency of alcohol, narcotics and other drugs. Even lifestyle factors such as diet, lack of exercise and smoking are common (The National Board of Health and Welfare, 2010)

⁴ Case Management is a structured method aiming to facilitate when giving care services for, among others, persons with serious mental illness. The method ‘case management’ emerged in the Social work in the U.S. in the 1970’s. The aim is to coordinate care for these persons so that they can live as independently as possible. A designated person – a Case Manager – has the primary responsibility for a person with serious mental illness receives adequate care and support. The Case Manager has therefore a coordinating function, he/she is responsible for investigating, planning, and that adequate measures are implemented (Björkman, 2002).

2.5 DEFINITIONS AND DELIMITATIONS

The aim of this section is to offer an overview of contemporary scientific perspectives within the psychiatric field. Psychiatry involves two areas of knowledge; the medical-biology perspective that follows the principles of natural science and the psycho-social perspective that has its origin in human science (Cullberg, 2003; Ottosson 2004: a). In order to characterise different paths of research and to further clarify, Ottosson (2004: a) divides psychiatry into biological psychiatry, social psychiatry and psychological psychiatry. Due to the fact that somatic and psycho-social aetiology in general interact, he comments similarly to Cullberg (2003), that the scientific theoretic view must be applied alternately based on the patient's condition and disease combined with the care provider's cultural and professional background.

2.5.1 Medical science

Within western science there are various theories regarding mental illness and odd behaviour. The most dominating theories of mental illness are derived from medical science that originally was the first established discipline within the field of psychiatry and has its origin in observations made by physicians (Cullberg, 2003). Mental illnesses are thus explained as bodily injuries or pathological changes and the patient's behaviour is interpreted as symptoms of inner organic processes. The deviating behaviour is often considered to be the cause of genetic or inherited factors (Sachs, 1983; Sachs & Uddenberg, 1988; Qvarsell, 1991; Sjöström, 1992; Hydén, 1995; Sanner, 2009).

According to Cullberg (2002), psychiatry was established during the latter part of the 1800's, as a clinical scientific field. Through observations, medical science contributed to the classification and systemization of mental illness. Various forms of treatment such as prolonged baths, insulin-coma treatment, lobotomy induction of convulsions; later on electroconvulsive therapy (ECT) were also common as well as pharmaceutical treatment in the form of barbiturates with long-term effect and opium preparations. Pre-frontal lobotomy as a treatment of mental illness was first tested in Sweden in the middle of the 1940's (Ögren, 2007). The big breakthrough within medical science did not occur until the 1950's when Chlorpromazine became the first actual medical treatment (Sjöström 1992; Cullberg 2000; Svedberg, 2002).

2.5.2 Social and behavioural science

The psychodynamic developmental psychology derived from the psychosocial areas of knowledge within human science and made its entry into psychiatric care at the beginning of the 1900's. The symptoms of mental illness became significant importance and were considered to both conceal and reveal the underlying mental conflicts which were considered to be established in early age. According to his theory about the subconscious, Sigmund Freud (1856 – 1939) put forward the notion that there is a connection between inhibiting feelings that later in life result in anxiety and behavioural disturbances. Other psychological directions such as experimental behavioural psychology are also of importance within the field of social and behavioural science. Reinforcing and rewarding therapies with conditioning as basis were established as effective methods of treatment as part of this (Jerlang *et al.* 2008).

During the 1960's the development of cognitive psychology gained momentum. Within this direction, human intellectual functions such as thinking, language, memory and perception is at the centre, with emphasis on how information is received and valued (Sjöström 1992; Cullberg 2000; Svedberg, 2002). Topor (2002), discuss the gradual change within today's psychiatric care, with emphasis on health and resources, instead of illness and problems, particularly within the community-based care. It is here argued that the health process and relationship to life and conditions of life contribute to health. Within this perspective the patient is considered a social being with a possibility to

health. To support the health promoting process and to encourage the patient's own resources and capacity to change is also a goal within psychiatric nursing (Arvidsson & Skärsäter 2006; Hedberg & Skärsäter, 2009)

2.5.3 Health care science and psychiatric nursing

There are several fields of knowledge within health care. Healthcare science with a human scientific focus and an individualised patient care perspective compliments the medical field of knowledge. Within health care science as well as in other human sciences the human's subjectivity is in focus. The areas of interest within healthcare science are the person, the health, caring and the environment. These consensus concepts are based on the patient's perspective, which always is prioritized and paid attention to. Psychiatric nursing is based on an ethical perspective composed on a system of values that uphold patient's integrity and dignity; which is the fundamental component within psychiatric care. It originates from a holistic view of the person, incorporating the physical, psychological, social and existential dimension in interaction with each other Dahlberg *et al.*, 2003).

Since health care science was established during the 1980's, it forms the main base of nursing. A particular meaningful area in nursing is the building of good relationships that is acknowledged in all encounters between care receivers and the professionals. According to Hallberg (1997), the most important resource within a psychiatric care unit is the care provider as an individual and a person. She maintains that the care provider interact with the patients on an emotional level and answers to their needs and behaviours. The way in which the relationship between patients and nurses is viewed by registered nurses, mental care providers and occupational therapists within psychiatric care is described by Hallberg (1997). Based on a survey, she found that all of the above professions focused on the care receiver's sense of self and his/her functions in everyday life. The area of responsibility for the registered nurses, in addition to the recently mentioned and beyond the traditional nursing duties, included patient information and family education.

Several theorists form the background to the development and advancement of nursing. The first theorists within the field of psychiatric nursing, Hildegard Peplau (1909-1999), who published her first book; *Interpersonal Relations in Nursing* in 1952, emphasizes the significance of the relationship between patient and nurse and the mutuality in their encounter. Peplau maintains that the reference source for her nursing theory, *interpersonal relations in nursing*, should be perceived as a partial theory for the practice of nursing. Peplau defines health as a development of personality and other ongoing human processes towards creativity, constructivism, productivity and social life. The patient's wellbeing and health is made possible by that he/she is supported in the processing and integration of life experiences.

According to Peplau, nursing care is both a therapeutic process and a learning process, where the process has an aim towards learning. The patient is guided to understand his/her health problems and thus is better equipped to face difficulties in relation to health and life situation. Psychiatric nursing is therefore a pedagogical instrument that leads to maturity with an aim to encourage health (Marriner-Tomey & Alligood, 2002). As the psychodynamic theory is weaved into Peplau's nursing care model, it has an apparent, stringent theory, and can be considered to be quite appropriate within psychiatric care (Nyström, 1999).

From a healthcare scientific perspective, the two concepts mental health and mental ill health along with mental wellbeing and mental illness can be considered as two dimensions.

One ‘health dimension’⁵, where the subjective experience is emphasized and habits of living stand in the centre, and one ‘illness dimension’⁶, where the biological factors meaning for psychological disturbances and illness is given prominence. To adopt a healthcare scientific perspective is to precede from how the patient describes his/her illness (Medin & Alexanderson, 2001; Antonovsky, 2005). This way of describing the concept has also been adopted by The National Board of Health and Welfare (2005) that describes mental health – mental ill health and mental wellbeing – mental illness, from a healthcare scientific perspective where the concept pairs are defined as opposites.

Psychological illness is often associated with an experience of low self esteem and reduced ability to withhold and sustain satisfactory relationships with other people (Hummelvoll, 2000). In order to counteract the emergence of mental ill health, factors of psychological nature such as social networks, employment/activities and a sense of connection and meaning in life are regarded as important protective factors (The National Board of Health and Welfare, 2005, 2009). According to Wiklund (2003), mental health – mental ill health always stems from the patient’s own experience.

2.6 CLASSIFICATION, CATEGORIZATION AND CONCEPTUALIZATION

The purpose of this section is to, in a comprehensive and summarised way; clarify the variations of the many different terms that are used to describe mental illness. The description is not comprehensive. A more in-depth revision is thus required.

Perceptions’ regarding what mental illness and mental ill health is, their causes and emergence and how it should be treated has during different periods been widely dissimilar. Views and interpretations regarding what mental illness is, is closely related to perceptions regarding mental health and normality, which in turn is included within societal and cultural contexts. Mental illness has both fascinated and frightened people throughout time. People with serious mental illness have been called many names over the years. Even the theories regarding the underlying causes and treatment methods have shifted (Qvarsell, 1991). Among ordinary people, there are divided opinions and a certain degree of confusion with regards to the difference between mental ill health and mental illness. The fact that mental ill health and mental illness within the Swedish language often is used synonymously does not help to provide clarity (Strömberg, 2004). Within the English language, there is a distinction between different types of illnesses and understanding of illnesses, for example ‘illness’ and ‘disease’. ‘Illness’ is based on the patient’s experience of the illness, its cause, course and cure, whereas ‘disease’ refers to the medical scientific understanding of the illness and its biomedical understanding of the cause of the illness and its course (Ottosson, 2004; Hydén, 1995). ‘Ill’ is also used as a term within the English language that, according to Sachs & Uddenberg (1988) can be defined as the collective picture of the sick considered in a social and cultural perspective.

The illustration of mental illness is therefore considered connected to culture and the understanding about what is sick and what is healthy has varied over the years. Today,

⁵ In ‘*the health dimension*’, the subjective experience of the mental health problems is emphasized – i.e. how the person feels. The condition is considered to be conditioned by the environment (living condition) or the result of the individual’s choices, i.e. how the person chooses to live. Lifestyle and living habits are central, and mental ill health depends largely on the individual’s ability to balance different stress situations (The National Board of Health and Welfare, 2005, p. 131).

⁶ In ‘*the illness dimension*’, the influence of biological factors and how these cause mental disturbances or illness is emphasized (i.e. what has gone wrong in the body, especially in the brain). The condition is not in the same way possible to influence on their own (i.e. the person is suffering from an illness) and the condition should be treated so that the person becomes well. The interest is therefore directed towards fighting the disease-causing (pathogenic) conditions. In this context, heredity plays a major role (The National Board of Health and Welfare, 2005, p. 131-132).

the causes of mental illnesses are multi-factorial. Just as physical illness, mental illness involves a spectrum of different problems and suffering. In comparison to many physical illnesses, mental illnesses are not as easily defined. Social factors play a vital role for a person's mental wellbeing. This is a well known factor as well as the fact that illnesses are not evenly distributed amongst the population. It is the economically and socially underprivileged citizens who suffer more badly and more frequently of mental illness (Sachs, 1983; Sachs & Uddenberg, 1988; Craig, 1999; Riving, 2008).

Mental illness, serious mental illness, mental disorder, severe mental disorder, mental ill health, mentally disabled, mental impairment etc are some of the terms that are available to describe various sides of mental suffering. They are all classifications that are based on syndromes or pictures of illness that can be connected to various scientific models of explanation within the psychiatric field. The scientific philosopher Ian Hacking (2000) calls these classifications for 'interactive categories' which have been used in institutional like situations when they are known to people or by those in their vicinity. This changes how these people view themselves, which in turn leads to the development of feelings and behaviours that partly are due to how they have been categorised. The picture of the illness has then been internalised and inculcated in the human consciousness and thus become 'as one with the illness' (Johannisson, 2008).

This is in accordance with Hydén (1995), who maintains that the hospitalised patient's 'world of sickness' can eat away the patient's 'life-world'⁷; particularly with regards to chronically ill patients within psychiatric care as well as somatic care. Hydén further maintains that the symptoms and illnesses can be seen as a result of social constructions based on the patient's description of the illnesses symptoms. With language as help, the patient organises the symptoms and experiences in a way that they become an illness. As this occurs in conjunction with other surrounding people, cultural understandings about the illness also play a role in the development of these social constructions. Lastly, he comments that illnesses are not solely constructed as they are frequently re-constructed and re-formulated with a starting point in new situations. This is why the expression of the illness should be understood as a link to different social situations.

Mental illness can therefore be defined and interpreted in various ways within different cultures and within different context. According to the National Board of Health and Welfare (2009), mental illnesses in the past were regarded as interrelated conditions with varying degrees of problems; from mental ill health to mental disorder, and ultimately lead to mental illness. Within traditional, western science, the Swedish terms 'mental health', 'mental ill health', 'mental illness', 'mental disorder' and 'mental disability' are common and therefore in the following text have been summarised and defined as they are relevant to the understanding of this thesis and the interpretation of the results.

2.6.1 Mental Health

Often, mental health is described as an absence of signs of mental ill health. The World Health Organization (WHO) defines health 'as a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (WHO, 1964). Furthermore, the WHO point out that the term mental health contains many aspects such as subjective wellbeing, autonomy, ability to understand one's intellectual and emotional capacity, ability to handle stress and to work and contribute to society. The

⁷ The term 'life world' is here defined by Hydén (1995) as the patients 'common world', where it is important to clarify how the illness affects the patients way of life. Hydén's definition is similar to Edmund Husserl's 'life-world concept' which also is based on the common world, i.e. the world we live in on a daily bases, experience, and talk about and take for granted in all our activities (Nyström, 1999). However, Hydén (1995) does not refer to Edmund Husserl's 'life-world concept' in his description of the concept.

above can be interpreted that the world health organisation's has, in their definition provided health with three dimensions: physical, psychological and social.

According to WHO, 'subjective wellbeing', is an aspect of mental health that can be viewed as 'a holistic experience which means that a person is content with their life and work, has a positive fundamental attitude and is active as well as accepting oneself'. Mental health is therefore about the individual experiencing his/her existence as meaningful, that he/she can utilize his/her inherent resources, participates in society and experience that he/she has the ability to handle the normal hurdles of life (Institute of Occupational Health, 2007).

The above is in agreement with Bergsten *et al.*, (2003) and Hansson, *et al.* (2009), which defines mental health as a 'state of the individual, which is affected, in a continuous interaction with their surrounding in different phases of life' and that this condition is built on four pre-conditions:

1. The ability to develop and assert one's own identity
2. To uphold and maintain social relationships
3. To have access to varying mental approaches which the individual can utilize depending on the surrounding demands and that provides, for the individual, positive development
4. To be conscious about and have trust in one's own resources.

2.6.2 Mental Ill Health

Mental illness and emotional pain is today the most common reasons as to why one may experience one's state of health as poor. Contributing factors to today's mental ill health can be due to separations, violations of self-esteem, life crises, serious somatic illness or long-term stress (The National Board of Health and Welfare, 2005, 2009). Mental ill health as a historical term is difficult to capture. To a higher degree, the focus has been on highlighting 'insanity' as a historical term (Foucault, 1992). Mental ill health seems to be a wide term incorporating everything possible from mental problems that affects the individual's everyday life and his/her wellbeing to a mental disease – that can include everything from normal feelings as unhappiness to sadness and acute psychotic illness. The complexity in defining the term can be explained that at the time, the prevailing culture that determined what should be considered healthy or sick as well as normal or abnormal was not documented in different texts; it was rather a reflection of the ruling culture's value system (Foucault, 1992).

Forsell and Dalman (2004) found in a literature review, that mental ill health is a vague term lacking an actual overarching definition. However, there is a tendency to ascribe mental ill health to the type of general mental problems that the common person can experience during pressured situations, i.e. subjective experiences and self reported problems. This does not mean that those temporary problems lead to mental ill health, but it limits our potential as humans and can lead to more serious problems. Within various studies and reviews, Forsell and Dalman (2004) encountered different explanations and limitations and therefore consider it difficult to make comparisons. In some cases, their interpretation is that different authors define mental ill health as occasional, mild mental symptoms such as difficulty with sleeping, anxiety, low-spiritedness and milder depression or grief. In other cases they have found that the definition represents fully developed mental disease. The authors explain the differences found, that in some studies, the identified symptoms are based on psychiatric diagnostic instruments and in other cases they have used self-constructed scales that have only measured a few symptoms, which mean that these latter studies have not reported any well-defined illustrations of definitions or descriptions of cause.

Genetics, lifestyle and access to healthcare are important to health, but other factors often play a greater role such as how we live in society and how our employment is. In the Public Health Report by The National Board of Health and Welfare (2005, 2009),

describes that mental wellbeing within the population has deteriorated since the 1980's and that mental ill health begins to appear as an increased public health problem within all age categories in Sweden during the 1990's. The increase did not involve people with existing diagnosed mental conditions of health and patients within psychiatric care. The problems that were depicted were unclearly described experiences of mental ill health such as suffering from anxiety, worries, constant tiredness, numbness, diffuse muscle pain and aches in both body and soul. Within English literature, these patients are described as '*those who have only minor mental health problems*' and are called for '*the worried well*' (Bowers, 1997).

The increase in mental illness is attributed to that people often feel that the mental stress is increasing, which is explained due to reductions in staffing and poor working conditions and higher demands on productivity placed on the fewer people left working. This confirms by Ljungdahl *et al.* (2007), who in a study implemented by the Institute of Public Health describes mild mental ill health as worry/nervousness, difficulty with concentration, mood swings and sleep disturbances, often of temporary character, that has become more and more common among the Swedish population. Furthermore, the study supported for the belief that mild mental symptoms increase the risk of developing serious mental illness as well as for dysthymia, milder depression and suicidal thoughts, which in turn increases the risk of developing even more serious mental illnesses.

To have ill health implies that individuals suffer physically and/or mentally/socially. Ill health as described above is often referred to as the subjective and psychological experience of a certain state Wiklund (2003) consider health to be a complex phenomenon, where an exact and clear line can not be drawn between health and ill health. Health and ill health is based on the individual and therefore varies between different people and at different times. Health can be described as an experience of healthiness, freshness and wellbeing. Finally, Wiklund (2003) argues that the concept illness refers to the pathological, i.e. the reduced biological and/or psychological function which is described below.

2.6.3 Mental Illness

As previously explained, mankind has historically had shifting beliefs regarding what causes both mental ill health and mental illness; which was considered for a long time to be a punishment from God or caused by a demon that had taken hold of the body of the affected person. These illustrations of mental illness still exist in certain cultures (Foucault, 1992; Kent, 2003; Hanssen, 2007).

There are many different types of mental illness. Often these illnesses involve feelings such as low-spiritedness and anxiety. When these feelings reach such intensity and last for so long that it becomes difficult for a person to deal with daily life, it can be called mental illness (Psyche-campaign, 1993). Within today's western medicine, mental illness is a well defined medical term involving well defined psychiatric conditions of illness. The medical definition of illness is based on the existence of pathological-anatomic or pathophysiological changes (Ottosson, 2004). To have a mental illness means that a person has a psychological and/or behavioural change which means that the affected has torturous symptoms and/or does not function socially. The illnesses can have varying lengths of time and process (Cullberg, 2003; Forsell & Dalman, 2004). The medical diagnosis is primarily used to alleviate communication between care providers (Cullberg, 2003). The classification system 'Diagnostic and Statistical Manual of Mental Disorders' (DSM-IV) published by the American Psychiatric Association and primarily suited for clinical use, describes the diagnostic criteria for mental illness. The criteria are categorised into different groups with mood disorder, symptoms of anxiety disorder, psychosis and addiction disease as the most common groups. In addition to DSM-IV, the international diagnostic system 'International Classification of Diseases' (ICD) is also used in Sweden in order to diagnose mental illnesses (Ottosson, 2004).

