Needs of Support and Service in Mentally Disabled Clients

Population-Based Studies in a Swedish County

LENNART JANSSON
Abstract

The general aim of the present thesis is to investigate needs of support and service in clients with long-term mental disabilities living in the community. A further aim is to study changes in these client needs during a 3.5-year follow-up.

A questionnaire, The Need of Support and Service Questionnaire (NSSQ), was developed to provide staffs in psychiatric care and social services with a brief instrument to assess how their clients live in the community and to identify their needs.

The results are based on 1,759 clients. The prevalence of clients in urban and rural areas was 6.4/1,000 and 4.5/1,000 inhabitants, respectively. The clients living in the urban setting were more frequently male, older, with a diagnosis of schizophrenia and needed more support in activities of daily living than rural clients.

Clients identified by staff in psychiatric care only were more often living with a partner, with children living at home and more often had a rehabilitation allowance than clients identified by social services staff. In clients assessed by both organizations similar needs at a group level were identified. However, agreements were lower at the individual level.

Although clients reported fewer needs than staff in psychiatric care, the reported needs were in the same areas.

A majority of the clients with unmet needs of service at baseline had their needs met at the 3.5-year follow-up. New unmet needs were also identified at the follow-up, however. The results demonstrate less improvement in clients with schizophrenia as compared with non-schizophrenic clients.

In conclusion, needs of support and service present a dynamic process and both psychiatric care and social services should critically evaluate assessments of these needs.

Keywords: Needs assessment, Questionnaires, Epidemiology, Schizophrenia, Community Mental Health Services

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To Inta, Linnea and
Björn
List of Papers

This thesis is based on the following original papers, which will be referred to by their Roman numerals in the text.


II. Jansson Lennart, Sonnander Karin, Wiesel Frits-Axel, Clients with long-term mental disabilities in a Swedish county – conditions of life, needs of support and unmet needs of service provided by the public health and social service sectors. *European Psychiatry* 2003; 18: 296-305.


IV. Jansson Lennart, Wiesel Frits-Axel, Changes in needs of support and service among long-term mentally disabled clients. (Manuscript).

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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<td>ANOVA</td>
<td>Analysis of variance</td>
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<td>CAN</td>
<td>The Camberwell Assessment of Need</td>
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<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of mental disorders, 4th edition</td>
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<td>GAF</td>
<td>The Global Assessment and Functioning Scale</td>
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<td>ICD-10</td>
<td>International Classification of Diseases and Related Health Problems, 10th revision</td>
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<td>LR</td>
<td>Likelihood Ratio</td>
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<td>NSSQ</td>
<td>The Need of Support and Service Questionnaire</td>
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<td>QoL</td>
<td>Quality of Life</td>
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<td>SOFAS</td>
<td>The Social and Occupational Functional Scale</td>
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Introduction

In the late 18th century, Philippe Pinel (1745-1826), French psychiatrist and the superintendent of the French institution Bicêtre, ordered the removal of the chains binding the patients and argued in favour of the asylum’s therapeutic potential. He took the first steps to humanize the living conditions for the mentally ill patients and gave them back some of the dignity they had been deprived of for so long. Pinel and other staff members endeavoured to bring the patients back to a normal life through psychological methods, i.e., they began to talk to the patients (Haugsgjerd, 1974).

During the first half of the 19th century, institutions for treatment of people with mental illness were established in Sweden and throughout Europe. The asylums grew in size and they soon became overcrowded. The construction of new institutions began at the end of the 19th century and continued into the 1960s when the four last psychiatric hospitals were opened in Sweden (National board of Health and Welfare, 1982). These institutions, which were totally closed, were magnificent, castle-like structures with pavilions surrounding the courtyard as a means of protecting patients from undesirable external influence (Ottosson, 1995).

During the 1930s, new therapy methods were introduced, including insulin shock therapy, psychosurgery and electro convulsive therapy (ECT). For the patients, the first regulated connection between mental hospitals and the community was the ‘Association of Relief Activities.’ Patients could either come to the out-patient clinic or were visited in their homes by small mobile units. Family care provided by private homes was another form of care, making it possible for psychiatric patients to live outside institutions.

The introduction of psychopharmacological drugs in the 1950s has been described as a revolution in psychiatric care. Hospital stays became shorter and the patients’ living conditions improved dramatically. However, rehabilitation took place mainly at the mental hospitals in the forms of ADL (activities of daily living).

In 1967, the running of Swedish mental hospitals was transferred from the state to the county councils. This reorganisation was primarily intended to reduce the number of beds at mental hospitals and to expand psychiatric units at general hospitals and to develop treatment facilities in open care.

The introduction of sectorised psychiatric care, based on out-patient care, a minimum of in-patient care and multi-professional and varied treatment content within a limited catchment area, was reinforced by policy documents.
The sectorised psychiatric care period has been thoroughly described and evaluated (Lindholm, 1983; Stefansson, 1985; Crafoord, 1987; Eliasson, 1979; Sandlund, 1998), with the evaluations indicating that the sectorised psychiatric care did not fulfil the needs of social support in long-term mentally ill persons (Stefansson, Cullberg & Steinholtz-Ekecrantz, 1990; Stefansson & Hansson, 2001). This development of community psychiatry during the 1970s in Sweden as well as in other European countries led to important changes in the living conditions of long-term mentally ill patients. The changes involved many problems associated with patients living in the community (Bachrach, 1996; Bollini & Mollica, 1989; Borgå et al., 1992). Although patients’ needs for medical treatment were mainly fulfilled (Stefansson & Cullberg, 1986), other needs such as accommodation (Bachrach, 1996; Nordenstoft et al., 1992) and social rehabilitation (Stefansson, Cullberg & Steinholtz-Ekecrantz, 1990) were not satisfied. A parliament commission (Committee on psychiatric care, 1992) concluded that the efforts of social services were still largely inadequate. There were also results indicating that increased mortality among severely mentally ill persons could be ascribed to deinstitutionalisation (Belfrage, 1994; Hansen, Jacobsen & Arnesen, 2001; Ösby, 2000). In Sweden, it was evident that there was a strong need of a mental health care reform (Swedish government bill 1993/94:218).

The Mental Health Care Reform

The mental health care reform was implemented on 1 January 1995. The overall goals for the new reform were to reintegrate clients with mental disabilities into the community and to allocate specialized care, support and service resources to those clients most in need of help. Thus, there was a major shift in perspective in describing the problems in persons with mental illness. A mental disability arises because of illness. One important component of the reform was the necessity of co-operation and mutual support between psychiatric health care and community social services. A greater number of responsibilities were given to both psychiatric health care and community social services.

One way to reach these goals was to make changes in the Swedish legislation. Accordingly, changes were made in the Swedish Social Services Act and the Health Care Act. The social services, among else, are obligated to conduct outreach activities among the elderly and the disabled. Social services are also obliged to plan their assistance programmes for people with disabilities in collaboration with the county council and other organizations. Moreover, the law also established the responsibility of the county councils and municipal social services for rehabilitation and habilitation.
The Municipal Financial Responsibility Act requires the municipalities to pay for the continued hospital care of those patients who, after three consecutive months of treatment, have been deemed by physicians as fully medically treated within the psychiatric in-patient system. The problem with these patients is that they are still being cared for in hospitals because they cannot be mainstreamed into the community (e.g., into homes of their own) with assisted living service.

The new Swedish Disability Act on support and service to people with disabilities and the Assistance Compensation Act is designed for people with comprehensive physical or mental disabilities to be able to live like everyone else. The laws state a number of specific forms of assistance that mentally disabled people can receive, including counselling and support, personal assistance, housing with special services, contact persons and companions. The Disability Act is, however, only a complementary law and therefore may not entail any further rights if the individual is entitled to help under other laws.

In order to speed up the implementation of the mental health care reform the counties received a general state subsidy over a period of 3 years. The subsidy was primarily directed towards improving interaction between social services and psychiatric care. To qualify for this general subsidy social services and psychiatric care organizations were required to enter into formal agreement on which psychosocial rehabilitation units would be transferred from psychiatric care to social services (along with their budgets) and with respect to how the organizations jointly would make use of the subsidies in various programmes. Furthermore, the organizations were to come to agreements in the form of developmental plans on how they would collaborate in the future to serve the needs of mentally disabled people.

The National Board of Health and Welfare was given the responsibility from the government to perform follow-ups on the implementation of the reform. In a series of reports the National Board on Health and Welfare has, in addition to yearly-reports (National Board of Health and Welfare 1996, 1997a, 1997b, 1998, 1999), reported on the evaluation process.