2.6.4 Mental Disorder

In practice, the term mental illness is broader and more heterogeneous compared to the medical diagnosis. 'Mental disorder' is a legal term and not a medical, and its interpretation is sometimes questioned. The term was introduced in the context of the current coercive laws 'The Act of Compulsory Psychiatric Treatment'. The benefits of the term 'mental disorder' are that it *'partly covers the whole psychopathology and eliminates the superficial divisions and partly marks that the medical illness model is complemented with the psychosocial illness model'* (Ottosson, 2004a, p. 14). Ottosson (2004a) maintains that the increased use of the term 'mental disorder' is due to the fact that careful illustration and cause analysis is more important than the division of sick – healthy / disturbed – not disturbed since psychiatric measures in practice are determined based on the nature and extent of symptoms as well as the pattern of cause and consequence. One consequence of mental disorder may be that a person has had considerable difficulties in performing activities within important areas of life. If these difficulties/limitations have existed or are considered to remain during a longer period, the person can be judged as having a mental disability (SOU 2006:5).

2.6.5 Mental Disability

Up until 2006 when the national co-ordination of psychiatric care (SOU 2006:5) presented a definition, the term mental disability has not been easily described. Through a change in focus, from chronically mentally ill to handicapped, the use of language also changed, from chronic mental illness to mental disability. According to Strömberg (2004), previous different concepts were used to label what is now contained within the term 'people with mental disabilities'. Concepts such as 'chronically mentally ill', 'chronics', 'long-term mental illness', 'people with severe mental disorder' as well as 'people with long-term and serious mental disabilities' were common. Characteristic for many forms of mental illnesses is, as previously mentioned, the negative affect on the social life; for example through reduced capacity to cope with work due to complete inability to act or withhold different forms of social relationships due to lack of trust (The National Board of Health and Welfare, 1999:1; Ottosson, 2004; Erdner, 2006).

The concept of mental disability alludes to the consequences of mental illness experienced by the individual. According to the national co-ordination of psychiatric care, the fundamental principle is that all conditions that have been diagnosed as mental illnesses can result in mental disability. These 'reductions in functionality', can lead to the individual feels 'handicapped', which is not the same as a characteristic of the individual, but rather refers to barriers or limitations to participate and exist within social life (SOU 2006:5). The reduction in functionality is enduring and makes it more difficult for the individual to live a 'normal' life. The symptoms and problems for people who have mental disabilities are different for different individuals. A mental disability is not static; instead it often varies over time. A person with a mental disability can therefore function like other people at times, but can sometimes have difficulties in everyday life. Mental disabilities can even be temporary, for example in a time of crisis, or more long-term, for example after a psychosis. Many people, who have had for example schizophrenia, can have remaining, and sometimes significant, reductions in functionality that demand significant support efforts. Out of all of the people who fall ill in schizophrenia, it is estimated that approximately 80 per cent will be in need of long-term treatment, rehabilitation and/or support from society of varying degrees (Erdner, 2006). Therefore historically, there have been different explanation models with regards to mental illness, but irrespectively of the theory that has been in charge, people with mental illnesses have always been affected by social marginalisation and considered to be insufficient and unpredictable as citizens (Svedberg, 2002). Negative attitudes and prejudice can also be disabling and worsen

the person's mental disability. These obstacles need to be cleared in order for people with mental disabilities to live like other people (Government bill 1999/2000:79).

2.7 EVALUATION OF THE 1995 PSYCHIATRIC CARE REFORM

The National Board of Health and Welfare has compiled the evaluation of the 1995 psychiatric care reform in 'The final report of the evaluation of the 1995 psychiatric care reform, Welfare and freedom of choice?' (SoS 1999:1). The report concludes that the situation of persons with serious mental illness since the reform's implementation had been made aware of to a higher degree like that the psychiatric reform most important driving force, that is legislation and governmental financial support have had positive effects. However, the evaluation revealed that the possibilities to participation and influence were still delayed for people with serious mental illness as well as the remaining lack of cooperation between social services and County Councils. The evaluation further showed that people with serious illness still are affected by stereotypical, negative attitudes with stigmatization as a result of their medical record (SoS 1997:6; SoS 1997:8; SoS 1999:1; Arvidsson, 2004; SOU 2006:100)

2.8 SOME CONSEQUENCES OF THE 1995 PSYCHIATRIC CARE REFORM

According to The National Board of Health and Welfare's report in 2009, the physical health amongst Sweden's population has in many regards improved. However, the general mental health amongst the population has worsened since the middle of the 1980's. Mental ill health and emotional pain are, as mentioned before, the most common reasons as to why the conditions of health have been experienced as bad. Approximately between 20 to 40 per cent of the population has been affected by some form of mental difficulties; from milder mental problems to diagnosed mental illnesses. More serious illnesses such as psychosis have not change in proportion over time. Other mental ill health such as worry and anxiety, with milder mental symptoms has become increasingly common within the population, especially since the beginning of the 90's (The National Board of Health and Welfare, 2009). To this should be mentioned that studies demonstrate that milder mental symptoms increase the risk of serious mental illness (Ljungdahl, *et al*, 2007).

The 1995 Psychiatric care reform had its starting point in principles based on normality (SOU 1992:73; Nirje, 2003). The motto for change was 'from patient to citizen' (Markström, 2003). The reform's target group was in 1992 '*predominately people with long-term and serious mental disorders*'. Today, approximately 0.6 per cent (40.000 – 46.000 people) out of Sweden's adult population i.e. people > 18 years of age, suffer from serious mental illness (SoS 1998:4). Out of these, approximately 70 per cent (34.000 people), live out in society in their own home, which is a consequence of the psychiatric care reform (Ivarsson, 2002; Erdner, 2006).

2.9 THE NATIONAL CO-ORDINATION OF PSYCHIATRIC CARE

Despite the 1995 Psychiatric care reform, the Swedish government still considered there to be weaknesses in psychiatric care and social services. Subsequently, in 2003 it was decided to set up a post for a national coordinator of psychiatric care with the task to supervise matters that involve cooperation, organization, resources, personnel and competency within psychiatric care, social services and rehabilitation of people with mental illness and mental disabilities.

The national coordinator of psychiatric care was mainly directed towards people who suffered from serious mental illness. The work was carried out in broad dialogue with county councils, municipalities, the Federation of County Councils, Swedish

Association of Local Authorities, relevant authorities, government committees and consumer organizations (The government's directive 2003/133). The national coordinator of psychiatric care stated that the living conditions in general, at that time, was still worse for people with mental illness compared to the rest of the population within most areas, both material and economic, as well as social and health-wise. This was remarkable as year 2006 marks 11 years since implementation of the psychiatric care reform. Using the directives from 2003 as a springboard, the national coordinator of psychiatric care suggested measures aimed to give positive effects on the psychiatric care, social services and rehabilitation of persons with serious mental illness (SOU 2006:100).

When the psychiatric care reform was implemented in 1995, and people with serious mental illness would become more involved in community life, the expectation was that the prevailing attitudes in society towards people with mental illness would change in a positive direction (SOU 1992:73, 1998:4 SoS, SoS 1999:1). However the official report presented by the national coordinator of psychiatric care, showed that a change of attitude has failed to materialize, partly because of lack of resources. The municipalities did not manage to provide enough support for people with serious mental illness in terms of housing and employment, which may be one explanation why the public maintains negative attitudes towards persons with serious mental illness, resulting in continued stigmatization (SOU 2006:100).

2.10 STIGMATIZATION

Negative attitudes and societal discrimination is one of the major barriers to overcome in order to achieve quality of life for persons with mental illness. These negative attitudes lead to an increased risk for marginalization and social rejection – *stigmatization* – and has been identified as one of the most significant obstacles to overcome in order to facilitate social integration of persons with serious mental illness (Lundberg *et al.*, 2008; 2009). Research about stigma, internationally as well as nationally, is quite extensive; thus within the following text, I do not make any claims on a comprehensive description of stigma. My intention is to provide an orientation to the concept of stigma in relationship to mental illness.

The concept of stigma originates from Greek language and can be translated as 'a stick' or a 'mark'. The term was earlier used to denote bodily signs intended to show something unusual or defamatory in a person's moral character. Today, stigmatization is seen as a phenomenon that is connected to values of social roles in society. The concept of stigma is considered to be a social construction that involves at least two fundamental components; 'acknowledgement of differences based on specific characteristics and a consistent disparage of the person' (Björkman, 2005; p. 57-58).

Stigma, according to Björkman, (2008) is a comprehensive and complex phenomenon that includes psychological and social aspects as well as sociological. Different theories have been highlighted in order to explain what functions stigmatization serves. On an evolutionary level, the formation of social groups, consisting of people with shared norms was necessary for human survival. To be able to hold together as a social group, it is necessary for people to establish norms and rules for how they should behave. Actions and behaviour that are contrary to these norms and rules threaten the group's cohesion. Thus, persons that do not behave in accordance with the norms and rules are often consigned to alienation (Stensaasen and Sletta, 1997). In the western world and irrespective of explanatory models to mental illness, people with mental illness have always been affected with social exclusion and regarded as inadequate and unpredictable citizens. As mentioned earlier, the large mental institutions were often located outside the cities. As a consequence, the patients lost contact with their social context which in turn contributed to alienation (Svedberg, 2002; Hydén, 2005; Erdner, 2006). Goffman (1963) even argued that the large 'institutions-like' mental hospitals by their mere existence contributed to the creation and the establishment of the social and deviant alienation affecting people with serious mental illness.

To live with a serious mental illness poses to the stricken person that he/she often has to deal with several problems at one time. Initially he/she is forced to deal with the illness per se and the symptoms that many times make it difficult to live an independent life and achieve a satisfactory quality of life. Moreover, he/she must deal with the public's intolerance, stigmatizing verbal expressions and being met as a less intelligent person as well as the public's lack of knowledge about mental illness. All of this will ultimately lead to negative attitudes, prejudices and reactions that further cause stigmatization (Cullberg, 2005; Rüscher *et al.*, 2005).

Stigmatization of persons with mental illness can lead to more than solely social rejection since the affected person's experiences of stigmatization and discrimination even contribute to strengthen their own feeling of being alienated. When the negative stereotypical images are transposed to the 'own self', it causes a psychological damage that results in the internalization of the stigma that is associated with the illness. The overall consequence is that persons with mental illness degrade themselves and feel shame that in turn leads to a lower self-esteem and self-confidence as well as a poor self image (Erdner, 2006).

One influential theory about society's view of and thoughts about people that deviate from the 'normal' has been Goffman's theory of stigmatization. Goffman (1963) describes three types of stigma:

1. Bodily stigma, for example a physical handicap
2. Stigma of the character, such as mental illness and addiction
3. Group stigma, among other religion, ethnicity, social class and sex

The theory is based on the assumption that people's social life is influenced by prevailing norms regarding how a 'normal person' is defined in a specific society. Social norms, values, and conceptions of what is 'normal' can provide us with a basis for our decisions about what is mentally deviant and is thus the link between society and attitudes towards persons that deviate from 'the normal' (Hinshaw, 2007). Persons who cannot live up to current norms are marked as deviants; which means that they are expected to actualize special roles with low status and with distance to other citizens. Goffman (1963) as well as Erdner (2006) point out that the stigmatized person contributes to his/her own alienation and disparagement since he/she, as described earlier, has internalised social norms and expectations, which among other things, can lead to an avoidance of seeking help for problems because of poor self-confidence and sense of shame, thus obstructing recovery. According to Goffman (1963), the individual now has been reduced to only what the stigma symbolizes.

Consequently, a stigma can be visible as well as invisible for the surroundings. The stigmata cannot always be concealed, which means that the individual is required to learn to live and deal with it in everyday life. Stigmatization and loneliness appears to be inevitable for persons with serious mental illness. The existential life conditions also mean that forming relationships with others is not self-evident, since enormous willpower is necessary in order to sustain an interest for other people as well as to make contact with another person (Hayne & Yonge, 1997; Erdner, 2006). Loneliness in persons with mental illness is also a consequence of that others actually keep a distance from them (Erdner, 2006). When MacDonald *et al.*, (2005) describes young persons' experience of social relationships during the time of recovery from a first time episode of psychosis, they especially emphasize feelings of having lost friends from the time before they became ill. A social avoidance need not merely be a consequence of the mental illness but also by the perceived stigmatization that can be related to prejudices and negative attitudes from family, friends, society and personnel within psychiatric care (Knight *et al.* 2003)

In summary, there are thus many factors that contribute to the stigmatization of persons with serious mental illness. Nevertheless, it seems that the negative attitudes and prejudices existing in the surroundings are a primary cause for this to happen.

2.11 ATTITUDES

The 1995 Psychiatric care reform (SOU 1992:73) is regarded as an important and substantial change of the psychiatric care in Sweden. The reform has had far-reaching implications for how ordinary people perceive and experience and defines mental illness as well as how they relate to people with mental illness (Hyden, 1995; Hellzén, 2000).

In recent years, attitude research in psychiatry has made considerable progress. Several studies reveal poor knowledge about mental illness among the general population as well as stigmatizing attitudes towards persons suffering from a mental illness. The public's attitudes to mental illness and people with mental illness can be summarized with the inference that the majority of the public consider that people with mental illness is in need of help and that they are entitled to receive support why the majority of the public promote their integration into society. However, a substantial part perceives persons with mental illness as unpredictable and dangerous and reacts with fear which has caused them to distance themselves from persons with mental illness (Angermeyer *et al.* 2006).

There are several ways to define and describe the concept 'attitude', as well as the relationship between a person's specific attitude and their tendency to act. In order to facilitate the reader of this thesis, the following section provides an overview of the concept of attitude, its origin and its correlation to mental illness.

The concept of attitude is considered to originate from the Latin *aptitudo*, which means 'aptitude, attitude or approach'. In different scientific disciplines the term attitude is commonly used to describe a sustainable standpoint that has been built up by experiences, which is revealed in that one is for or against something, i.e. an attitude-object. Attitude can be defined as a general and sustained positive or negative feeling for a person, an object or a topic (Albarracín, 2005).

According to Niven and Robinson (1994) it is more productive to investigate the most important components in attitudes than to define the concept of 'attitude'. The most important are 'the affective, the cognitive and the behavioural components'. Social environment also plays an important role in shaping attitudes because these are created by interaction with the environment. The term 'attitude' is described as a tripartite concept, consisting of a cognitive, an affective, and a behavioural component. The cognitive component consists of beliefs, the affective component of emotions, and the behavioural component covers actions or the intention to act (Kruglanski & Higgins 2003; Niven & Robinson 1994). Some types of behaviours e.g. social distance are more responsive to emotional-based attitudes and some more belief-based attitudes e.g. political opinion (Röndal, 2005). According to Niven and Robinson's (1994), most of a person's attitudes originate in childhood and the authors conclude that theory, instrumental conditioning, models and personal experience are the three main elements in the process of forming attitudes. In addition, attitudes formed by personal experience are stronger and more resistant against alteration than attitudes formed by indirect experience (*ibid.*).

Different attitudes that individuals bear with them, are thought to be hierarchically structured. Some are more encompassing and reflect a view on phenomena that in different ways touch on something central or important in the individual person's life. Attitudes lower in the hierarchy are connected to more specific objects. More encompassing attitudes have been shown to be more stable. Attitudes vary in both meaning and intensity, from intensively positive to intensively negative. A special subgroup among the negative attitudes is prejudices that can lead to discriminating actions

to them the prejudice concerns. Furthermore, it is often highlighted that the verbally expressed attitude is not always accompanied with a similar behaviour. Many factors and forces influence our behaviour and our actions, which give an explanation to why several attitude questions to a person do not often provide justice to a person's real behaviour (Andersson, 1985; Oppenheim, 1992; Rudder-Baker, 1995; SOU 1998:16, Albarracin, 2005).

How can a researcher be certain that persons who respond to questions in a questionnaire have not 'corrected' their responses on the basis of what is considered to be politically correct, but have answered what they truly mean? As noted above, the link between thoughts, beliefs and action are not always clear. According to Oppenheim (2000) Rudder-Baker (1995) and SOU (1998:16), the following conditions are therefore important to take into consideration in order to reach reliable results in attitude research:

1. The attitude has to be linked to concrete situations
2. The research has to measure both the respondent's attitude towards the object in common as well as the respondent's attitude to interact with the object
3. The population has to be well-defined
4. Consideration must be taken to the social context and to potential attitudes connected with the respondent's different social roles

Brockington *et al.* (1993), claims that people with advanced education and high occupational level as well as high standard of living seem to have more positive attitudes towards persons with mental illness. Furthermore, people with personal experience of mental illness often display positive attitudes (Wolff, *et al.*, 1996a, b; Palmblad & Cullberg, 1992; Palmblad, 1993).

The level of knowledge that are described above can be sorted into general knowledge, experiential knowledge and knowledge gained by information, lectures and education. General knowledge is achieved by education and reflects the person's overall level of knowledge, social function and social status. If a person's overall knowledge is good, then attitudes towards persons with mental illness living in the community are usually positive. Persons with different types of experience of mental illness; own mental illness or family or friends with mental illness also convey positive attitudes. Knowledge that is achieved by information, lectures and education are often gained via own interest and usually influence attitudes in a positive direction (Brockington, *et al.*, 1993; Wolff, *et al.*, 1996a, b, c).

However, a more detailed examination of these so-called 'positive attitudes' sometimes reveals hidden and negative aspects of these mindsets. This can be illustrated by the commonly observed acronym NIMBY (i.e. 'not in my backyard') which is sometimes of occurrence. The NIMBY-phenomenon gives expression to peoples prejudice and negative attitudes which stereotype and, by extension stigmatizes, persons with serious mental illness as dangerous and unpredictable (Brockington *et al.* 1993; Cowan 2003; Leff & Warner 2006). The NIMBY-phenomenon represent one example among others of the difficulties there are when trying to achieve a change in attitudes.

One common way considered to be effective in reducing negative attitudes towards mental illness and persons with serious mental illness is to inform and educate the general public. For example, the final report of the evaluation of the 1995 psychiatric care reform states that the need to educate the general public regarding mental illness is crucial because negative attitudes of the general public towards persons with a serious mental illness obstruct the social integration of these people (SOS, 1999:1). On the other hand, this can be questioned since a study by Högberg *et al.* (2005) reveals that it is not obvious that individuals with considerable knowledge about mental illness always have positive attitudes towards persons with a serious mental illness and want to have them living in the same neighbourhood as themselves.

The above studies illustrate on one hand that positive attitudes towards mental illness and persons with mental illness are correlated to personal experiences of mental illness, advanced education and higher occupational level as well as high standard of living. On the other hand, they also reveal that individuals with considerable knowledge and experience of mental illness not always have positive attitudes towards persons with a serious mental illness and want to have them living in the same neighbourhood as themselves.