Furthermore, independent studies have carried out separate evaluations on different parts of the reform. Markström (2003), for instance, described, analysed and critically reviewed the planning and implementation of the reform. One reported problem is the phenomenon of transinstitutionalization i.e. patients discharged from mental hospitals turn up in other institutional arrangements such as nursing-homes. In a process-outcome study, Björkman (2000) evaluated case management for individuals with severe mental illness in 10 areas of Sweden. Nyström (1999) studied the daily life of severely mentally ill people and Topor (2001) analysed the recovery process from severe mental illness. Severely mentally ill clients in the municipality of Jönköping have also been studied after the implementation of the mental
health care reform (Arvidsson, 2004). Finally, severely mentally ill substance abusers have also been studied (Schaar & Öjehagen, 2001).

The reform in the investigated area of Uppsala County

The conditions for the implementation of the mental health care reform in Uppsala County were favourable in that there was already an agreement between psychiatric care and community social services concerning contact persons and the Individual Plans. The organizations ambitions were to let the client be the centre of attraction.

The general state subsidies were mainly used to develop new activities for the clients. New forms of housing, assisted care living with home help service, supported education, job-training projects, social and scheduled activities and a mobile team for support in the homes are examples of this kind of projects. Other important projects were co-ordinators to facilitate the collaboration between the organizations and the individual plan project. A small part of the subsidy was used for developing new forms of collaboration of staff in different organizations (e.g., teaching seminars to improve the knowledge of each other’s working area).

To accomplish the goals of the mental health care reform a few steps need to be carried out. First, the clients need to be identified. Second, the clients’ present conditions of life have to be identified. Third, assessment of client needs for professional care, support and service has to be accomplished. When all three steps are fulfilled, the client can be offered relevant help according to his or her needs.

The concept of need

There is, however, no consensus on how needs should be defined or who should define them. Bradshaw (1972) developed a taxonomy of four types of social need. In this scheme, normative need is a need defined by professionals in given situations. Felt need is equated with want and may not truly represent need at all. Expressed need is felt need turned into action, i.e. it is a demand. Finally, comparative need is the gap between service receipts between two similar groups.

In a normative model, needs assessment should be based on the judgement of an expert, performed on the basis of his or her own competence (Brewin et al., 1987). In a negotiated model, needs are not a fixed concept that can be objectively measured, but are best viewed as a dynamic and relative concept that can be influenced by a range of contextual factors and on which there is no single correct perspective (Slade, 1994). In this context, needs assessment should therefore include both staff and patients’ percep-
In a negotiated approach it is important to assess differences between staff and users’ perceptions of needs for care. If the differences are insignificant and predictable, it will be sufficient to take into account either staff or patients’ perceptions, which would allow for a simpler and quicker assessment. If, on the contrary, the differences between staff and users are significant and unpredictable, it will then be necessary to consider both sets of perceptions.

One has also to distinguish between met and unmet needs. A need is met when an intervention is efficacious and the clients are offered effective help. A need is unmet when an intervention has only a partial effect or does not exist (Brewin et al., 1987). Needs (what clients benefit from) must be separated from a demand (what clients ask for) and utilisation (what is provided) (Thornicroft, Phelan & Strathdee, 1996).

In this thesis staff in either psychiatric care or community social services assess the clients’ needs. Clients are invited to participate in an assessment study to compare assessments made by staff and clients.