3 PROBLEM AREA AND RATIONALE FOR THE THESIS

The final report from the committee on psychiatric care (SOU 1992:73) highlighted certain factors that were assumed to impede the goals set out by the 1995 psychiatric care reform. One of these factors was the general public's lack of knowledge of mental illness (SOU 1992:73). As mentioned earlier, attitudes towards mental illness and persons with serious mental illness have historically been marked by fear and prejudice (Foucault, 1973). Although there had been some improvements at the time of the 1995 psychiatric care reform, the majority of people still approached persons with serious mental illness with fear and caution. In addition to fear of violence, prejudices and gaps in knowledge about different types of mental illness and their expression existed and constituted obstacles of change. The general public's inadequate knowledge about mental illness as well as their negative attitudes towards persons with serious mental illness was thus regarded as key obstacles to overcome. This was believed to be necessary in order to increase the opportunity for these persons to feel a sense of community and participation in society and to improve their life situation (SOU 1992:73).

Opinions and attitudes about mental illness in general and specifically to persons with serious mental illness were thus raised as an important issue to consider, and to influence in a positive direction in order to achieve a constructive result in the reformation work. The final report from the committee on psychiatric care (SOU 1992:73) emphasised, therefore, that knowledge about mental illness must be disseminated amongst the public. It should also be mentioned that, at that time, analyzes of the Swedish research situation showed that studies concerning the public's encounter with persons with serious mental illness in Sweden, then as well as currently, to a large extent were absent (Palmblad & Cullberg, 1993).

Normalisation and integration were the health political principles guiding the reformation work. To 'normalise' someone's life condition suggests that the individual should attempt to live a life that is rated as being 'normal' and culturally accepted. However, an individual person's life conditions are not only dependent on material conditions but are also equally dependent on how these persons are approached by others in the surrounding environment and their ability to understand the needs of persons with mental illness. The concept of normalisation can thus not replace the requirement for public understanding and acceptance of persons with serious mental illness in order for them to achieve integration and civic co-existence (SoS 1999:1).

As a result of the de-institutionalisation, areas of contact between persons with serious mental illness and others in society have increased compared to the time before the de-institutionalisation. When housing accommodation in the form of group or communal living as well as independent living arrangements were localised to the communities, reports of protests from neighbours sometimes were of occurrence. At times, these protests have resulted in difficult conflicts. Furthermore, it has become evident that in many cases, local communities were not ready to receive these persons. This situation could be related to lack of knowledge and inadequate information from the authorities who had the responsibility for arranging the housing accommodation. In some cases, the general public had raised questions concerning the support and supervision and what type of accommodation persons with mental illness were allocated. Other questions that were raised included whether persons with mental illness could become a danger to children living in their vicinity. However, it was often unclear as to what the protests actually expressed, which suggested there were significant obstacles to overcome when attempting to normalise the life of a seriously mentally ill person (Palmblad, 1992).

The final report of the evaluation of the 1995 psychiatric care reform performed by the National Board of Health and Welfare (1999:1) shows that not all goals have been reached. For example, it was noted that the general public's attitudes had influenced the result of the reformation work. In order for the reforms' fundamental intent of increased welfare and community participation of persons with serious mental illness to be realised as optimally as possible, there was a need for a change in the common man's attitudes towards mental illness and persons with serious mental illness. It was emphasised that various types of information regarding mental illness and persons with serious mental illness was of great importance. However, in what manner this information should be disseminated was unclear, yet regarded as an important future question (SoS 1999:1).

Thus, the outcome of the reform work relied on society's values and the public attitudes. Society's ability to allow for persons with serious mental illness to become involved in the residential area as well as in the workplace was also deemed as crucial.

After the studies included in this dissertation commenced, the national co-ordination of psychiatric care (SOU 2006:100) was established. Again, it was emphasised that the general public's knowledge of mental illness still remains limited, ten years after the psychiatric care reform was implemented. Therefore, efforts to combat stigma and discrimination must be taken in a systematic and focused manner. Consequently, the national co-ordination of psychiatric care in a motion to the Swedish parliament suggested that 'society's goal should be that all people with mental illness or mental disabilities feel that they have the opportunity to participate in the community and that they are treated with understanding and respect' (SOU 2006:100). In order to realise this intent, it was considered essential that society adapts and accepts differences between people. A change in attitudes must take place, which means that the general public's view of mental illness must change in a positive direction. The national co-ordination of psychiatric care (SOU 2006:100) points out that this is only possible to achieve through increased knowledge and social integration; in addition, also noted that skills development of personnel, who in different contexts encounter persons with serious mental illness, is appropriate to begin with.

As mentioned previously, due to a poorer prognosis and in many cases pronounced functional disabilities which require more social support, the target group of the psychiatric care reform included to a large extent persons with psychosis, especially those with a diagnosis of schizophrenia. It is underscored in The National Board of Health and Welfare's preliminary version of national guidelines for psychosocial interventions in schizophrenia that the problem of the general public's limited knowledge of mental illness, particularly psychosis, still persists. In order to correct this situation, the National Board of Health and Welfare (2010, p. 109) suggests that 'information campaigns and broad conferences should be conducted and made available to the entire local community in order to increase the general level of knowledge and awareness of the problem'. In contrast to this strategy, a question can be raised whether information campaigns are the best way to increase the general level of knowledge about mental illness and in the long run rectify negative attitudes towards persons with serious mental illness. Can negative attitudes be 'educated' away? This question is especially important to contemplate since studies reveal that personnel in psychiatric care, who are assumed to be positive towards persons with mental illness, in actual fact, have less favourable attitudes towards them (Callaghan, *et al.*, 1997; Högberg, *et al.*, 2005; Nordt, *et al.*, 2005; Foster, *et al.*, 2008; Rao, *et al.*, 2009).

3.1 THE OVERARCHING GOAL OF THE THESIS

Supported by research, persons with serious mental illness largely lack the ability to build stable and meaningful relationships with fellow human beings in their close surroundings. The opportunity for them to become integrated within the community and to live a life similar to others is limited, which leads to isolation and subsequently, a deterioration of their experienced quality of life (Erdner, 2006). The

overarching goal of this thesis is to generate knowledge which ultimately can lead to improved quality of life for persons with serious mental illness. By exploring the public's opinions about mental illness and their attitudes towards persons with serious mental illness, a readiness to understand and manage reactions could be constructed. This knowledge could also be used in the long-term to create acceptance and to increase the understanding within society of persons who suffer from a serious mental illness. In addition, this may also contribute to the integration of these persons into the community and for them to achieve civic co-existence.

4 MATERIALS AND METHODS

4.1 DESIGN OF THE THESIS

The research that comprises this thesis began with the question whether negative attitudes towards persons with mental illness existed in Sweden. If this was the case, a subsequent question was whether educational efforts could promote more positive attitudes towards persons with serious mental illness. When I became interested in this specific area of research, I could not find any significant research that highlighted this problem-area in Sweden. Therefore, I decided that an explorative approach with focus on the general public's knowledge of mental illness and their attitudes towards persons with serious mental illness would be most appropriate. An exploratory research approach is methodologically appropriate when an unexplored area should be identified and a problem is to be exposed (Kvale & Brinkmann, 2009).

The first sub-study focuses on psychiatric nurses' experiences of living as a neighbour to persons with mental illness. As previously mentioned, research indicates that persons with professional experiences of persons with mental illness do not always have such positive attitudes as would be expected. Of interest, no studies about the experience of being a neighbour to persons with mental illness from the perspective of psychiatric personnel could be found.

As described above, already in the final report from the committee on psychiatric care (SOU 1992:73) is the need to increase the public's general knowledge about mental illness emphasized in order to overcome the prevailing negative attitudes towards people with serious mental illness. Later, the final report of the evaluation of the 1995 psychiatric care reform (SoS 1999:1), in which the psychiatric reform was evaluated, showed that the attitudes among the general public had influenced the implementation of the reform in a negative manner and that information and education to the public was important.

4.2 THE OVERALL AIM OF THE THESIS

The overall aim of this thesis was to explore, analyze and describe the public's opinions and attitudes to mental illness in general and towards persons with a serious mental illness in particular. An additional aim was to evaluate the reliability of an existing questionnaire; Community Attitudes Towards Mental Illness (CAMI), and thereafter adapt and develop the questionnaire in accordance with Swedish conditions.

4.2.1 Specific aims of the sub-studies

The thesis comprises four separate sub-studies with the following specific aim (s):

- I. The aim of sub-study I was to explore and describe psychiatric nurses' experiences of living next to people with mental illness. An additional aim was to identify and describe how psychiatric nurses' handle situations arising in a neighbourhood where people with a mental illness live.
- II. The aim of sub-study II was to describe psychiatric nurses' experiences of different types of supportive dwelling for persons with long-term mental illness and their views on what they consider to be important principles to provide for in order to facilitate their social integration into the community.
- III. The aim of sub-study III, conducted in Sweden, was to evaluate an existing instrument's: (CAMI) validity and reliability. An additional aim was to adapt and develop the questionnaire to Swedish circumstances.

- IV. The aim of sub-study IV, also conducted in Sweden, was to analyze and describe public opinions and attitudes to mental illness in general and to persons with a mental illness in particular and thereafter analyze the views and attitudes in relation to the respondents' socio-economic background.

4.3 DATA COLLECTING METHODS

There were two main methods of data collection. Data for sub-study I and II was collected through individual interviews. In order to collect data for sub-study III and IV, two surveys were carried out, one for each sub-study.

4.3.1 Individual interviews

Sub-study I focuses on psychiatric nurses' experiences of living as a neighbour to persons with mental illness and its origin with the question whether it is possible to 'educate away' negative attitudes and if 'information and education' was the answer that solved the problems with negative attitudes. If this was the case, then persons with advanced education in psychiatric care combined with professional experiences of persons with serious mental illness would be more positive and welcome them into their own community. Since the view that knowledge and experiences of mental illness counteracts prejudices can theoretically be supported, the methodological approach of the sub-study was openness towards psychiatric nurses' attitudes towards, and experiences of interaction with, people with a mental illness who were living as their neighbours. As the intention was to explore and describe psychiatric nurses' individual experiences, a qualitative design – based on and inspired by some aspects of grounded theory (Glaser & Strauss, 1967; Schreiber, 2001) – was considered to be the most appropriate method to collect the data, as it emphasizes interactions and processes.

Oppenheim (1992) comment that an interview is not an ordinary conversation even if there appear to be similarities. In a research interview, the aim is to collect information in some area; for example, the interviewee's experiences, feelings, thoughts and ideas on a particular area. Furthermore, Kvale and Brinkmann (2009), points out that by using unstructured or semi-structured interviews, the interviewer can achieve a greater breadth and depth of the data compared when using structured interviews. The idea behind the implementation of sub-study I was consequently to interview psychiatric nurses, specialised in psychiatric care, that lived or had lived next door to a person with a mental illness and to identify and describe their experiences of this. The respondents selected the locations for interviews, which lasted for between 40 to 80 minutes. The participants were informed about the aim of the sub-study, and measures were taken to ensure anonymity. In accordance with Kvale and Brinkmann (2009) and in conformity with the basics of grounded theory (Schreiber, 2001) the individual interviews with the participating nurses as above began with an open question: 'What has it been like for you to live near a person who suffers from a mental illness?'

Beyond the participants' experiences of being neighbours to persons with mental illness, it was found that all participants had experiences and firm opinions about living conditions for persons with mental illness, which they were very willing to talk about and explain during the interview. Therefore, at the end of each interview, the participants were asked to describe the type of supported living which they experienced met the needs of the patient in best way and would ease social integration. This data forms the basis of sub-study II.

4.3.1.1 Participants; sub-study I and II

Participants were selected based on their response to an advertisement in a Swedish national journal for mental health nurses. This provided volunteers from various parts of Sweden. The psychiatric nurses who were invited to participate had experienced living near to individuals with a mental illness. Nine psychiatric nurses who responded to the advertisement and who met the criteria participated in the sub-study. Two were men and seven were women, whose ages ranged from 30 to 56 years. They all had experience providing care for individuals with mental illness, in institutions, as well as in the patient's own home; in addition they also had experience of living close to people with a mental illness. Their professional experience ranged from 8 to 32 years. Most of them had worked as a nurse for more than 25 years in different areas of Sweden.

The question of the number of interviews that should be conducted for a study can not be definitely answered. Among other factors to be considered is the content and quality of the interview. Kvale and Brinkmann (2009), gives the simple but evasive answer to the question that, depending on the purpose of the study, the interviewer has to interview as many people as needed to find out what he/she want to know. Oppenheim (1992) means that in-depth interviews are costly and time-consuming; therefore, the author argues that there is a pressure to reduce the numbers of interviews as much as possible. However, about thirty interviews are probably appropriate to conduct in order to find answers to the questions (ibid.).

4.3.2 Construction of a questionnaire for data collection

As mentioned earlier, the research started with a question whether negative attitudes towards mental illness and towards persons with mental illness exist among the general public in Sweden. In a literature review, it was found that research related to these questions is quite extensive in the Western world. In connection with the literature review the questionnaire CAMI, consisting of 40 items (Taylor & Dear, 1981), was found. The questionnaire was constructed in the early eighties, and used in several studies in English-speaking countries in the Western world but not in Sweden. It was therefore adapted and modified to Swedish circumstances. This process was consistent with Beaton and Guillemin (2000) who points out that the items must not only be translated well linguistically, but also they have to be adapted culturally to maintain the content validity of the questionnaire at a conceptual level across different cultures. The result of this process was one part of sub-study III.

4.3.2.1 Participants; sub- study III

The population was selected as a type of convenient sample, based on easy accessibility to respondents. The Swedish version of the CAMI questionnaire (CAMI-S) was distributed to all student nurses (n = 421) in the beginning of their second term at three programmes of nursing in three different universities in Sweden located in urban areas. The student nurses who participated in this sub-study had not yet taken any courses in psychiatry or mental health nursing. Although student nurses may represent a biased category of the population, considering their choice of profession, it was judged that this selection of respondents would be suitable in order to test the instrument's validity and reliability in relation to Swedish circumstances.

The CAMI-S questionnaire was sent by mail to each of the respondents. The questionnaire was attached with a covering letter explaining the purpose of the sub-study and the procedure for completing the questionnaire together with information about voluntarily participation and anonymity. Respondents were asked to rate each statement on a 6-point Likert-type scale with the anchors 'totally disagree' and 'totally agree'. Standard socio-economic and demographic data were also collected

for each respondent. The covering letter also explained that the Swedish reform of psychiatric care has led to 'persons with serious mental illness' living in society as anyone else. This implied that the concept 'persons with serious mental illness' refers to the target group for the reform, that is persons with long-term mental disturbance or illness that results in altered functions in daily life, requiring long-term treatment and care (Appendix 1). The completed questionnaires were returned in a coded and sealed envelope to a research-assistant. Two reminders were sent out.

4.3.3 Using a questionnaire for data collection

After modifying the CAMI-questionnaire it was considered appropriate to use in a survey among the Swedish population, namely in sub-study IV with the aim to analyze and describe public opinions and attitudes to mental illness in general and to persons with a mental illness in particular. The CAMI-questionnaire was also renamed to the CAMI- S questionnaire and consisted of 20 questions of 20 statements categorized into three factors labelled *Open-minded and Pro-Integration*, *Fear and Avoidance* and *Community Mental Health Ideology*. Each factor contained statements relating to views on ways to treat and take care of persons with a mental illness. This is in accordance with Oppenheim (1992) who emphasise the importance of being clear about what is going to be measured from the very beginning. There are, according to the author many technical aspects involved in the developing and validating of a questionnaire. Accordingly, in order to make the response process more attractive to the respondent and motivate him/her to continue to co-operate, it is important that the focus and the content of the questions are correct and that the questions are short and easy to understand. Moreover, it is important that the questions are adapted so that the respondent understands its contents (ibid.).

As previously described, in order to succeed with attitude research it is of great importance to measure both the respondent's attitude towards the object in common as well as the respondent's attitude to interact with the object (Oppenheim, 1992; Rudder-Baker, 1995; SOU 1998:16). Accordingly, the CAMI-S questionnaire was supplemented with 9 items concerning the respondents' intention to interact with a person with a mental illness, so-called behavioural intention-items. In the following text the completed questionnaire is therefore once again renamed, this time to the 'New CAMI-S'. Consequently, the data gathered through the 'New CAMI-S' serves as the basis for sub-study IV.

4.3.3.1 *Participants; sub- study IV*

The population consisted of the Swedish population aged 18-85 years. The sampling frame was created out of the Register of Total Population (RTP) and consisted of all registered residents of Sweden aged 18-85 years. The number of individuals in the sampling frame was 7.055 235 people. An independent random sample consisting of 5.000 people were drawn from the sampling frame. The identification control of the prospective informants showed that 15 persons no longer belonged to the population.

The New CAMI-S questionnaire attached with a covering letter explaining the purpose, background and implementation of the sub-study were distributed by regular mail. The letter also described that the personal data was retrieved from the RTB and that all information were protected by the Data Protection Act and the Official Secrets Act, along with a declaration that participation was voluntary. Also in this sub-study, respondents were asked to rate each statement on a six-point Likert-type scale with the anchors 'totally disagree' and 'totally agree'. Standard socioeconomic and demographic data were also collected for each respondent. The covering letter explained that 'the 1995 psychiatric care reform' had led to that 'persons with a serious mental illness' nowadays live in the community as anyone else. This explanation implied that the concept 'persons with serious mental illness' referred to the target group for the reform i.e. persons with long-term mental disturbance or illness which resulted in dysfunctions

in daily life, requiring long-term treatment and care (SoS 1999:1; SOU 2006: 5). The completed questionnaires were returned in a coded and sealed envelope to a research assistant at the Central Statistical Agency (CSA). Two reminders were sent out. The dropouts consisted of object-loss and partial-loss. In this sub-study the partial loss is less than 5 percent, which was considered approved according to (CSA). The returned questionnaires were scanned and controlled regarding double-marking and that only valid values occurred in the material.

4.4 METHODS FOR DATA ANALYSIS

4.4.1 Grounded theory

As mentioned before; the aim of sub-study I was to explore and describe psychiatric nurses' experiences of living next to people with mental illness and also identify and describe how they handled situations arising in their neighbourhood when people with a mental illness were involved. Thus, a qualitative design – inspired by some aspects of grounded theory (Glaser & Strauss, 1967; Schreiber, 2001) – was considered to be the most appropriate method to collect the data, as it emphasizes interactions and processes.

Each individual interview with the psychiatric nurses' was tape-recorded and transcribed verbatim. Data collection and analysis occurred simultaneously by using the method of constant comparison (Glaser, 1978). In accordance with the sampling technique of grounded theory, the selection of respondents was based on the emerging core category and conceptual framework. Saturation, a sense of closure in the core category, was assessed to be reached after the ending of the ninth interview.

The analysis commenced with 'first-level coding' by reading through the text and carefully examining the data (Glaser, 1978; Schreiber, 2001). This consisted of line-by-line analysis in order to select phrases, words and incidents that might describe and exemplify the interviewee's experiences of living nearby persons with a mental illness and how the interviewee managed situations that arose in the neighbourhood when these persons were involved. The data were continually compared incident-by-incident and code-by-code in order to identify similarities and differences. Throughout the analysis process, existing codes were used whenever possible. When conceptual similarities were identified during the first-level coding, second-level coding commenced, involving the examination of codes and merging them into categories (Glaser, 1978; Schreiber, 2001). As a result, by subsuming and abstracting categories, a core category was identified in the form of a process. The process represented by the core category consisted of four interrelated subcategories, also in the form of processes.