Psychiatric epidemiological studies in Sweden

Epidemiological studies in the community are rare, probably because they are expensive and time-consuming. Studies that have been made are difficult to compare because of differences in the use of diagnostic criteria. In Sweden, only a few studies exist. The most well-known study is the 1947 prevalence study in southern Sweden. The point prevalence rates of psychosis for men and women, aged 15 years and more, were 0.3% and 1.3%, respectively. The rates of neurosis were 1.4% in men and 9.6% in women (Essen-Möller et al., 1956). Halldin (1984) studied the 12-month prevalence of mental disorder in an urban population aged 18-65 years. In this population, 47% (40% of the men and 54% of the women) received a psychiatric diagnosis (psychosomatic conditions and alcoholism included). However, if only moderate and severe degrees of impairment were included, the figures were considerably lower. A study by Widerlöv (Widerlöv et al., 1989) of the epidemiology of long-term functional psychosis (schizophrenia, paranoia, major affective disorder with psychotic features and psychosis not elsewhere classified) in three catchment areas in Stockholm County, including the Nacka catchment area, showed a 1-year prevalence in 1984 of 3.41/1,000 in a rural catchment area, 5.61/1,000 in a suburban area and 6.61/1,000 in an urban area, including a rural-urban gradient of the 1-year prevalence. A similar study in 1991 was performed in three areas of Uppsala (Widerlöv, Lindström & von Knorring, 1997). The 1-year prevalence of long-term functional psychoses was found to be 7.3/1,000 inhabitants, with a clear gradient from central city area (8.7/1,000 inhabitants) to the rural area (6.0/1,000) inhabitants. The 1-year prevalence of schizophrenia was 4.2/1000 inhabitants, with
a clear gradient from the central city area to the rural area (5.3/1,000, 4.4/1,000 and 3.0/1,000 inhabitants), respectively. These cohorts included patients who had been in contact with any psychiatric service during the preceding 10-year period. Taken together, these studies showed large differences. In summary, these prevalence studies indicate that severe mental illness constitutes 2% of the population, whereas other forms of less severe mental illness make up 11-13%.

Two other studies in the Stockholm County were performed in the 1970s. Bygren (1974) reviewed models that have an effect on the use of service. He investigated the needs for medical and social services occasioned by illness, symptoms and social problems in a population. Björk (1977) investigated needs for psychiatric care.

In the proceedings of this thesis, the term ‘client’ rather than ‘patient’ is preferred because of the former concept’s particular relevance within the psychiatric care and social services sectors. An unmet need is defined in this paper when health care or social services were not provided adequately or were not provided at all.
Aims of the Thesis

The general aim of this thesis was to investigate support and service needs in clients with long-term mental disabilities living in the community. A further aim was to investigate changes in these needs and changes in social and occupational functioning during a 3.5-year follow-up period. The specific objectives were:

- to identify all clients with long-term mental disabilities with at least one need of support or one unmet need of service in a Swedish County and to describe the clients present conditions of life, need of support and service in urban and rural settings (Papers II and III).

- to develop an instrument (the Need of Support and Service Questionnaire, NSSQ) to identify and assess needs of support and service in the clients and to establish test-retest and inter-rater reliability of the instrument. (Paper I).

- to validate the NSSQ with the Camberwell Assessment of Need (CAN) instrument, the Social and Occupational Functioning Scale (SOFAS) and the Global Assessment of Functioning (GAF) scale (Paper I).

- to investigate if staff in psychiatric care and community social services identified the same clients and the same number of needs and in the same areas (Paper III).

- to compare assessments of need of support and service as reported independently by staff in psychiatric care and their clients (Paper II).

- to identify changes in needs, to evaluate which needs of support and service that had been satisfied and to determine which characteristics that distinguished clients who had changed their needs (Paper IV).
Methods

The study area
The studies in the present thesis are population-based investigations conducted in the county of Uppsala, which includes urban as well as rural areas, with 225,409 inhabitants 18 years or older (at the end of the index year 1999). The urban area (146,233 inhabitants 18 years or older) mainly comprises the Uppsala municipality while the rural area (79,176 inhabitants 18 years or older) comprises five municipalities. The total population density, including inhabitants younger than 18 years, was 74 inhabitants per km$^2$ in the urban area and 22 inhabitants per km$^2$ in the rural area.

Subjects
The inclusion criteria
The inclusion criteria for the clients were: (a) 18 years of age and older, (b) a resident of Uppsala County during one of the index years 1996 or 1999, (c) suffering from a mental disorder that had caused a decrease in function and significantly interfered with daily life activities for at least 6 months and (d) at least one need of support in activities of daily living, or one unmet need of service provided by the public health care or community social services sectors in 1996 or 1999. Individuals with known mental retardation or dementia were excluded. Sample sizes in the different studies are displayed in Figure 1.

Psychiatric diagnoses
The main psychiatric diagnoses for each client were obtained from medical records. To obtain uniform data all diagnoses classified according to the DSM-IV (American Psychiatric Association, 1994) or the ICD-10 (World Health Organization, 1992) were converted into seven diagnostic groups: schizophrenia (DSM-IV=295 or ICD-10=F20), affective psychosis (DSM-IV=296 and 311 or ICD-10=F30-F39), other psychosis (DSM-IV 297-298 or ICD-10=F21-F29), neurotic disorder (DSM-IV=300 or ICD-10=F40-F48),
Clients identified by staff in 1996
n = 1261 (Paper II)

Clients self-reported needs
n = 406
(Paper II)

Clients identified by staff in 1999
n = 1290 (Paper III)

Reliability study
n = 84
(Paper I)

Validity study
n = 529
(Paper I)

Follow-up study in 1999
n = 792
(Paper IV)

Non-follow-up clients
n = 469

New identified clients in 1999
n = 498

Figure 1. Sample sizes in the different studies.
personality disorder (DSM-IV= 301 or ICD-10=F60-F69), substance-related disorder (ICD-10=F10-F16), and all other diagnoses.

Instruments
The development of the Need of Support and Service Questionnaire (NSSQ)
Several instruments have been developed to assess needs among clients with severe mental illness (McDowell & Newell, 1996; Scott & Lehman, 1998). One of these instruments is the Camberwell Assessment of Need, CAN. However, the priority for the CAN instrument is to identify, rather than to describe in detail, needs of the clients (Phelan et al., 1995). In order to provide adequate interventions, more specific information concerning the clients’ needs of support and service, than could be obtained from the CAN instrument was requested from the psychiatric care and community social services organizations. For that reason, a new questionnaire, the Need of Support and Service Questionnaire (NSSQ), was developed that could be used by professionals in both psychiatric care and social services without any formal training.

The items of the NSSQ are based on the most frequent reported needs found in earlier studies (Borgå et al., 1992; Ford et al., 1992; Phelan et al., 1995) and from a questionnaire, designed by the National Board of Health and Welfare. This questionnaire was developed to facilitate data collections for assessing living conditions and needs for the severe mentally ill in nationwide surveys conducted during the implementation of the psychiatric reform. From these studies, the NSSQ instrument was developed in close cooperation with psychiatric care and social services providers as well as with the clients. Before the final version was compiled, experienced staffs in psychiatric care and social services, clients and relatives of the clients were asked to give their comments on an earlier version of the questionnaire. Their opinions were sought on the content, language and structure of the NSSQ. Based on these opinions, adjustments were made and the final format was compiled. The NSSQ focuses on needs of support in activities in daily living and service provided by the public health care and social services.

The Needs of Support and Service Questionnaire
The final format of the questionnaire consisted of 33 items subdivided into three domains: (i) Sociodemographic information and present living situation: gender (male or female), age, place of birth (Sweden, Nordic countries or non-Nordic countries), living area (urban or rural), current accommodation (independent or assisted care living), cohabitation status (living alone,
living with a partner or living with parents), children living at home (yes or no), educational level (primary school, secondary school or university), income (salary, rehabilitation allowance, social allowance, disability pension or age pension), and work (open market, sheltered, self-employed, study or unemployed) (10 items); (ii) Need of support in activities of daily living: personal hygiene, preparing a meal, buying food, cleaning and washing, buying clothes, handling finances, taking medication, interpersonal skills, using a telephone, handling contact with public authorities, using public transportation and to move (12 items assessed on a 3-point scale with the response categories ‘no help needed’, ‘some help needed, and ‘unable to manage without help’); and (iii) Need of service provided by the public health and social services sector: psychiatric care, dental care, home-help service, mobility service, trustee, social activities (i.e. to have somewhere to go and meet other persons), scheduled activities (more planned and scheduled than social activities), job training and occupational rehabilitation (9 items assessed on a 5-point scale with the response alternatives ‘service can be reduced’, ‘adequate service provided’, ‘inadequate service provided’, ‘need of service’ and ‘no need of service’), need of assisted care living (yes or no) and need of work (yes or no) (2 items). The response ‘need unknown’ was also possible.

The Camberwell Assessment of Need Questionnaire – CAN

The CAN instrument was designed to provide a comprehensive assessment of the needs of people with severe mental illness (Slade, Thornicroft, Loftus et al., 1999).

The CAN assessment is carried out as a structured interview, evaluating the following 22 areas of needs: accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information about condition and treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, child care, basic education, telephone, transport, money and benefits.

Ratings of need are performed on a three-point severity scale (0= ‘no problem’, indicating no need; 1= ‘no or moderate problem because help was given’ indicating a met need; 2= ‘serious problem’ indicating an unmet need) or rated as 9, ‘not known’. In this study the Swedish version of the CAN was used (Ericson, Hansson & Teike, 1997).