In grounded theory, which is linked to the symbolic interactionist perspective (Blumer, 1969; Charon, 1998, 2006), reality is socially and culturally based. The assumption that attitude is expressed and change in interactions between individuals in a social context (Charon, 1998, 2006) – which sub-study I partly assumes – contributed to the decision to base the data collection on the epistemology of the symbolic interactionist perspective.

4.4.2 Qualitative content analysis

For analysing of data from sub-study II, a qualitative content analysis method inspired by Denzin and Lincoln (1998) was used to identify major themes related to the aim of the sub-study. First, in order to obtain an overall picture of the content of each interview and of all the interviews together and to get an overall feeling of the total text-content as well as to generate ideas about how to analyze the text in more detail, the transcribed interviews were read independently several times. This was followed by a new, thoroughly perusal, sentence by sentence, of the entire text from

each interview. At the same time notes were made about the content⁸, emanating from the nurses' views and experiences of 'high quality supported dwellings' for individuals with mental illness, i.e. supported dwellings that they considered best met the needs of the residents/the patients in order to ease their social integration. This was in accordance with Kvale & Brinkmann (2009) who consider that by going beyond what was actually articulated in the interview the text were interpreted in order to establish structures and identify connected meanings that were not immediately apparent. When the whole text had been coded, the codes were compared to each other in order to condense the data into themes related to the sub-study's aim. These sub-themes were then further analyzed and condensed in order to finally identify a main-theme, which also was related to sub-study's aim. Finally, the respondents' statements, in the form of quotations, were used to illuminate the meaning of each sub-theme.

It should also be noted that the main theme and the sub-themes were discussed and compared by all of the researchers of the sub-study in order to validate the results. Thereafter, the main-supervisor questioned and refined the interpretation in order to guard against researcher bias and to increase credibility.

4.4.3 Statistical analysis of data from sub-study III

Sub-study III was conducted with a quantitative approach.

The Statistical Package for the Social Sciences (SPSS) version 14.0 was used for analysis of the returned CAMI-S questionnaire.

In step one; Cronbach's alpha was used to test internal consistency of the CAMI-S questionnaire as a whole. In the next step, a corrected inter-item total correlation was carried out on all the 40 original statements in order to test each item's correlation to all other items. Twenty items showed weak loading (less than 0.43) and consequently were excluded. This is in accordance to Norman and Streiner (1994) who claims that loadings of less than 0.4 might be considered 'weak'. In step three, a factor analysis (extraction method: principal component analysis with a varimax rotation) was carried out on the 20 items that showed moderate to high loading (0.43–0.64) in order to test their internal structure (Gorsuch 1983; Kim & Mueller 1978). This revealed that the data could be adequately represented by extraction of three factors. In the fourth step, a Cronbach's alpha was used to test internal consistency at the remaining 20 items above.

It should also be noted that the meaning and content of the three factors were discussed and compared by all of the researchers of the sub-study in order to validate the results. Thereafter, the main-supervisor questioned and refined the interpretation in order to guard against researcher bias and to increase credibility.

4.4.4 Statistical analysis of data from sub-study IV

Sub-study IV was conducted with a quantitative approach.

The Statistical Package for the Social Sciences (SPSS) version 15.0 was used for analysis of the returned new CAMI-S questionnaire. The statistical analysis of data from sub-study IV was carried out by a statistician from the Central Statistics Office (CSA) in Stockholm.

⁸ i.e., the text became coded.

In step one; Cronbach's alpha was used to test internal consistency of the New CAMI-S questionnaire as a whole. In the next step a corrected inter-item-total correlation was carried out on all the 30 statements in order to test each item's correlation to all other items. All items showed loading > 0.44 . Consequently, none of them were excluded since loadings of less than 0.4 might be considered 'weak' (Norman and Streiner, 1994). In step three, a factor analysis (extraction method: Principal Component Analysis with a varimax rotation) was carried out on the 30 items in order to test their internal structure (Gorsuch 1983; Kim & Mueller 1978). This revealed that the data could be adequately represented by extraction of four factors. In the fourth step, a Cronbach's Alpha was used to test internal consistency at the 30 items.

Thereafter, a linear multiple regression analysis was used to determine the relationship between socio-demographic data and opinions and attitudes towards mental illness and persons with a mental illness. Conventional levels of statistical significance were reported where P-value < 0.01 or 1% was taken to be statistically significant. Statistically significant correlation between each item and demographic variables were reported where appropriate (P < 0.01).

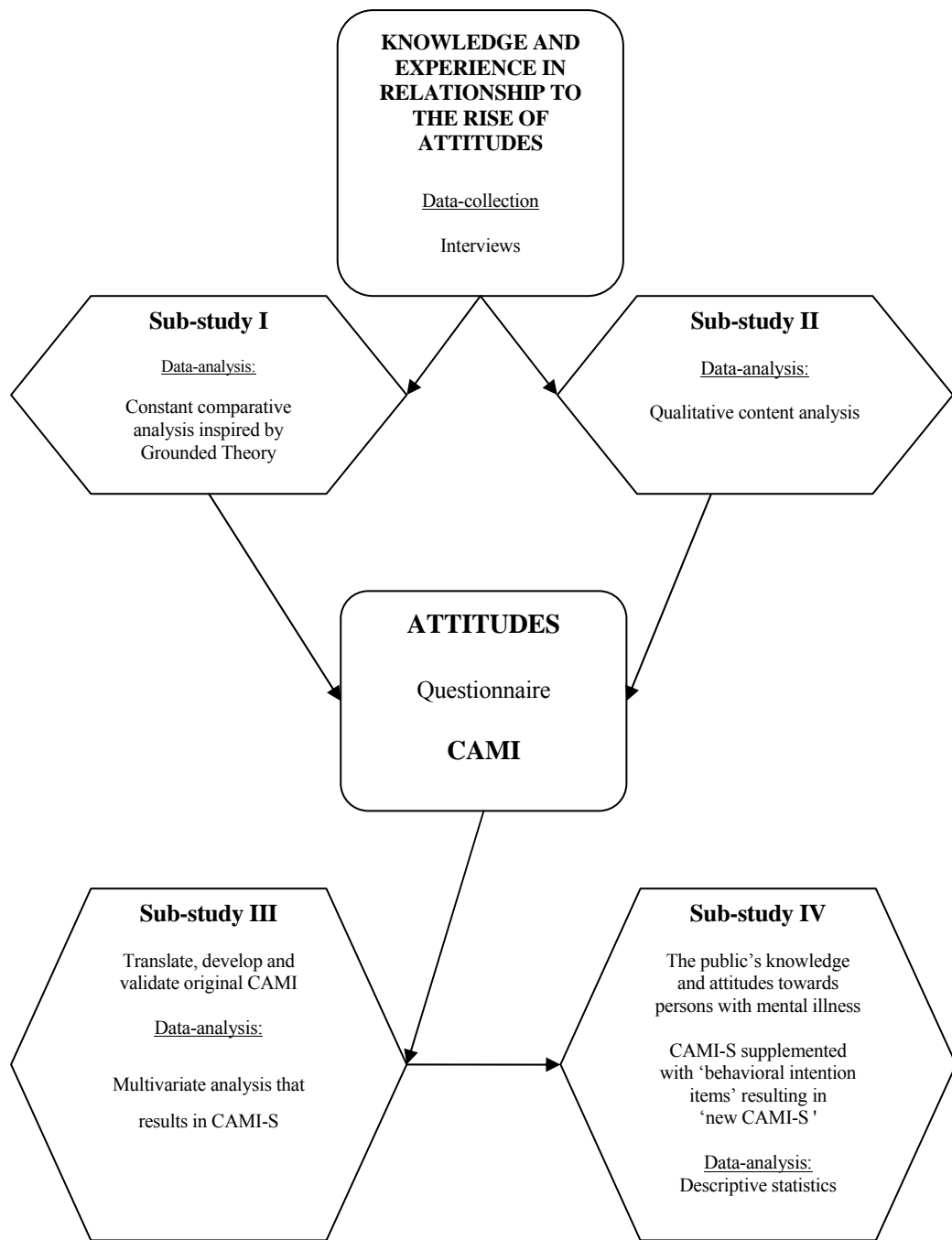


Figure 1: Development of the research process

4.5 METHODOLOGICAL PERSPECTIVE

4.5.1 The Symbolic Interactionist perspective

The overarching focus of this thesis is the public's opinions and attitudes to mental illness in general and towards persons with a serious mental illness in particular. The symbolic interactionist perspective provides a basis for an analysis of social reality and encompasses for example interpretations of other individuals' attitudes; '*where attitudes can be regarded as a tendency to react in a particular way, in a particular situation*' (Trost & Levin, 2004, p. 62). The awareness of these attitudes can be seen as a stream of thoughts that occur when an individual comes in to contact with his/her social surroundings. The symbolic interactionist perspective implies a processed view of human interaction, stemming from a sociological perspective that views the whole society as a sum of all occurring interacting events. Therefore, society is perceived to be made up of processes which are constantly changing (Blumer, 1969; Trost & Levin, 2004; Charon, 2006).

Since the symbolic interactionist perspective is an approach and an analytical tool to form a better understanding of the individual's actions in reality, I have chosen this to be the thesis methodological perspective. Therefore, this will affect how I interpret the empirical data and how the analysis is carried out, which in turn forms the results. The chapter below describes the components of the symbolical interactionist perspective that I consider to be of relevance to my thesis.

George Herbert Mead (1864 – 1931) is regarded as the primary founder of the perspective and the focus that later on Herbert Blumer calls '*symbolic interactionism*'. Within the symbolic interactionist perspective, with a cognitive view of the individual as a reflective being, the individual is emphasised as a social being. From the beginning, the individual has been socialised into society through interaction with other individuals, which is considered essential for the development of the individual's social abilities and skills. The surrounding is perceived as social, in which the individual through interaction develops acts and exists. The individual does not respond immediately and direct to other individual's actions; first, on an unconscious level he/she interprets, the meaning/intention by defining the situation he/she exists in. This interpretation then steers their own, purposeful behaviour towards the individual's within their surroundings (Blumer, 1969; Trost & Levin, 2004; Charon, 2006). The term 'behaviour' incorporates the individual's language, thoughts, feelings and actions and is used broadly speaking within the language of the symbolic interactionist perspective. The 'behaviour' can reveal itself within the person's attitude or disposition to act in a certain way (Trost & Levin, 1996).

According to Blumer (1969), the symbolic interactionist perspective can be used as a tool to study human behaviour, human group life and also the social group that represents various sectors of society, and it emanates from, three basic premises:

1. Individuals act towards things on the basis of 'the meanings they ascribe to those things', how he/she perceives the surroundings and also what happens within the surroundings
2. 'The meaning things have to him/her' has its origin within, or arises out of the social interaction with other individuals within their surroundings
3. The 'meaning' is handled in, and modified through an interpretive process that takes place within the individual. The interpretation process is affected by the things and those individuals he/she encounters and the context in which the individuals exist in, as well as its underlying history.

Joel M. Charon (2006) has in his interpretation and use of 'the symbolic interactionist perspective' further developed and clarified Blumer's three basic premises. He abandons the term 'symbolic interactionism' in favour of the broader concept of 'symbolic

interactionist perspective', which he explains is based on five basic premises: social interaction, thinking, definition of the situation, the present and the human as an active being:

1. Within social interaction, individuals communicate in different ways, which leads to mutual influence
2. Thinking is a form of social interaction that takes place within the individual. The individual's reflection of a situation determines how he/she acts
3. The individual's definition of the situation does not steer the individual's behaviour and actions based on reality as such, but based on how the individual perceives reality
4. New experiences and situations constantly affect the individual. How the individual acts in the present, depends on how the individual defines the instantaneous situation based in the individual's immediate thoughts and momentary interaction
5. The fact that the individual is active means that he/she is participative in a process and is therefore continuously changing.

Within the symbolic interactionist perspective, the social surroundings are regarded to consist of concrete as well as less concrete 'objects'; from factual, physical objects and individuals/beings – such as humans and animals – to structures such as organisations. The social surrounding also consists of more abstract 'objects' as norms, standards and values. The 'objects' are constructed and formed into so-called 'social objects' in pace with the individual's subjective perceptions of them appear in social contexts where the individual exists and interacts with the surroundings. Subsequently, for the individual, the 'social objects' then forms the reality that 'meaning' is created in for him/her.

4.5.2 The Symbolic Interactionist perspective and attitudes

The above described ways to assess how objects are constructed and formed has relevance to this thesis as the term attitude today is commonly used as an enduring approach that has been developed through experiences and is expressed by the individual either being in favour or against something; an '*attitude-object*' (Albarracín *et al.*, 2005). Since the 1920's, attitude is an important term within social psychology and other social sciences. Based on Blumer's basic premises, citizens can be seen as individuals who construct and form their own actions based on an unconscious interpretation process of situations as well as other forms of social objects. The actions then affect how the citizen perceives the situation that led to their own behaviour and actions (Blumer, 1969). See figure 2.

As previously explained, within the symbolic interactionist perspective, the social surrounding can consist of concrete as well as less concrete 'objects'. The objects are social as they have been created in the interaction with other individuals within the surroundings, but they can also take physical shape in the form of organisations such as psychiatric hospitals.

In addition, the objects can be more abstract as norms and values. In order for the citizen to interact with the social objects, the distinctive characteristics of the social objects must be internally understood by the individual; moreover, reciprocal agreement about the social objects must also have been made. The social objects can also take on the form of 'attitude-objects', such as a person who suffers from a serious mental illness. Despite reciprocally created attributes and concepts, the attitude-objects are constituted by the meaning they have for the individual citizen, as he/she interprets them in relation to his/her previous experience and current context. The significance of the attitude-objects can vary between individuals, but they are social constructions that are upheld through the actions of humans. Attitude-objects are agreed upon and the citizen can organise his/her actions towards them and also control his/her actions and work through new behaviours. However, he/she can also decide to maintain behaviours (Blumer, 1969).

4.6 TABLE I: OVERVIEW OF THE STUDIES INCLUDED IN THIS THESIS

SUB-STUDY	AIM	DATA-COLLECTION AND MATERIAL	METHODS OF ANALYSIS AND INTERPRETATION
<p>Title / Sub-study I Högberg T., Magnusson A. & Lützn K. (2005) To Be a Nurse or a Neighbour? A moral concern for psychiatric nurses living next door to individuals with a mental illness. <i>Nursing Ethics</i> 12, (5), 468-478.</p>	<p>The aim of sub-study I was to explore and describe psychiatric nurses' experiences of living next to people with mental illness.</p> <p>An additional aim was to identify and describe how psychiatric nurses' handle situations arising in a neighbourhood where people with a mental illness live.</p>	<p>Nine psychiatric nurses were interviewed.</p> <p>Two men and seven women participated in the study.</p>	<p>Interviews were used for data collection. The way to interview and the analysis were inspired by the constant comparative method of 'grounded theory'.</p>
<p>Title / Sub-study II Högberg T., Magnusson A. & Lützn K. (2006) Living by themselves? Psychiatric nurses views on supported housing for persons with severe and persistent mental illness. <i>Journal of Psychiatric and Mental Health Nursing</i>, 13, (5), 735-741.</p>	<p>The aim of sub-study II was to describe psychiatric nurses' experiences of different types of supportive dwelling for persons with long-term mental illness and their views on what they consider to be important principles to provide for in order to facilitate their social integration into the community.</p>	<p>Nine psychiatric nurses were interviewed.</p> <p>Two men and seven women participated in the study.</p>	<p>Interviews were used for data collection. A qualitative content analysis was used for the analysis.</p>
<p>Title / Sub-study III Högberg T., Magnusson A., Ewertzon M. & Lützn K. (2008) Attitudes towards mental illness in Sweden: Adaptation and development of the Community Attitudes towards Mental Illness Questionnaire. <i>International Journal of Mental Health Nursing</i>, 17, (5), 302-310.</p>	<p>The aim of sub-study III, conducted in Sweden, was to evaluate an existing instrument's: (CAMI) validity and reliability.</p> <p>An additional aim was to adapt and develop the questionnaire to Swedish circumstances.</p>	<p>The English version of CAMI, translated into Swedish was distributed to all nursing students in the second year of their studies at three universities situated at large to mid-size cities in Sweden (n = 421).</p>	<p>The Statistical Package for the Social Sciences (SPSS) version 14, 0 was used for analysing the returned and completed questionnaires.</p> <p>Of 421 distributed questionnaires, 256 (60, 8%) were returned and analyzed.</p>
<p>Title/ Sub-study IV Högberg T., Magnusson A. & Lützn K. (2010) Public's Views and Attitudes Towards Mental Illness: A Swedish Survey. Resubmitted.</p>	<p>The aim of sub-study IV, also conducted in Sweden, was to identify and describe public views and attitudes to mental illness in general and to a person with mental illness in particular; and thereafter analyze the views and attitudes in relation to the respondents' socio-economic background.</p>	<p>The population consisted of the Swedish population aged 18-85 years. The sampling frame was created out of the Register of Total Population (RTP) and consisted of all registered residents of Sweden aged 18-85 years. The number of individuals in the sampling frame was 7.055 235 people.</p> <p>An independent random sample consisting of 5.000 people were drawn from the sampling frame.</p>	<p>The Statistical Package for the Social Sciences (SPSS) version 15.0 was used to analyze the returned and completed questionnaires.</p> <p>Of 5000 distributed questionnaires, 2391 (47.9%) were returned and analyzed.</p>

5 ETHICAL CONSIDERATIONS

In terms of the structure and implementation of all parts of the thesis, various ethical issues have been considered and taken into account with regards to the respondents' participation. Prior to the interviews for studies I and II, within this thesis, the participating respondents received both written and verbal information regarding the aim, content and extent of the study.

The respondents were guaranteed that neither they nor their workplace/unit could be identified within the studies. The respondents were also informed that their participation was voluntary and that they had the right to cancel the interview at any time as well as that collected data material would be treated with privacy and confidentiality. This means that the collected data is stored in such a manner that any unauthorised person is unable to access the information.

As a researcher, it is important to maintain a balance between being too detailed or omitting information that can be important (Kvale & Brinkmann, 2009). Questions regarding identity and integrity can be difficult to handle, especially if the research is carried out in units, places or within a context where there are a limited number of people whose participation in the study could be identified. During the close contact between the researcher and interviewee, it is the responsibility of the researcher to protect the respondents from harm and to be sensitive when it comes to questions being posed during the interview. Within the first two studies of this dissertation, data has been collected from interviews, requiring close contact with the interviewee.

The use of quotes to highlight events and situations, but also to strengthen an interpretation is common within qualitative studies as is the case within the first two studies of this thesis. The use of the quotes in relation to research has been discussed due to the risk of the quotes leading to the identification of the respondent. This has especially come to the attention in these two sub-studies, as the numbers of participants are relatively few as well as the locations where the studies have been conducted. The quotes that have been used in the first two studies cannot be inferred as they have taken place in different parts of the country. When quotes have been used, corrections have been made to the language; so that the people from a foreign background and have difficulty in the Swedish language cannot be identified.