The mean kappa coefficient for test-retest reliability in the Swedish version of the CAN was 0.79 (all kappa coefficients were above 0.54) (Arvidsson, 2003b). The mean kappa coefficients for the inter-rater reliability in the Swedish version of the CAN was 0.87 (all kappa coefficients were above 0.49) (Hansson, Björkman & Svensson, 1995).
Global Assessment of Functioning Scale - GAF
The GAF -scale (American Psychiatric Association, 1994) provides a global measure of symptomatology and social functioning and is rated on a scale from 1 to 100, with higher scores indicating better functioning and with descriptions for each 10-point band. The GAF -scale is to be rated regarding psychological, social and occupational functioning only. The instructions specify, “Do not include impairment in functioning because of physical (or environmental) limitations”. The GAF -scale has proved to be a reliable and a valid measure of psychiatric disturbance (Jones et al., 1995).

Social and Occupational Functioning Assessment Scale - SOFAS
The SOFAS instrument (American Psychiatric Association, 1994) was used to rate the level of clients’ social and occupational functioning during the past month. The scores on this scale range from 1 to 100, with higher scores indicating better functioning and with descriptions for each 10-point band. In contrast to the GAF -scale, any impairment in social and occupational functioning, including those because of general medical conditions is considered in the SOFAS rating.

Procedures
The thesis is based on six separate studies presented in four papers.

The reliability study
A reliability study was performed to establish test-retest and inter-rater reliability of the NSSQ (Paper I). Clients were chosen that had regular contact with two key workers from a psychiatric rehabilitation team. One of the key workers rated the client on two separate occasions during a 15-day period (on average) to calculate the test-retest reliability. The other key worker did one independent rating of the same client. The period between ratings in the inter-rater reliability part of the study was on average 5 days.

The validity study
In the validity study (Paper I), information from the NSSQ was compared with information from the CAN Questionnaire with the CAN serving as the reference standard. To further establish the concurrent validity of the NSSQ two other instruments were also used: (a) the GAF -scale and (b) the SOFAS.
The data set for the validity study was compiled from the following two sources (A and B).

A. Staff in psychiatric care were asked to independently identify all clients with long-term mental disabilities that met the inclusion criteria and with whom they had personal knowledge and regular contact. The staff filled out the NSSQ, the SOFAS scale and the GAF-scale for each client and then returned them to the first author.

B. Longitudinal assessments are conducted each year regarding the needs of out-patients with severe mental illness in psychiatric care in Uppsala County. The clients’ key workers perform the ratings using the Swedish version (Ericson, Hansson & Tieke, 1997) of the CAN. The results of the assessments are recorded in a case register.

The NSSQ data were compared with the CAN data on the same clients. The assessments were done at the same period during regular psychiatric care.

The cross-sectional studies
The first population based cross-sectional study was carried out during a 3-month period (April – June) in 1996 (Paper II). Staff in psychiatric care (mental nurses, social workers, registered nurses, physiotherapists, occupational therapists, psychologists and psychiatrists) and social services (social service workers, work managers, and registered nurses) were asked to identify clients with long-term mental disabilities who met the inclusion criteria and with whom they had personal knowledge. Staff in psychiatric care and social services filled out the NSSQ and the SOFAS questionnaires independently for each client.

The second population based cross-sectional study was carried out in the same way during a 3-month period (October– December) in 1999 (Paper III).

The client–staff comparison study
A comparison study was carried out to investigate staff and clients’ perspectives on needs (Paper II). Identified clients were invited to take part in the study. Questionnaires were administered to the clients who were in personal contact with psychiatric care or social services during the data collection period. Staff in psychiatric care asked 855 clients and staff in social service asked 66 clients to participate in the study. The clients completed the self-report version of the questionnaire and returned it by mail to the author.
The prospective follow-up study

A prospective follow-up study was performed to investigate changes in needs of support and service during a period of 3.5 years. The study was carried out at the same time as the second cross-sectional study during a 3-month period (October–December) in 1999 (Paper IV).

Ethical considerations

The studies were approved by the Research Ethics Committee of the Medical Faculty, Uppsala University.