Ethical problems can arise when questioning people's knowledge and experience with mental illness and their attitudes towards people with a mental illness. Conflict can also exist between the knowledge that is sought and the issues that have been questioned. The respondents in sub-studies III and IV received in conjunction with the questionnaire, information in the form of a cover letter. The respondents were citizens over the age of 18, who decided themselves if they wanted to answer the questionnaire or not. The cover letter provided information regarding the aim of the study as well as that participation was voluntary and that they could at any time cancel their participation without an explanation.

Despite the information that their participation was voluntary, a question could be raised whether the respondents in sub-study III, who were nursing students, thought they were specifically encouraged to answer the questionnaire as they were studying within a care providing profession. Irrespectively, the nursing students were selected based on the fact that they were considered to be a 'sample of convenience', as they were easy accessible. Another ethical consideration is to report the results in such a manner that the respondents are not identifiable. In the presentation of results, the individual's answer can not be identified.

Issues regarding mental illness could give cause to reflect over one's own health. In order for the respondents in sub-studies III and IV to review and complete the questionnaire, it was necessary to take a position on one's attitudes towards people with

a mental illness. To reflect and take a stance on the questions about mental illness, can for some people mean an increased awareness, but also evoke feelings the person in question does not wish to be confronted with. The researcher has a significant responsibility not to cause the respondents personal harm. Therefore the researcher's name and telephone number was included in the written information distributed to the respondents. The respondents were encouraged, if need be, to contact the researcher who has solid experience with mental care.

Additionally, they were informed that the collected data was going to be treated with privacy and confidentiality and the data at the time of collection and in the future would be stored in such a way that it would not be accessible to anyone unauthorised. Based on the fact that the respondent completed the questionnaire and returned it in the accompanying envelope, their agreement to participate was confirmed. Each questionnaire was coded and linked to a list of the names of the respondents in order for a reminder to be sent out, if a reply was not received within a reasonable timeframe. The questionnaires were received by one, part of the study, objective assistant who was also responsible for the reminder to be sent out. The code-list was kept in a locked safe until sub-study III was completed. Thereafter, the code list was destroyed. Collection of data for sub-study IV was completed with the assistance of the Central Statistics Office in Sweden.

The completed questionnaires in addition to any other relevant research material are stored in a locked and fire safe cabinet. Personal information such as names or social security numbers, as well as other details that can be linked to a specific individual has been or is accessible to the researchers.

All of the sub-studies have been reviewed and approved by the Regional Ethics Review Board at the Karolinska Institutet in Stockholm, Sweden. Studies I & II, registration number: 2006/1315-31; Studies III & IV, registration number 2006/1163-31

6 SUMMARY OF FINDINGS

6.1 SPECIFIC FINDINGS FROM EACH SUB-STUDY

Sub-study I

Through constant comparative analysis of respondents' descriptions of concrete situations and the perceptions of being a neighbour to a person with a mental illness, a pattern was identified, demonstrating the mental process of being a nurse or not being a nurse, during leisure time.

The core category '*behaving as a nurse or not*' consisted of two processes; the nurse's mental process, and the interactive process between the nurse, the mentally ill neighbour/patient and other neighbours. The nurse's cognitive process can be described as a conflict concerning whether or not he/she is in an off duty capacity and has a moral duty to intervene when recognizing that a neighbour with a mental illness is in an unusual situation. The interactive process between the nurse, the mentally ill neighbour/patient and other neighbours arose when the nurse consciously or unconsciously took command in an unusual situation.

Accordingly, the process of '*behaving as a nurse or not*' was identified as a core category. Four subcategories were also identified:

1. '*Receiving involuntary information*', which describes that these nurses received a substantial amount of involuntary information about the neighbour, whether they wanted it or not since they experienced that 'it was difficult to defend themselves against noise and information that indicated that the neighbour was not ok'.
2. '*To take action or not*', which describes that these nurses experienced a conflict between being a nurse or a neighbour (i.e. that they confused their role as a professional nurse with their role as a private person). If something unusual occurred in the neighbourhood with which they felt familiar as a psychiatric nurse, they were unsure if they should take action or not because they were off duty. In situations like this, an inner conflict developed and became a moral dilemma. This dilemma consisted of the desire 'to do good' and show compassion towards another individual's well-being versus the knowledge that they should make a distinction between their role as a professional nurse and their role as a private person.
3. '*Behaving as a mediator in the neighbourhood*', which describes that these nurses considered it ethically difficult to put the nursing role aside during their private life because the professional role is explicitly one of care-giving. During the interviews these nurses expressed that they had a care-giving and a mediating role (i.e. that they sometimes, in different situations, were asked to act as a spokesperson for the person with mental illness as well as for other people living in the neighbourhood). The nurses commented that this was probably due to the fact that both the patient and other neighbours knew that the respondents' profession was psychiatric nursing. Furthermore, most of these nurses generally believed that it was natural for them to help a person in need.
4. '*The freedom of choice*', which meant that these nurses, given the opportunity to choose, would sometimes prefer not to have a person with a mental illness living next door to them. This was justified by; 'I don't want my leisure time to be disturbed', and 'I don't want to work night and day'. They also mentioned that they did not want to live next to people who suffered from

mania and psychosis, especially if they were addicted to drugs because they were afraid of knives and other kinds of weapons.

To summarize; the findings showed that psychiatric nurses with professional knowledge about mental illness have moral concerns about their role as nurses during their leisure time.

Sub-study II

The content analysis resulted in a main theme – ‘*attempting to uphold the principle, respect for the patient’s right to self-determination*’ – which consequently describes one of the overarching principles that guides registered nurses in the exercise of their profession

This theme was closely linked to three sub-themes:

1. ‘*The nurses’ views on their moral responsibility*’ which describes the nurses’ belief that they had a moral responsibility to ‘keep an eye on the patient concerning his/her well-being in the context of the supported dwelling’
2. ‘*The nurses’ views on social norms that patients must follow in order to be accepted by their neighbours*’. In order to avoid that people with a mental illness became isolated and lonely the nurses thought that they once again needed to become aware of social norms and follow them, which would help them to be accepted and participate in society. Furthermore, the nurses also consider that it was important that their neighbours were acquainted with them and understood that they were different but not dangerous.
3. ‘*The nurses’ views on supported dwelling of good quality*’ which describes the nurses’ views and experiences of what they considered best met the needs of the residents/the patients in order to ease their social integration.

Sub-study III

Of the 421 questionnaires that were distributed, 256 (60.8%) were returned by mail. Of these were 210 female, 36 male and 10 unknown. The age ranged between 18 years to 50 years, with a mean of 27.9 (standard deviation (SD), 7.5) and a median of 26.0. Almost all (94.9%) of the respondents had some kind of experience of mental illness. Most of them have had personal contact with a person with a mental illness.

The overall Cronbach’s alpha coefficient was 0.90 of the original CAMI-S questionnaire as a whole. The corrected inter-item total correlation on all the 40 original statements excluded 20 items since they showed weak loading (less than 0.43). Of the remaining 20 items, nine out of 10 originated from the factor community mental health ideology from the original CAMI. In addition to this, among the 20 items that showed moderate to high loading; five items originated from the factor social restrictiveness, four from the factor authoritarianism and two from the factor benevolence.

The overall Cronbach’s alpha coefficient on the 20 items that showed moderate to high loading was 0.903. A factor analysis was then used to uncover the latent structure of the 20 items that showed moderate to high loading (0.43– 0.64). The factor analysis revealed that the data now could be adequately represented by extraction of three factors. The three factors were inspected and the underlying themes were identified and labelled as ‘*open-minded and pro-integration*’, ‘*fear and avoidance*’, and ‘*community mental health ideology*’.

Sub-study IV

Of the 5000 questionnaires that were distributed, 2391 (47.9 %) were returned by mail. Of these were 1354 (56.6 %) female and 1037 male (43.4 %). The internal loss, question by question, ranged from 76 (item 8) to 140 (item 30). The age ranged between 18 years to 85. 55.7 % of the respondents had no experience of mental illness. 4.7% of the respondents had different kinds of experience of mental illness. 23.5 % had relatives or friends who suffered from a mental illness and 3.0 % had experienced mental illness on their own.

Four factors were inspected and the underlying themes were identified and labelled as; '*Open-minded and Pro-Integration*', '*Fear and Avoidance*', '*Community Mental Health Ideology*' and '*Intention to Act*'. Except from the factor '*Intention to Act*', which is new, these factors are generally consistent with the factors that were revealed in sub-study III.

In this population survey conducted in Sweden, a majority of the respondents demonstrate moderately positive opinions and attitudes towards mental illness and persons with a mental illness. Respondents in the age group 31-50 year appear to have more sympathetic attitudes towards persons with a mental illness. Moreover; it is worth noting that contrary to previous research, results in this sub-study showed that persons with lower educational level tend to reveal a more sympathetic attitude towards persons with a mental illness than persons with higher level of education. However the degree of positivity is due to the respondents' socio-economic background and experience of life; including, their own experiences of mental illness.

Percentages of acceptance and/or rejection of the different statements regarding opinions and attitudes towards mental illness and persons with a mental illness are presented in table II below. The six-point Likert-type scale was merged into three levels in order to more clearly illustrate and describe the differences between the various response options. The response levels as shown in the table are 'totally disagree', 'neutral' and 'totally agree'. Item 1 – 16 belongs to the demographic data.

6.2 TABLE II: RESULTS ACCOUNTED IN PERCENT

Statement nr: 19, 21, 23, 27, 29, 31, 34, 36, 41, 42 and 45 were negatively worded. In this table their scoring is therefore reversed.			
	Totally disagree	Neutral	Totally agree
17. The best therapy for many mental patients is to be part of a normal community	9.5	42.7	47.8
18. As far as possible, mental health services should be provided through community based facilities	12.2	38.5	49.3
19. I am against that someone with mental illness lives in my neighbourhood?	61.0	26.3	12.7
20. We need to adopt a far more tolerant attitude toward the mentally ill in our society	10.7	34.2	55.1
21. It is frightening to think of people with mental problems living in residential neighbourhoods	61.6	26.4	12.0
22. I can consider working together with someone who has a mental illness?	18.0	31.3	50.7
23. I would not want to live next door to someone who has been mentally ill	65.3	23.6	11.1
24. Residents have nothing to fear from people coming into their neighbourhood to obtain mental health services	13.3	35.1	51.6
25. I would invite someone to my home even if I know they had a mental illness?	14.6	30.8	54.6
26. No one has the right to exclude the mentally ill from their neighbourhood	9.6	26.2	64.2
27. It is best to avoid anyone who has mental problems	69.1	20.7	10.2
28. I can consider being friends with someone who had been a patient in the psychiatric care?	7.9	20.3	71.8
29. The best way to handle the mentally ill is to keep them behind locked doors	77.6	17.9	4.5
30. Most persons who were once patients in a mental hospital can be trusted as babysitters	41.0	39.8	19.2
31. I would avoid talking with neighbours who have had a mental illness in the past?	79.9	15.2	4.9
32. Residents should accept the location of mental health facilities in their neighbourhood to serve the needs of the local community	16.3	37.9	45.8
33. The mentally ill are far less of a danger than most people suppose	13.2	37.4	49.4
34. I would be worried if I visited someone with a mental illness?	64.0	26.2	9.8
35. The mentally ill should not be treated as outcasts of society	7.2	16.4	76.4
36. The mentally ill should be isolated from the rest of the community	80.8	14.4	4.8
37. If someone who had been a patient in the psychiatric care became one of my neighbours, I would welcome them into my home sometimes?	14.6	34.8	50.6
38. Locating mental health services in residential neighbourhoods does not endanger local residents	20.1	37.0	42.9
39. Mental illness is an illness like any other	22.6	25.0	52.4
40. I would speak in a natural manner with neighbours who have had a mental illness?	5.5	19.2	75.3
41. Mental health facilities should be kept out of residential neighbourhoods	43.9	33.0	23.1
42. Local residents have good reason to resist the location of mental health services in their neighbourhood	49.8	32.4	17.8
43. If someone who had a mental illness in the past became my neighbour, I would visit him/her?	13.2	35.0	51.8
44. Less emphasis should be placed on protecting the public from the mentally ill	18.9	40.4	40.7
45. Having mental patients living within residential neighbourhoods might be good therapy but the risks to residents is too great	47.2	35.7	17.1

7 INTERPRETATION AND GENERAL DISCUSSION

In order for people with mental illness to become socially integrated into society and rebuild a valuable and meaningful life, the public's knowledge and attitudes must be improved. As pointed out in the background, the public's negative attitudes towards mental illness and people with mental illness living in Sweden are likely to have influenced the social integration of these people in an unhelpful way. Accordingly; the overall aim of this thesis was to explore, analyze and describe the public's opinions and attitudes to mental illness in general and towards persons with a serious mental illness in particular. An additional aim was to evaluate the reliability of an existing questionnaire; Community Attitudes Towards Mental Illness (CAMI), and thereafter adapt and develop the questionnaire in accordance with Swedish conditions.

In this section, the findings from study I – IV are discussed in the light of the research questions. In addition to what has previously been discussed in each sub-study and in the methodology section; methodological issues related to this thesis, especially sub-study I and II, are reflected on in the following text. Furthermore, unless stated otherwise, the references beneath the headings 'Credibility and transferability' together with 'Confirmability and dependability' are from Lincoln & Guba (1985).

7.1 METHODOLOGICAL CONSIDERATIONS

In qualitative research, it is important to consider what criteria to use in order to assess the 'truth value'. Common criteria for establishing the trustworthiness of qualitative data are credibility, transferability, confirmability and dependability. In this thesis, trustworthiness was enhanced through the strategies detailed below are described and discussed in the following text.

7.1.1 Credibility and Transferability

Credibility is an evaluation of whether or not the researcher's findings represent a "credible" conceptual interpretation of the data drawn from the participants' original data, consequently the criteria for establishing credibility involve that the results of qualitative research are credible or believable from, among others, the perspective of the participant in the research. Credibility can be said to address the issue of confidence in the 'truth' of the findings and depends among other things on the ability and effort of the researcher. Credibility is similar to internal validity and is assumed to be strengthened by the so-called *validation performed by the interviewee's*; that is, those who were interviewed are asked to inspect the researcher's interpretations in order to confirm or reject them. Since from this perspective, the purpose of qualitative research is to describe or understand the phenomena of interest from the interviewee's eyes, the interviewee are the only ones who can legitimately judge the credibility of the results. In sub-study I and II, those who were interviewed did not take part in confirming the researcher's interpretations, which could be seen as a limitation. However, in these studies a 'peer-debriefing' also called 'outside readers' was used to establish credibility i.e. the researcher and co-researchers who all had extensive experience in the field, together with other highly qualified doctoral students in the field, discussed the researcher's interpretations, which can partly be considered to offset the above-described limitation. It should also be mentioned, with regard to sub-study I, that credibility is integrated in Grounded theory, through the constant comparative analysis.

Triangulation can also enhance credibility. Triangulation involves interpretation of several different methods and is also a way to increase a study's quality. Triangulation is, among other things, based on the idea that all methods are incomplete and have their own shortcomings, but by using more of these incomplete methods, preferably in a

combination, the risk of misinterpretation reduces and the reliability increases. Moreover, by using triangulation, the false representations and interpretations of social situations are minimized. Methodological triangulation was used in this thesis i.e. different data collection methods, that are interviews and surveys, were used in order to get the research questions answered as well as illuminated from different angles with the intention to gain a deeper understanding of what the interviewee says.

Transferability corresponds to external validity and refers to the degree to which the results of qualitative research can be generalized or transferred to other contexts or settings, in other words, it shows whether the findings have applicability in other contexts or not. In research with a qualitative approach the researcher can enhance transferability by doing a thorough job of describing the research context and the assumptions that were central to the research. Consequently, in order for external reviewers to assess whether the results can be transferable to another similar context; the researcher when analyzing the data material, must provide thick, rich and detailed descriptions of what he/she tries to describe in order to add depth to it instead of breadth and variety. Due to the small sample, sub-study I and II can not claim generalisability. The aim of the studies was not to achieve empirically derived data that could be generalised, and applicable to a wide variety of settings; instead, the studies intended to increase knowledge about psychiatric nurses' experiences of living nearby persons with a serious mental illness. Furthermore, the study also aimed to give direction for continuation of the research project. However; in sub-study I and II, the transferability was tested through discussions, in meetings with other highly qualified doctoral students in the field of health care science and psychiatric nursing. In addition, the interpretations of the findings are clarified with rich quotations which can be seen as one way to address the issue of transferability.

7.1.2 Confirmability and Dependability

Confirmability refers to the degree to which the results could be confirmed or corroborated by other researchers as well as the objectivity or neutrality of the data. Confirmability reflects the degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not influenced by researcher bias, motivation, or interest. In the sub-studies carried out with a qualitative approach, that is sub-study I and II, the researcher who conducted the interviews can be seen as the 'research instrument' throughout the research process. The credibility and trustworthiness of the results thus depends on the interviewer's knowledge and skills. There are a number of strategies for enhancing confirmability. Among others, documentation of the procedures for checking and rechecking the data throughout the study are strongly recommended as well as another researcher can take a 'devil's advocate' role with respect to the analysis procedures and the results. In addition he/she should also make judgements about the potential for bias or distortion. This process must also be documented. In all sub-studies, careful notes were made throughout the whole research process which can be seen as a guarantee to satisfy the issues of confirmability. As mentioned before, methodological triangulation was used in this thesis which also is a way to deal with the issue of confirmability.

Dependability can be described as an assessment of the quality of the integrated processes of data collection, data analysis, and theory generation aiming to show that the findings are consistent and could be repeated. An inquiry audit was performed at different stages of this thesis. This can be described as having researchers not involved in the research process examine both the process and findings of the study. The purpose is to evaluate the accuracy and evaluate whether or not the findings, interpretations and conclusions are supported by the data. In order to attend to the issues of dependability in this thesis, the research-plan was discussed and evaluated by postdoctoral researchers as well as highly qualified doctoral students in the field. In addition, feedback was obtained during the research-process on the mandatory biannual checks as well as at the obligatory half-time control where the research was reviewed

and questioned by one professor and two associate professors. Furthermore, the researchers pre-understanding were discussed and made clear, in discussions with other highly qualified doctoral students, in order to prevent bias.

7.1.3 Psychometric analyses

Unlike qualitative research in which illumination, understanding, and extrapolation to similar situations is the goal, quantitative research seek causal determination, prediction in order to generalize findings. In this thesis, sub-studies III and IV were carried out with a quantitative approach focusing on psychometric analyses. Psychometrics is a statistical discipline, and methods used here, are for measure/evaluate tests claiming to measure a persons personality which, among other things, includes his/hers attitudes, i.e. examine the quality of the test/questionnaire used. Consequently, psychometric analyses have been performed in order to evaluate the original questionnaire, 'Community Attitudes towards Mental Illness' (CAMI) and then develop and adapt it to Swedish conditions. Evaluation and testing of existing questionnaires, including scale development, is a process characterized by a relatively integrated series of activities for which there are some common practices and some consensual criteria. Good scale development starts with a well-thought-out theory about the construct that leads to construct specification, item development, initial testing, psychometric analyses and revision of the scale (Djurfeldt *et al.* 2003)

After a thorough review of relevant research and literature the questionnaire, the existing instrument CAMI, was found, and was considered appropriate to use if the psychometric analysis showed that validity and reliability was acceptable. The validity of the instrument was assessed by so called 'Face Validity', 'Content Validity' and 'Construct Validity'. Reliability was assessed through 'test of internal consistency'. The Statistical Package for the Social Sciences (SPSS) version 14.0 and 15.0 was used for statistical analysis of the collected data; below is a description of this process.

Face Validity implies that an assessment of the instrument's validity is made i.e. by examining the questions included in the instrument and how they are addressed, it is established that the instrument really measures the phenomenon that is intend to be measured (Norman & Streiner, 2003).

Content Validity means that an analysis of the election and composition of the questions have been made as well as an appraisal of the extent to which the questions are representative of the phenomenon contemplated to 'be captured'. When assessing Content Validity, it is ensured that the questions cover all relevant and necessary areas required to measure/describe the phenomenon. In order to conduct Content Validity and Face Validity, relevant theoretical knowledge in the field is required, e.g. knowledge of current research in the field as well as awareness of other comparable instruments (Nunnally & Bernstein, 1994, Norman & Streiner, 2003). Consequently, the terms Face Validity and Content Validity are relatively equal; both of them imply that a person with specialized knowledge assesses that the instrument's appearance are acceptable.

Construct validity examines the extent to which the instrument's structure confirms with the theoretical basis on which it is based on (Nunnally & Bernstein, 1994). Construct Validity can, among other things, be carried out with an exploratory factor analysis in order to examine the factor-structure of the instrument, and then put this in relation to a theory. The purpose of an exploratory factor-analysis is that – given a set of variables – find the underlying dimensions which may explain the pattern, created by the correlation between the variables (Gorsuch, 1983).

Cronbach's alpha is one of the most common methods for testing 'internal consistency', which measures whether a number of questions – together – measure a particular phenomenon. Internal consistency can be described as an estimation of

reliability, based on an average correlation among the questions included in the questionnaire (Nunnally & Bernstein, 1994). The value of Cronbach's alpha is based on the average correlation between each question and the number of questions, and the alpha-value increases if any of these parameters are increased. In theory, if the questions are uncorrelated is $\alpha = 0$ and if all the questions are identical is $\alpha = 1$. Alpha-values of >0.70 , is sometimes considered as tolerable, but it is generally recommended that the alpha-value is >0.80 in order to be considered as perfectly acceptable. (Nunnally & Bernstein, 1994; Streiner & Norman, 2003).

The corrected item total correlation is another method to show 'internal consistency' and reveal whether there is a connection between each item and the sum (or average) of all the other items. Accordingly, this method is used when determining the contribution of each item to internal consistency. Each item each in the questionnaire should correlate with the test in its whole (Gilbert & Miles, 2005; Leong and Austin, 2006).

The results from sub-study III showed that the original CAMI instrument, consisting of 40 questions, had a good validity. Face Validity and Content Validity was ensured by examining the form, structure and query design. Particularly taken into account were content, wording, the items relevance in Sweden of today, scoring method, and easiness and appropriateness of the questionnaire administration. When the translation phase was carried out, all the assessors, which consisted of postdoctoral researchers and highly qualified doctoral students – all of which were active in the field, were in full agreement that all of the questions were relevant or entirely relevant, linguistically as well as culturally. However, one disadvantage pointed out was that the instrument contained relatively many questions which were feared to discourage potential respondents; on the other hand, Sjöberg (1996) argues that a large number of questions of a questionnaire do not tend to reduce the response rate.

Another dilemma that was paid attention to, was the concept 'the mentally ill' which were used in the origin questionnaire. The concept was considered to be obsolete, reflecting an era when 'persons with a serious mental illness' were 'lumped together' and looked upon as something unnatural and abnormal. In addition, the concept was regarded as broad and imprecise, withholding a variety of psychiatric disorders such as, among others, depression, anxiety, alcoholism and schizophrenia. Consequently, it was decided that in the Swedish version of the questionnaire the contemporary concept 'persons with serious mental illness' should be used, referring to the target group for the 1995 psychiatric care reform.

Internal reliability of the translated CAMI-questionnaire, renamed to CAMI-S, was tested by performing a corrected item-total correlation and by measuring the Cronbach's alpha. However, the reliability was considered as unsatisfactory since the corrected item total correlation revealed that twenty items showed weak loading (less than 0.43) and consequently were excluded (Norman & Streiner, 1994). Despite this, the overall Cronbach's alpha coefficient was 0.90 of the original CAMI-S questionnaire as a whole thus deemed as acceptable.

As mentioned before, adaptation and development of a questionnaire for use in a new setting may be difficult. The fact that the corrected item total correlation revealed that twenty items showed weak loading may be due to the fact the original CAMI-questionnaire actually is more than 25 years old and was developed and used in English-speaking countries, a language with a large vocabulary. Translating the English version of the CAMI-questionnaire to Swedish may have resulted in a minor shifting of the meaning of words. The exact translation of words or concepts from one language to another is almost impossible, which means that nuances can be missed. Thus, this was considered to be one of the causes of to the weak loading of the corrected item total correlation. However, the overall Cronbach's alpha coefficient on the 20 items (new CAMI-S) that showed loading, >0.43 was 0.903 and the corrected item total correlation of these items revealed that the data could be extracted in three factors labelled as: open-minded and pro-integration, fear and avoidance and community mental health ideology.

As noted in the background; in order to reach reliable results in attitude research, it is important to measure the respondent's attitude towards the object in common as well as the respondent's attitude to interact with the object, therefore it was considered important to add behavioural intention items to the 'new CAMI-S'. Accordingly, a new literature search was made and 9 items concerning the respondents' intention to interact with a person with a mental illness was found. After permission from one of the originators' Thomas Craig to translate and adapt the behavioural intention-items to Swedish circumstances, the CAMI-S questionnaire were supplemented with, they so-called behavioural intention-items (Wolff *et.al.* 1996a; b). In the following text the completed questionnaire is named the 'New CAMI-S'.

In order to test internal consistency reliability of the New CAMI-S questionnaire as a whole, Cronbach's Alpha was used. In the next step a corrected inter-item-total correlation was carried out on all the 29 statements in order to test each item's correlation to all other items. All items showed loading > 0.44 . Consequently, none of them were excluded. In step three, a factor analysis (extraction method: Principal Component Analysis with a varimax rotation) was carried out on the 30 items in order to test their internal structure. This revealed that the data could be adequately represented by extraction of four factors. The four factors were inspected and the underlying themes were identified and labelled as; *Open-minded and Pro-Integration*, *Fear and Avoidance*, *Community Mental Health Ideology* and *Intention to Act*. These factors are generally consistent with the factors that were revealed in sub-study IV. In the fourth step, a Cronbach's Alpha was used to test internal consistency at the 30 items above.

For both sub-study III and IV, the relatively large loss may be a threat to external validity, which may make it difficult to generalize the results. However, this response rate can be regarded as satisfactory, especially since the risk for dropping-off can be high if the questions, as in this study, may be experienced as sensitive and/or insulting of the personal integrity. In addition, failure analysis indicated that the loss was not systematic which means that the external validity can be considered as acceptable. The strength of the study IV is that the random sample is large; accordingly the study results should be representative of the Swedish population. Another problematic aspect is that the concept of mental illness is complex and therefore difficult to classify or have various meanings for ordinary people. As a consequence, it was difficult to know what the respondent actually responded to, since their answers probably were based on personal experience, inner values and own ideas of what mental illness is and how a person with a mental illness behaves; which is hard to compare with another respondents answer since it could be based on entirely different values and experiences.

As mentioned before, the goal of quantitative research, among other things, is to determine for links between various variables. When attempting to predict an individual's attitude given several socio-economic a multiple linear regression is appropriate to use which is a technique for modelling and analyzing several variables. When using multiple regressions, the term "independent variables" is consistent with those variables considered to influence some other variable which is called "dependent variable". As for the regression analysis performed on the data from sub-study IV; the dependent variable is the item, i.e. the statement which expresses the respondent's attitude, which might be influenced by the respondent's socio-economic background, i.e. the independent variables.

To summarize and clarify; Multiple regression predict one variable on the basis of several other variables which is useful when predicting human behaviour, as our actions, thoughts, emotions and attitudes which all are likely to be influenced by some combination of several factors. In sub-study IV, a linear multiple regression analysis was used to determine the relationship between socio-demographic data and opinions and attitudes towards mental illness and persons with a mental illness. The use of a

linear multiple regression analysis and conventional levels of statistical significance may be regarded as fully sufficient in order to meet the requirements of for reliable results.

7.1.4 The Symbolic Interactionist perspective and the formation of attitudes

To decide what methodological perspective the thesis shall be based on depends on a number of decisions that must be taken during the trip. One decision to take is the focus of the research and another one is e.g. what shall be the basis for the final text. Since I, among other things, was interested in trying to understand the processes that contribute to the creation of attitudes, the symbolic interactionist perspective was a natural choice since the perspective is suitable for use in studies of social processes and can provide understanding through visibility of the social processes that the citizens creates and give meaning to, based on their inter-subjective experiences (Trost & Levin, 2004).

According to the symbolic interactionist perspective, social organisations such as society are social constructions in which the inhabitants create and develop their actions. Structures within organisations; as its culture, social systems and different roles that are created, sets up the conditions for actions but do not decide on these – this is carried out by the individual citizen in his/her behaviour. Neither is it against the culture, system or roles that they act. Their actions are according to Blumer (1969) directed towards the specific situation and the other citizens' actions.

Based on the three basic premises according to Blumer (1969), the construction of the citizen's attitudes towards a person with serious mental illness can be explained as follows. Attitudes towards a person with serious mental illness can be seen as social constructions that precondition the citizen's actions. These actions can be understood and explained based on the meaning; in the form of pre-understanding and history of the meaning of serious mental illness has for them. This means that previous experiences or encounters with a person with serious mental illness influences actions and thoughts that shape the citizen's attitudes towards a person with serious mental illness. This affects other citizens' actions since they in turn steer their action based on how they interpret others' actions in specific situations. The way the citizen's, in different situations and meetings, responds to a person with serious mental illness affects the citizen's interpretation of the situation and thus on the action for the moment. Moreover, current norms for how a person with serious mental illness should be approached influence the citizen's behaviour. Finally, the citizens become co-creators of one another's identities and actions that ultimately influence how attitudes towards a person with mental illness develop which is exemplified in figure 2.

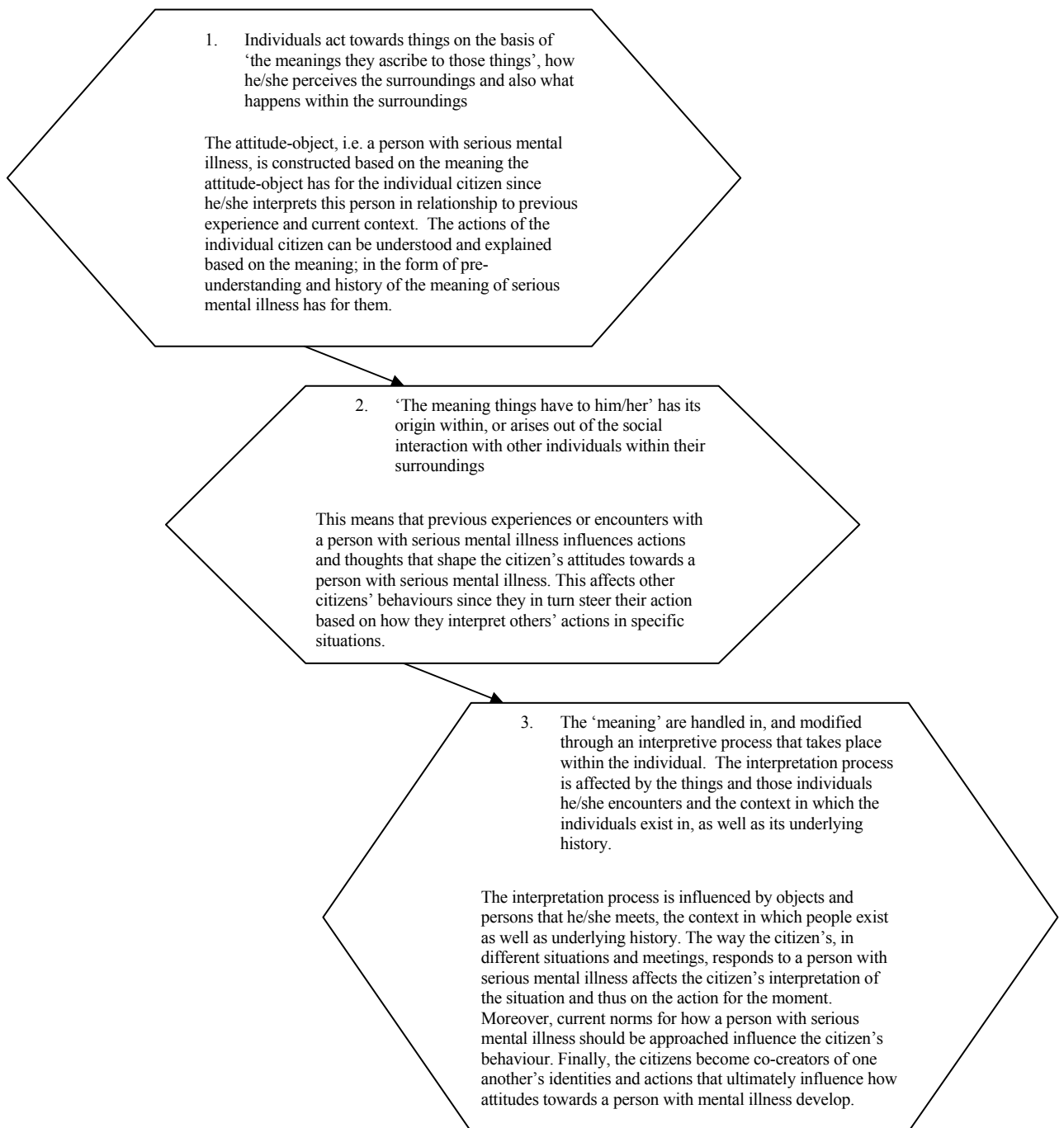


Figure 2: The construction of the citizen's attitudes towards a person with serious mental illness, explained on the basis of three basic premises that according to Blumer (1969), the symbolic interactionist perspective emanates from.

7.2 DISCUSSION OF FINDINGS

7.2.1 The dilemma with the multi-faceted concept of mental illness

To arrive at the assumption above has not been obvious and easy, for one thing because the concept of mental illness is broad and full of nuances with the result that it has different meanings for different persons. Granerud (2008) comments that each individual's experience of mental illness differs and depends on various factors such as partner, social network, friends and family as well as his/her previous experience of mental illness which in turn affects what the individual puts in to the concept of 'mental illness'. When analyzing the answer from a respondent who have been asked to answer a question regarding if he/she is willing to live next door to a person with a mental illness the researcher must take into consideration that it is unclear what the concept means to the respondent. How does the respondent imagine a person with mental illness? What has the respondent for experience of a person with a mental illness? Has the respondent met a person with a visible mental illness? The answer to the last question is not obviously yes, since the majority of people, according to WHO (2001) come in contact with mental health problems through their own difficulties or those of their friends and family members.

The concept 'mental health illness' covers a wide range of conditions from mild depression to acute schizophrenia. According to Sartorius (1998), the general public often associates mental illness with hallucinations, delusions – often of a bizarre kind – psychomotor abnormalities and incoherent speech, which is frightening for people and sometimes leads to different kinds of avoidance. Further, according to Heginbotham (1998), many people are frightened of mental illness and mentally ill people, a fear partly rooted in lack of knowledge and ignorance, resulting in negative attitudes towards persons with mental illness. This is similar to Ottosson (2004) who points out that these persons often give an impression of incomprehensibility, abnormality and strangeness that in different ways contributes to the publics' dissociation. When Svensson & Hyltén (1995) examined laymen's everyday perceptions of persons with mental illness they found that the informants presented two different descriptions of a person with a mental illness; 'the embarrassing and ridiculous one' and 'the menacing and frightening one'. This is a simplified image and should, according to the authors be seen as two superior typological concepts, each of which can be problemized and sub-specified in different ways.

However, when analyzing the result, it is very important to take into consideration which of these images the respondent bear in mind when he/her answers the question. As mentioned before ordinary people have a tendency to regard a person with a mental illness as unpredictable and unreliable. This is comparable to what the respondents in sub-study II experienced, that is; that the neighbours acted as if they were afraid of the mentally ill neighbour's unpredictable behaviour, which the respondents considered to be one of the reasons for the formation and maintenance of negative attitudes towards people with mental illness. In addition, they also 'hypothesized' that the patient's often-bizarre expressed feelings and behaviour, i.e. the patient's capability of functioning, might be one reason that could increase the neighbours' fear of the person with mental illness. It is worth noting that they also believed that sometimes it might be difficult to see any differences between persons with mental illness and those with other behavioural deviations.

Despite the above reflections, the question remains regarding what image of a person with mental illness the respondent had in mind when he/she answered the questions. However, in sub-studies III and IV it was clarified in the survey's covering letter that according to the implementation of the 1995 psychiatric care reform - 'persons with serious mental illness' now live in the community. The intention of this information

was to clarify to the respondents that they should have these people in mind when they answered the questions. However, based on reports outlining the public has a tendency to consider people with a mental illness as dangerous; there is a risk this was the dominant image they had in mind when they answered the questions.

The reporting on the tendency to regard people with a mental illness as dangerous can lead to that a person with a mental illness who in fact, in any way, is dangerous becomes a form of archetype for all persons with a mental illness which is an unfortunate consequence since the link between mental illness and violence is weak according to Swanson *et al.* (2002) and Bülow (2004).

Furthermore, it is important to clarify that violent behaviour of those with serious mental illness has been associated with more severe clinical symptoms such as substance misuse, transient living conditions (including homelessness) low level of functioning, lack of social support and a history of previous victimization (Walsh *et al.*, 2003). The aforementioned psychiatric conditions shall not be associated with the target group for the 1995 Psychiatric care reform since they mainly live in orderly circumstances in contact with mental health facilities. However, how the respondent's picture a person with a mental illness when answering the questions is not something we can be sure of yet could be an interesting future research focus.

7.2.2 Mental health professionals' attitudes to mental illness and people with mental illness

Mental health professionals are specifically trained to meet individuals suffering from mental illness. Bayar *et al.* (2009) claims that it would be natural to assume that mental health professionals, as a group, would have less negative and stigmatizing attitudes towards persons with mental illnesses compared to the general public, especially those who are not trained in health care. However, this does not seem to be the case. Mental health professionals' attitudes to mental illness and people with mental illness have been examined in different studies and the results of these studies can be summarized with the inference that negative and stigmatizing attitudes towards persons with mental illnesses also occur among mental health professionals (Nordt *et al.*, 2006; Schulze, 2007; Bayar *et al.*, 2009; Rao *et al.*, 2009) as well as among professionals within the somatic care (Thornicroft *et al.* 2007).

One of the issues discussed in this thesis was whether professionals, with several years of experience of psychiatric care and working with people with a mental illness, would willingly live next to a person with a mental illness? The issue arose since the National Board of Health and Welfare asserted that negative attitudes towards people with a mental illness could be 'educated away'. If this was the case, professionals within the field of psychiatric care, would automatically welcome them into their neighbourhood. Or would they?

However, the nurses specialized in psychiatric care; that were interviewed in sub-study I, emphasized that there was a strong need for them to separate their time as a professional nurse from their time as a private person. Furthermore, if a choice existed, the respondents in the study preferred not to live close to a person with a mental illness; especially if this person suffered from mania and psychosis or were addicted to drugs. The reason for this was that they were 'afraid of knives and other kinds of weapons' with reference to their children's safety. In addition, the respondents also claimed their right to use their leisure time as they wished, in order to have pause before going back to work again. The question implicitly expressed in the respondents reasoning is whether or not there is a distinction between their professional responsibility as a nurse and their moral responsibility as a human being. The respondents seemed to perceive that they had a moral obligation to assure that the mentally ill neighbour received adequate care and support. Deciding whether or not to

be a responsible psychiatric nurse during their leisure time or to be just a neighbour among other neighbours, resulted in a moral dilemma about whether to intervene or not in situations when they saw or heard that a person with a mental illness needed help.

An interesting question is whether these views are specifically for nurses since nursing, according to is fundamentally a moral art in which moral values and norms guide nurses in their communicative and caring interactions with patients (Sarvimäki, 1988; Sarvimäki & Stenbock-Hult, 1996) as well as to care is a moral attitude in nursing Gastmans (1999). If so, more emphasis should be placed on raising awareness of the mental health professionals, as well as the public's, moral stance regarding their attitudes towards people with a mental illness.

The nurses, who were interviewed in sub-study II, pointed out that it was of great importance that the neighbours saw the individual with mental illness as a human being, and not as a mentally ill person despite his/her odd behaviour. 'It has to do with attitudes', as one respondent said, 'but attitudes can be influenced by information' she continued. 'I think we have a long way to go before the prejudices of today will disappear and I think we have an important work to do' she concluded. The respondents also pointed out that ignorance and fear of things which is unfamiliar to many people is one reason why people stay away from persons with mental illness. To summarize, one of the findings in sub-study II was that the respondents considered it to be of great importance that information about mental illness and perhaps even about the mentally ill person in question should be given to the neighbours. Otherwise, as one respondent said, there was a risk that the neighbours did not want to have anything to do with these persons, especially as neighbours.

However, is information and increased knowledge the best way to counteract negative attitudes? According to Zalar *et al.* (2007) psychiatric education with lectures and psychiatric clerkship in a standard psychiatric setting have the power to reduce negative attitudes toward persons with a mental illness, at least in terms of emotional barriers; but fail to eliminate most stereotypical beliefs, except for the perception about the mentally ill being dangerous.

Consequently, professional knowledge about mental illness and encounters with the patient do not seem to be enough in dealing with the problem of negative and stigmatizing attitudes among mental health professionals. Despite these recent research findings, the National Board of Health and Welfare, (2010) still assert that negative attitudes towards people with a mental illness should be 'educated away.' Despite the fact, with reference to current research in the background section, that it is primarily the personal meeting between people that counteract negative attitudes and prejudices, they suggest that; in order to overcome the problem with negative attitudes towards mental illness and persons with mental illness, information campaigns and wide conferences for the public shall be carried out with the intention to increase the general level of knowledge and awareness about mental illness and people with mental illness.

An interesting question which then arises is who is most suitable to conduct this? If it is meant that mental health professionals should accomplish this work, with the aim to counteract negative attitudes towards people with mental illness – then it must be taken into consideration that even they, according to recent research findings, display negative and stigmatizing attitudes towards persons with mental illness.

7.2.3 The Swedish public's attitudes towards people with a mental illness – an expression of the NIMBY-phenomenon?

The overall research question in sub-study IV was whether negative attitudes towards persons with a mental illness did exist among the Swedish population and if so; how they were expressed. Consequently the aim was to analyze and describe public opinions and attitudes to mental illness in general and to persons with a mental illness in particular. A summary of the results showed that a majority of the respondents revealed moderately positive opinions and attitudes towards mental illness and persons with a mental illness. As described in the background; surveys regarding the public's attitudes towards people with a mental illness have in recent decades been conducted in other countries in the Western world with similar results. What distinguishes the result of sub-study IV in this thesis, from results of other comparable studies is that the relationships between the respondents' answers and their demographic data differ. The respondents in sub-study IV, with lower educational levels tend to reveal a more sympathetic attitude towards persons with mental illness than persons with higher level of education, which is contrary to previous research (Havward & Bright, 1997). What could explain this difference? And how is it that the respondents with higher level of education, in sub-study IV, do not display positive attitude towards persons with a mental illness similar to respondents in other comparable studies?

The respondents' answers in this survey were given anonymous and treated with confidentiality, which may be one explanation to the differences. In sub-study IV, the respondents may have felt that they did not have to answer what was considered to be politically correct; instead they could answer what they really thought and felt despite the fact that the questions could be perceived as sensitive. Could one explanation be that the respondents with lower educational level in sub-study IV gave expression to similar, or just slightly more generous and welcoming attitudes, compared to the results from previous studies, and that the major difference actually was that those with higher level of education, this time provided more truthful answers? This is a speculation that is an interesting methodological challenge and that could be a future research focus.

But if the reasoning in the above paragraph is true – this could be explained by the so called NIMBY-phenomenon which is an abbreviation as well as an acronym for the phrase '*not in my backyard*'⁹. The acronym has become frequently used to describe reactions among the local population when they express opposition to something unwanted in their community, and can be described as a type of a social phenomenon that arises when people become territorial (Cowan, 2003). The term 'NIMBY' was coined in the 1980s; the practitioners of the phenomenon are known as 'the NIMBY:s' or 'the NIMBY:ists' and are considered to be narrow-minded and selfish. This has led to that the term most often is used to negatively describe the attitude of a person or a group of persons who oppose the development of anything they deem as inappropriate in their neighbourhood. They usually take this stance because they simply don't want '*it*' in their 'backyard,' and not because they think that '*it*' in itself is bad or unnecessary. It usually means that the persons who oppose the project would be totally pleased if '*it*' only was located in someone else's backyard (Piat, 2000; Guidotti & Abercrombie, 2008).

In the context of this thesis it can be interpreted as 'the NIMBY:s' express that they do not want to live nearby a person with a mental illness (Leff & Warner, 2006). However, the term is not specifically intended to highlight negative attitudes towards people with a mental illness, it may well be about other forms of resistance such as fighting the development of a nearby tall building because it might block their view. Nevertheless, the most prominent feature of 'the NIMBY:s' is, as mentioned earlier, that he/she opposes the location of something, which is usually a public necessity or a civic project

⁹ The term backyard can be variously defined as a neighbourhood or local community, local government area, a city or even a state (Guidotti & Abercrombie, 2008).

such as a nursing home, a treatment centre, a drug rehabilitation centre or a meeting hall for a minority group into their own neighbourhood. Yet, *he/she does not oppose these planned actions if they are located somewhere else*. Furthermore, the protests expressed may also involve an unwillingness to welcome specific individuals, representing a minority group. In order to succeed avoid receiving something or someone into their neighbourhood who they believe may create discomfort or causes the value of their houses or other forms of property to fall; it is common that the ‘NIMBY:s’ camouflage their actual views and instead construct and express motives that are considered be politically correct.

Furthermore, ‘the NIMBY:s’ usually consists of a small but active group of affluent people who protest loudly; thus influencing the rest of the neighbours. It should also be added that many residents of lower income areas do not have the economic or political resources to fight developments they may be opposed to. Consequently, since many ‘NIMBY:s’ reside in affluent or more powerful neighbourhoods, they are considered to be more successful when performing resistance, leading to that the ‘project’ lands on someone else’s backyard; someone who protests less, ultimately due to lower standards of living (Piat, 2000; Guidotti & Abercrombie, 2008).

According to the above, this implies that persons with lower level of education and lower standards of living are considered to have less strength and resources to oppose when local authorities for example build a treatment-home for people with mental illness, in their neighbourhood (Piat, 2000; Guidotti & Abercrombie, 2008). In other words, persons who do not have the resources to protest when a landlord leases the neighbouring-apartment to the Social services; which in turn will let a ‘specific individual’, representing a minority group, rent it on the condition known as ‘a social contract’. It shall here be noted that the ‘specific individual’ may very well be a person with a mental illness. It is therefore not uncommon that dwellings for people with a mental illness many times are located in areas with lower socio-economic standards (The National Board of Health and Welfare, 2003a).

In line with the above reasoning, persons with lower level of education and lower standards of living more frequently encounter people with a mental illness and establish a form of relationship with ‘the person behind the illness’. As mentioned in the background, people with some kind of personal experience of people with mental illness, preferably in the form of personal meetings, often display a more generous and positive attitude towards them (Wolff *et.al.* 1996a; b). In sub-study IV, the assumption can be made that the respondents with lower level of education and lower standards of living had some kind of a personal experience of a person with a mental illness. One explanation for this may be that they live in the same neighbourhood, which may have led to that they, in their responses, tended to present more positive and sympathetic attitudes towards persons with a mental illness. If so – it can be considered that when people with a mental illness are offered housing in the community a side effect occurs, i.e. the contact with the neighbours increases, which in turn has led to that the neighbours have established a personal relationship with them and therefore show a more positive attitude.

If, a treatment centre for people with a mental illness would be built in an affluent and powerful neighbourhood with citizens with higher level of education and higher standards of living; an interesting future research focus would be to capture the residents’ inherent views and avoid getting access to their possible politically corrected answers.

7.2.4 Stigma and mental illness

There seems to be no doubt that there is a stigma associated with mental illness, in general, and schizophrenia in particular (Thompson *et al.* 2002). Results from this thesis support this statement, i.e. that persons with mental illness frequently encounter public stigma as well as stigmatizing attitudes from mental health professionals. The concept of stigma is debated; nevertheless it is generally considered to be a social construction which arises when four interrelated components converge:

1. *People distinguish and label human differences*
 2. *Dominant cultural beliefs link labelled persons to undesirable characteristics to negative stereotypes*
 3. *Labelled persons are placed in distinct categories so as to accomplish some degree of separation of 'us' from 'them'*
 4. *Labelled persons experience status loss and discrimination that lead to unequal outcomes'*
- (Link, & Phelan, 2001; Link *et al.*, 2004).

A person with serious mental illness can be said to meet the criteria for all the four components as above as well as the three types of stigma that Goffman (1963) describes as follows:

1. *Bodily stigma.*

It is not unusual that a person who suffers from mental disability of a chronic type eventually exhibit physical symptoms in such way that he/she becomes bodily marked by the illness. Sometimes it can be side effects of neuroleptic-treatment (Ottosson, 2004; Cullberg, 2003; 2005)

2. *Stigma of the character.*

The so-called negative symptoms of mental disability of a chronic type, involving malfunctions that may affect multiple psychological functions; which ultimately influence the cognitive abilities, ultimately leading to a change of personality (Ottosson, 2004; Cullberg, 2003; 2005).

3. *Group stigma, among other religion, ethnicity, social class and sex.*

Instead of being seen as a group of individuals, persons with mental illness often are labelled and lumped together into one group, leading to increased stigmatization (Ottosson, 2004; Cullberg, 2003; 2005).

In summary, there are thus many factors that contribute to the stigmatization of persons with serious mental illness. Nevertheless, it seems that the negative attitudes and prejudices existing in the surroundings are a primary cause for this to happen.

The findings of sub-study I demonstrate that the respondents considered that an important task for them was to serve as a link between the person with mental illness and his/her neighbours – which was also the respondents' neighbours – to promote personal contact between the neighbour and the person with mental illness. They also believed that the personal contact between the neighbours and the person with mental illness was one way to reduce misconceptions and fear of persons with mental illness.

This finding is consistent with Warner (2001), who claims that one way to reduce stigma is to increase the contact between the person with mental illness and his/her neighbours; so that people in the vicinity get to know the person with mental illness as an individual and unique person; rather than, from a distance, regard him/her as an odd person with a bizarre behaviour. The respondents in sub-study I expressed that they, despite the fact that they were free from work, had a care-giving and a mediating role, in addition they described themselves as a spokesperson for the

person with mental illness, as well as for other people living in the neighbourhood; if it concerned matters which were related to the person with mental illness. The respondents described that this happened both on demand and on their own initiative. In the latter, the question arises in whose interests it was, since the respondents also expressed a desire to 'do good'; a desire that probably originated from their profession as nurses; and/or was grounded in their personality.

We do not know whether the person with the mental illness was pleased when the nurse, who lived in the same neighbourhood; unasked, represented him/her. Mental health professionals seem to see themselves as obvious in terms of representation of persons with a mental illness. The findings of sub-study I demonstrate that the respondents, i.e. psychiatric nurses, with solid knowledge of psychiatric care as well as other citizens, must examine their own moral attitudes, improve their ability to interact in a sincere and genuine way, with persons with mental illness in order to become more tolerant to counteract stigmatization. A question raised in one of the previous sections is also at issue here, namely whether mental health professionals are the ones who are best suited to make way for people with mental illness in society, since them to exhibit stigmatizing attitudes towards persons with mental illness.

Methods to reduce stigma has mostly been about implementing various educational programs, with the aim to influence prevailing negative attitudes among the public (Björkman, 2005; Warner, 2001). The National Board of Health and Welfare, (2010) assert that information campaigns and wide conferences for the public will be carried out with the intention to increase the general level of knowledge and awareness about mental illness and people with mental illness. However, the findings in sub-study IV show that there are those with lower level of education who exhibit more positive attitudes towards persons with mental illness compared with those who have a higher level of education. We have an interesting and perhaps important paradox here. As mentioned before, earlier research showed that those with lower level of education exhibited negative attitudes towards persons with mental illness. This implies that, until now, it is those who are the target group for information campaigns with the aim to raise their knowledge of mental illness. Due to the research-findings from sub-study IV, one issue of concern now arises; namely, to which groups in society shall these educational efforts be directed to? In addition, what shall the education and the information in this case consist of? Could it be that the general level of knowledge already is – if not good – then at least acceptable? If so, ultimately, as previously mentioned; instead it is about raising awareness of the public's moral stance regarding their attitudes towards people with a mental illness.

Information campaigns and conferences for the public have over the years been conducted with varied results (Björkman, 2005; Warner, 2001). In order to reach success when implementing these efforts, they should be directed to smaller and well-defined target groups (Wolff *et al.* 1996c; Byrne, 2000; 2001; Thompson *et al.* 2002). Furthermore, it is advocated that the educational content will focus on public perceptions of mental illness, as for example the idea that a person with a mental illness is dangerous; which is one important public perception that appears to remain. Thompson *et al.* (2002) argues that persons with mental illness are clearly thought to be dangerous by members of the general public; consequently, this is a specific factor that limits the extent to which overall stigma can be reduced. In addition, this view is especially common among those with children (Wolff *et al.* 1996a).

Moreover, what really seems to counteract the public's negative attitudes and reduce stigma appears to be interpersonal encounters between the person with a mental illness and the people in his / her immediate vicinity (Corrigan *et al.*, 2001). This statement is confirmed by the results from sub-study IV since one characteristic of the respondents who show a positive attitude towards persons with mental illness was that they all had some kind of experience of mental illness, either in the form of a relative or friend who was mentally ill, or they had experiences of their own mental illness. Furthermore, it should also be mentioned that those who were working within the psychiatric care also displayed positive attitudes towards persons with mental illness. With reference to the

previously mentioned about mental health professional attitudes in question, it can therefore be stated that this issue has not yet been clarified.

7.3 Conclusions

A summary interpretation of the main findings in this thesis reinforces the assumption, that negative attitudes towards people with mental illness living in Sweden is still in existence; leading to that persons with mental illness frequently encounter public stigma as well as stigmatizing attitudes from mental health professionals.

The present thesis also demonstrates that additional knowledge is not the only way of solving prejudice against mental illness and mentally ill people since mental health professionals also reveal stigmatizing attitudes towards persons with mental illness which implies that those, as well as other citizens, must examine their own moral attitudes, improve their ability to interact with persons with mental illness and become more tolerant in order to prevent alienation.

However, the results of sub-study I and II demonstrate that mental health professionals experience that they have a moral obligation to make sure that persons with mental illness who lives in the same neighbourhood as themselves are taken care of in a proper way. Therefore, mental health professionals, also when being off duty, considered it to be important to perform the functions of a link between the mentally ill person and other neighbours in order to promote personnel contact between the neighbour and the person with mental illness. As a professional in the community-based psychiatric care, the importance of being near the mentally ill person in order to be 'in presence' and give support if something goes wrong was considered to be of significance.

The present thesis also demonstrates that in order to reach reliable results in attitude research it is important to consider that the attitude to be measured is linked to concrete situations as well as that the questionnaire is designed to measure both the respondent's attitude towards the object in common as well as the respondent's intention to interact with the object.

The results from sub-study IV indicate that a majority of the respondents' displayed positive or at least neutral attitudes which implies that they had moderately positive views and attitudes towards mental illness and persons with mental illness; which can be considered as representative for the Swedish population. However, the degree of positivity depended on the respondents' socio-economic backgrounds; including, their own experiences of mental illness.

The results from sub-study IV also indicate that the intention to interact with a person with mental illness appeared to be greater among the respondents with lower educational level in the age group 31-50: born in the Nordic countries. Moreover; it is worth noting that contrary to previous research; the results of sub-study IV showed that persons with lower educational level tended to show a more sympathetic attitude towards persons with mental illness than persons with higher level of education.

7.3.1 Further research

There are still many areas to explore within the field of attitudes to mental illness and persons with mental illness:

1. Since mental health professionals display varying attitudes towards persons with mental illness; there is a need for further research on the relationship between literary psychiatric knowledge and attitudes towards people with mental illness.
2. The question whether information and education is the most effective and practical way to change negative attitudes towards persons with mental illness living in the community needs to be further explored.
3. The results of sub-study IV are based on an exogenous perspective on people with mental illness, namely the public attitudes. In the future, it would be of interest to explore what people with mental illness themselves consider regarding these research findings as well as their experiences of contact with the public.
4. More research is needed to shed light on the relationship between attitudes towards persons with mental illness and the respondent's actual behaviour and actions against them.
5. When conducting a survey aiming to display sensitive issues such as public attitudes towards persons with mental illness; it is hard to know if the displayed attitude is in accordance with the respondent's inner belief or if it is an idealized description, so called 'Beautiful Painting' in order to position oneself as politically correct. So called 'Beautiful Painting' is a problem in the use of questionnaires based on self-report data. However, the problem can be remedied by adding new items, which measure if the respondent, in its response, expresses what is considered to be 'social desirability' (Sjöberg, 2009) Therefore it is of interest to explore if it is possible to develop the 'New CAMI-S' in accordance with this.

8 SUMMARY IN SWEDISH

BAKGRUND

Den strukturförändring som skett inom den psykiatriska vården med inriktning mot öppnare vårdformer innebär stora förändringar för den enskilda patienten. En konsekvens av den svenska psykiatrireformen (SOU 1992:73) är att det idag bor ca 34 000 personer med psykisk allvarlig sjukdom¹ ute i samhället i eget boende. Platsen där människor med allvarlig psykisk sjukdom vårdas har skiftat från i huvudsakligen slutna institutioner till samhället. 1995 års psykiatrireform (SOU 1992:73) syftar till att förbättra situationen i samhället för personer med allvarlig psykisk sjukdom genom att bland annat stimulera utbyggnaden av bostäder och utveckla dagverksamheter. Genom ökad delaktighet, bättre vård och socialt stöd skall levnadsförhållanden och livsvillkor förbättras och därmed underlätta återgången till ett normalt liv. Genom att ges tillträde till de livssammanhang vi andra ingår i när det gäller boende, arbete och service, är avsikten att personer med psykisk sjukdom skall återföras till det sociala liv de under lång tid varit avskärmade ifrån (Palmlblad & Cullberg, 1993).

Psykiatrireformens intentioner har varit att öka välfärden och stärka valfriheten för personer med allvarlig psykisk sjukdom. Psykiatrireformen innebar med andra ord ett försök att förbättra livsvillkoren ute i samhället för dessa personer (SoS, 1999:1).

Ett flertal studier visar att positiva attityder till personer med allvarlig psykisk sjukdom är korrelerade till kunskap om psykisk ohälsa (Wolff, et al., 1996 a, b; Palmlblad & Cullberg, 1993). Attityderna tycks dock vara blandade, NIMBY-fenomenet, 'not in my backyard', är vanligt förekommande. Kunskapsnivån kan delas in i generell kunskap, erfarenhetsmässig kunskap och kunskap genom information, undervisning och utbildning. Generell kunskap erhålls genom vanlig utbildning och speglar personens allmänna bildningsnivå samt funktion och sociala ställning i samhället. Är den allmänna bildningsnivån god är i regel också attityder mot personer med allvarlig psykisk sjukdom som bor i närsamhället positiva. Personer med erfarenhet av psykisk sjukdom i form av egen psykisk sjukdom eller anhöriga eller vänner med psykisk sjukdom uppvisar oftast positiva attityder. Kunskap som erhållits genom information, undervisning och utbildning är oftast inhämtad av eget intresse och påverkar vanligtvis attityderna i positiv riktning (Hall, 1992; Brockington et al., 1993; Hall et al., 1993; Wolff, et al., 1996 a, b, c. ; Cowan, 2003; Leff and Warner, 2006).

Det finns ett flertal variationer av hur man avgränsar och beskriver begreppet attityd, samt hur man ser på förhållandet mellan en viss attityd och benägenhet att handla. Den sociala miljön lyfts ofta fram som en viktig faktor i utformandet av attityder då attityderna formas i interaktion med omgivningen. Begreppet attityd anses härstamma ur latinets *aptitudo* som bl.a. betyder lämplighet, inställning eller förhållningsätt. Inom olika vetenskaper används termen attityd vanligen för en varaktig inställning som har byggts upp genom erfarenheter och kommer till uttryck i att man är för eller emot något t.ex. ett attitydobjekt. Attityd kan definieras som en allmän och varaktig, positiv eller negativ känsla för en person, ett objekt eller ämne. En attityd anses bestå av flera komponenter; en kognitiv del, en affektiv del och en intentionell del. Den kognitiva delen innehåller vad en person tror eller vet om attitydobjektet. Den affektiva komponenten svarar för hur starkt man tar ställning för eller emot attitydobjektets olika egenskaper. Den intentionella komponenten är beredskapen till handling när det gäller attitydobjektet (Niven & Robinsin, 1994; Kruglanski & Higgins 2003). Gastmans (1999) menar att människans förmåga till ett gott bemötande kräver att hennes moraliska attityd är internaliserad. För detta krävs en väl utvecklad moralisk lyhördhet.

¹ Med "personer med allvarlig psykisk sjukdom" avses här personer som till följd av psykisk sjukdom 'har väsentliga svårigheter att utföra aktiviteter på viktiga livsområden och att dessa begränsningar har funnits eller kan antas, komma att bestå under en längre tid' (SoU 2006:5).

En speciell undergrupp bland attityder är fördomar som ofta kan leda till diskriminerande handlingar mot dem som fördomen är riktad. Den verbalt uttryckta attityden motsvaras inte alltid av ett likartat beteende. Sambandet mellan tanke och handling är inte alltid överensstämmande (Rudder-Baker, 1995; SOU 1998:16).

Omgivningens negativa attityder kan resultera i stigmatisering/stämpling (Palmlblad, 1992; Warner, 2001; Cullberg, 2003). En människa med psykisk sjukdom kan enligt Scheff (1970) upplevas bryta mot oskrivna normer som anses vara acceptabla eller önskvärda i en given kultur. 'Stämplingsteorin' innebär att omvärlden förhåller sig på ett speciellt sätt mot en människa som avviker från samhällets givna normer. Personen blir på så sätt stigmatiserad vilket kan ge vidare konsekvenser i dennes sociala liv (Johnstone, 2001).

PROBLEMRÅDE

Psykiatriutredningen (SOU 1992:73) pekar på olika faktorer som påverkar möjligheterna att uppnå syftena med 1995 års psykiatrireform. Det påpekas särskilt att vad som är möjligt att åstadkomma med förändringsarbetet är starkt beroende av allmänhetens attityder och förhållningssätt. Negativa attityder och förhållningssätt är viktiga hinder för att förbättra livssituation för personer med psykisk sjukdom och öka deras möjlighet till gemenskap och delaktighet i samhället. Sådana attityder är ofta omedvetna eller i varje fall inte uttalade.

Hos den breda befolkningen är kunskaperna om psykiska sjukdomar ringa. Synen på psykiska sjukdomar har i alla tider präglats av rädslor och fördomar och allmänhetens uppfattning om psykisk sjukdom har inte hållit jämna steg med den förändring som skett inom vårdområdet (Qvarsell, 1991). Även om det under senare år har skett en rad förändringar i positiv riktning närmar sig de flesta fortfarande personer med psykisk sjukdom med rädsla. Utöver rädslan för våld finns mer allmänna fördomar och brister i kunskap om de psykiska sjukdomarna och deras uttryck som utgör hinder för förändrade attityder. Kunskap om psykiska sjukdomar måste spridas och medvetenheten om att förhållningssättet till psykiska sjukdomar påverkar mötet med den psykiskt sjuka måste ökas (SOU 1992:73).

Socialstyrelsens slutrapport från utvärderingen av 1995 års psykiatrireform (SoS 1999:1) visar att alla mål inte uppnåtts. Allmänhetens attityder har påverkat reformens utfall. Reformens mål var att öka välfärd och delaktighet, vilket skulle ge personer med psykisk sjukdom större möjlighet att leva ett liv som andra. Normalisering och integrering har varit ledstjärnor i reformarbetet. Att normalisera en persons levnadsförhållande antyder att den enskilde skall närma sig ett sätt att leva som är statistiskt normalt och kulturellt accepterat. Normaliseringsbegreppet kan dock inte ersätta kravet på omgivningens/allmänhetens förståelse för och acceptans av människor med psykisk sjukdom för att uppnå integrering och medborgerlig samlevnad. Enskilda personers livssituation är inte enbart beroende av materiella villkor utan minst lika mycket av bemötande samt omgivningens förmåga att förstå personens behov. För att reformens grundläggande intentioner skall förverkligas i så hög grad som möjligt behövs en förändrad inställning i hela samhället kring psykisk sjukdom och till personer med psykisk sjukdom. Behovet av mer nyanserad information till allmänheten om psykiska sjukdomar är av största vikt. Hur denna information skall föras ut är emellertid oklart men ses som en viktig fråga för framtiden. (SoS 1999:1). Vidare menar Sartorius och Schulze (2006) att stigmatisering av människor med psykisk sjukdom är förödande och att det finns indikationer på att stigmatiseringen, trots framsteg inom psykiatrisk vård och behandling, fortsätter att växa. De betonar även att allmänhetens negativa attityder mot personer med psykisk sjukdom kvarstår trots att personen med psykisk sjukdom till fulla har återhämtat sig och lever ett socialt välordnat liv.

En genomgång av det svenska forskningsläget visar att studier som rör närsamhällets möte med personer med psykisk sjukdom till viss del saknas (Angermeyer *et al.*, 2006; Palmblad & Cullberg, 1993). Kontaktytorna mellan dem och den övriga befolkningen i närsamhället har ökat i och med avinstitutionaliseringen. När boendeenheter i form av gruppboendestäder och egna boenden har utlokaliseras till vanliga bostadsområden har det från olika håll rapporterats om protester från närsamhället mot att bli granne med personer med psykisk sjukdom. Det har också visat sig att lokalbefolkningen i många fall saknat beredskap att ta emot psykiskt sjuka människor med avvikande beteende. I en del fall har protesterna utmynnat i konflikter med grannskapet (Palmblad, 1992). Det är emellertid oklart vad protesterna egentligen är uttryck för, vilket tyder på att det fortfarande finns betydande barriärer att övervinna i arbetet med att normalisera tillvaron för personer med psykisk sjukdom.

ÖVERGRIPANDE MÅL

Studier som handlar om personer med psykisk sjukdom visar att deras förmåga att bygga upp bärande och meningsfulla relationer till medmänniskor i den omedelbara omgivningen är begränsade. Möjligheten för dessa personer att integreras i samhället och leva ett liv som alla andra minskar, vilket leder till isolering och en försämrad livskvalitet (Erdner, 2006).

Målsättningen för avhandlingsarbetet som helhet var att generera kunskap som leder till en förbättrad livskvalitet för personer med psykisk sjukdom som bor i egen bostad eller i gruppboende.

Genom att utveckla och anpassa ett instrument för mätning av attityder till svenska förhållanden kan kunskapen om omgivningens attityder till personer med psykisk sjukdom kartläggas. Denna kunskap kan bidra till att identifiera riskfaktorer som påverkar möjligheten för personer med psykisk sjukdom att integreras i samhället då de identifierade riskfaktorerna torde ha betydelse för hur offentliga insatser utformas.

Kunskapen kan även användas för att i förlängningen skapa acceptans och öka förståelsen för personer som lider av psykisk sjukdom vilket kan bidra till att dessa bättre integreras i samhället och därmed uppnår en medborgerlig samvaro.

ÖVERGRIPANDE SYFTE

Det övergripande syftet med avhandlingsarbetet var att kartlägga och beskriva omgivningens attityder till psykisk sjukdom samt till personer med psykisk sjukdom. Ett ytterligare syfte var att översätta, utveckla och pröva ett instrument, som mäter attityder till psykisk sjukdom samt till personer med psykisk sjukdom. Instrumentet har aldrig använts i Sverige men har tidigare använts i andra delar av västvärlden.

Denna sammanläggningsavhandling grundar sig på fyra delstudier vilka sammanfattas nedan.

Delstudie I

BAKGRUND

Flera studier visar att positiva attityder till personer med psykisk sjukdom är korrelerade med kunskap om psykisk sjukdom.

SYFTE

Syftet med denna studie var att utforska och beskriva psykiatriska sjuksköterskors upplevelser av att bo granne med personer med psykisk sjukdom. Därtill syftar studien till att kartlägga och beskriva hur de psykiatriska sjuksköterskorna hanterar situationer som uppstår i grannskapet där personer med psykisk sjukdom är inblandade.

METOD OCH MATERIAL

Två män och sju kvinnor intervjuades. Den konstant jämförande metoden 'grounded theory' användes för datainsamling och analys.

ANALYS OCH RESULTAT

Processen att 'agera som en sjuksköterska eller inte' identifierades som en central kategori.

Fyra underliggande kategorier identifierades: 'att ofrivilligt ta emot information', 'att vidta åtgärder eller inte', 'att agera som en medlare i grannskapet' och 'rätten att välja'. Resultaten visar att psykiatriska sjuksköterskor med professionell kunskap om psykisk sjukdom och psykiatrisk vård upplever att moraliska frågor uppstår rörande deras roll som psykiatriska sjuksköterskor under sin fritid.

KONKLUSION

Sammanfattningsvis kan sägas att det inte är självklart att psykiatriska sjuksköterskor vill bo i samma grannskap som personer med en psykisk sjukdom. Studien visar även att deras kunskap om psykisk sjukdom, för dem, skapar ett moraliskt dilemma som består av att de upplever en konflikt mellan den upplevda plikten att tillse att grannen som har en psykisk sjukdom blir omhändertagen och får vård samtidigt som de önskar få vara ifred och värna om sin egen fritid.

Delstudie II

BAKGRUND

En av huvudprinciperna som styr utvecklingen av stödboenden för personer med psykisk sjukdom är att de ska leva och bo ute i samhället eftersom det förbättrar deras livskvalitet.

SYFTE

Syftet med denna studie var att beskriva psykiatriska sjuksköterskors erfarenheter av olika former av boenden för personer med långvarig psykisk sjukdom och deras uppfattningar om vad de anser vara viktiga principer för att underlätta deras integrering i samhället.

METOD OCH MATERIAL

Nio psykiatriska sjuksköterskor intervjuades; två män och sju kvinnor.

ANALYS OCH RESULTAT

I en kvalitativ innehållsanalys identifierades huvudtemat 'att upprätthålla principen; respektera patientens rätt till självbestämmande'. Huvudtemat var sammanlänkat med tre delteman: 'sjuksköterskornas syn på sitt moraliska ansvar', 'sjuksköterskornas syn på sociala normer som personen med psykisk sjukdom bör följa för att accepteras av sina grannar' och 'sjuksköterskornas upplevelser av stödboenden av god kvalitet'.

KONKLUSION

Sjuksköterskorna upplevde att den personliga kontakten mellan grannarna och personen med psykisk sjukdom var viktig för att minska grannens eventuella rädsla för personen med psykisk sjukdom. Sjuksköterskorna såg sig själva fungera som en länk mellan personen med psykisk sjukdom och grannarna. Avslutningsvis ansåg de att utan den personliga kontakten mellan den psykiskt sjuka personen och dennes grannar finns det en risk att integrationen kommer att misslyckas oavsett hur bra stödboendena är utformade.

Delstudie III

BAKGRUND

Ett av de främsta syftena för utbyggnaden av kommunal vård och omsorg för personer med allvarlig psykisk sjukdom i Sverige var att säkerställa rätten för dessa personer att leva som medborgare i samhället. Tidigare forskning visar dock att negativa attityder till psykisk sjukdom utgör ett hinder för social integration av personer med allvarlig psykisk sjukdom.

SYFTE

Syftet med denna studie, som genomfördes i Sverige, var att utvärdera ett befintligt frågeformulärs tillförlitlighet; Community Attitudes towards Mental Illness (CAMI). Ett ytterligare syfte var att anpassa och utveckla frågeformuläret till svenska förhållanden.

METOD OCH MATERIAL

Efter översättning och modifiering av det ursprungliga frågeformuläret CAMI, utvecklades den svenska versionen av frågeformuläret (CAMI-S). CAMI-S delades ut till sjuksköterskestudenter vid tre olika universitet i Sverige (n = 421).

ANALYS OCH RESULTAT

Cronbach's alpha koefficient gällande den ursprungliga CAMI var 0,90. En korrigerad inter-item total correlation uteslöt 20 frågor eftersom de visade låg laddning, <0,43. Cronbach's alpha koefficient gällande de 20 frågor som visade hög laddning, > 0,43, var 0,903. En faktor analys av dessa visade att frågorna kunde delas in i tre faktorer benämnda: openminded and pro-integration, fear and avoidance and community mental health ideology.

KONKLUSION

Avslutningsvis, för att nå tillförlitliga resultat i attityd forskning är det viktigt att mäta informantens inställning till objektet i allmänhet samt informantens inställning till att interagera med objektet. Därför är det viktigt att till 'nya CAMI-S' lägga till frågor som belyser informantens inställning till att interagera med objektet. Förutom detta bör nämnas att frågor som exemplifierar hur något 'bör vara' på ett opersonligt sätt har en hög grad av stabilitet över tid oavsett context.

Delstudie IV

BAKGRUND

Flera studier visar att negativa attityder till psykisk ohälsa fortfarande existerar bland allmänheten och är ett av de största hindren för social integrering av personer med allvarlig psykisk sjukdom.

SYFTE

Syftet med denna studie, som genomfördes i Sverige, var att kartlägga, analysera och beskriva allmänhetens uppfattningar om psykisk sjukdom i allmänhet och attityder till personer med psykisk sjukdom i synnerhet. Därefter analyserades allmänhetens uppfattningar om psykisk sjukdom och attityder till personer med psykisk sjukdom i relation till respondenternas demografiska data.

METOD OCH MATERIAL

För att nå tillförlitliga resultat i attityd forskning är det viktigt att mäta informanternas inställning till objektet i samt deras inställning till att interagera med objektet. Således har frågeformuläret 'Community Attitudes to Mental Illness in Sweden' (CAMI-S) som ursprungligen utvecklades av Taylor och Dean 1981, ändrats genom att 9 frågor lagts till som belyser informantens intention till att interagera med objektet. Frågeformuläret delades ut till 5 000 personer i Sverige.

ANALYS OCH RESULTAT

En linjär multipel regressionsanalys användes för att fastställa förhållandet mellan informanternas sociodemografiska bakgrundsdata och deras uppfattningar om psykisk sjukdom och attityder till personer med psykisk sjukdom. En majoritet av de tillfrågade hade måttligt positiva uppfattningar om psykisk sjukdom och attityder till personer med psykisk sjukdom. Respondenter i åldersgruppen 31-50 år uppvisar en mer positiv attityd till personer med psykisk sjukdom. Dessutom, är det värt att notera att i motsats till tidigare forskning visade de statistiskt säkerställda resultaten i denna studie att personer med lägre utbildningsnivå tenderar att vara mer positivt inställda till personer med psykisk sjukdom än personer med högre utbildning.

KONKLUSION

Slutsatsen är att en majoritet av de tillfrågade hade måttligt positiva uppfattningar om psykisk sjukdom och attityder till personer med psykisk sjukdom och att graden av positiv inställning beror på informanternas sociodemografiska bakgrund, livssituation och eventuella erfarenheter av psykisk sjukdom.

SAMMANFATTANDE KONKLUSION

En sammanfattande tolkning av de viktigaste resultaten i denna avhandling förstärker antagandet att negativa attityder till personer med psykisk sjukdom som bor i Sverige fortfarande existerar. Detta leder bland annat till att personer med psykisk sjukdom möter stigmatiserande attityder från såväl allmänheten som personal inom den psykiatriska vården.

Denna avhandling visar också att ökad kunskap inte tvcks vara det bästa sättet att motverka fördomar mot psykisk sjukdom och människor med psykisk sjukdom, eftersom även personal inom den psykiatriska vården uppvisar stigmatiserande attityder gentemot personer med psykisk sjukdom. Detta innebär att allmänheten likväl som personal inom den psykiatriska vården bör ge akt på sina attityder och bli mer tolerant mot personer med psykisk sjukdom för att motverka stigmatisering och utanförskap.

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Stockholm in August - 2010

Yours Sincerely

Torbjörn Högberg

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