Statistical analysis and data handling

In the analysis, the NSSQ response alternatives ‘some help needed’ and ‘unable to manage without help’ were truncated to ‘help needed.’ The response alternatives ‘service can be reduced’ and ‘adequate service provided’ were truncated to a ‘met need’ and the response alternatives ‘inadequate service provided’ and ‘need of service’ were truncated to an ‘unmet need’.

Test-retest and inter-rater reliability (Paper I) were examined for each item separately and two measures of agreement were calculated: percentage of complete agreement and Cohen’s kappa coefficient (Cohen, 1960). The proportions of agreement and Cohen’s kappa coefficient were used to assess the degree of agreement between staff in psychiatric care and the clients (Paper II). Agreements were based on ratings of “need” vs. “no need” and “unmet need” vs. “no need” or “met need.” Values of kappa coefficients in the range 0.81-1.00 indicate ‘almost perfect’ agreement with 0.61-0.80 indicating ‘substantial’, 0.41-0.60 ‘moderate’, 0.21-0.40 ‘fair’ and 0.00-0.40 indicating ‘poor’ agreement (Landis & Koch, 1977).

Particular attention was paid to the marginal distribution of the ratings in order to avoid the paradox of discordance between total percentage agreement and Cohen’s kappa value (Feinstein & Cicchetti, 1990). Cohen’s kappa coefficient was also used as a measure of agreement between staff in psychiatric care and social services together with calculations of total percentage of agreement (Paper III).

To give a more complete description two separate indexes of proportionate agreement in the staffs’ positive ($p_{pos}$) and negative ($p_{neg}$) decisions were calculated (Cicchetti & Feinstein, 1990). A high $p_{pos}$ indicates high agreement on the presence of a need. A high $p_{neg}$ indicates a high agreement on the absence of a need. Staff agreement was based on ratings of ‘need of support’, ‘unmet need of service’ and ‘met need of service’.

Before making the comparison between the NSSQ and the CAN (Paper I), ‘met need’ and ‘unmet need’ on both instruments as well as ‘help needed’
on the NSSQ were combined into a ‘need.’ A missing value on either the NSSQ or the CAN was registered as no need.

When comparing the NSSQ and the CAN, some of the items on the NSSQ were combined into new variables in an effort to better fit the description of the CAN areas of need. The CAN variable names were used with the prefix ‘c’ to name these combined variables (e.g., c food is a combined variable made up from the NSSQ items ‘buying food’ and ‘preparing a meal’).

Sensitivity, specificity and likelihood ratio (LR) were used to evaluate the strength of the association between each comparable item on the NSSQ and the CAN (Paper I). Sensitivity refers to the fraction of the clients identified on the NSSQ as having a need that is also identified by the CAN and was calculated as follows: the number of clients with an identified need on both the NSSQ and on the CAN, divided by the number of identified clients with a need according to the CAN. Specificity refers to the fraction of the clients identified by the NSSQ as having no need correctly identified as no need by the CAN; it was calculated in the following manner: the number of clients with no identified need on both the NSSQ and on the CAN, divided by the number of clients with no identified need on the CAN. For clinical significance, a sensitivity of ≥70 and a specificity of ≥70 were chosen to prevent misses and false alarms. The LR indicates the likelihood that someone with a need identified on the NSSQ is likely to be identified by the CAN. The LR was calculated mathematically by the formulas: Sensitivity/(1-Specificity). For purposes of discussion, an item is a good predictor of a need if the LR ≥ 3 and both the sensitivity and the specificity are high (Jaeschke, Guyatt & Sackett, 1994; Sackett et al., 1998).

Spearman’s non-parametric correlation statistic was used to test concurrent validity (Paper I). The identified needs of support and service on the NSSQ were added for each client to the summary scores (number of needs of support, number of needs of service and total number of needs of support and service). These summary scores were compared with the total GAF -score and the total SOFAS -score. A correlation, below 0.3 was considered low, between 0.3-0.5 as medium and above 0.5 as high (Cohen, 1988).

Group comparisons were made using one-way analysis of variance (ANOVA) for the continuous dependent variables (Papers II and III). Post hoc pairwise comparisons were made by Bonferroni test statistics (Paper III). Student’s t-test was used for continuous dependent variables (Paper IV).

Chi-square tests and 95% confidence intervals (95% CI) for differences were applied for comparisons of non-parametric data (Paper I). Chi-square tests with pairwise follow-up comparisons were used for categorical variables (Paper III).

In the analysis of changes over time each client was used as his or her own control (Paper IV).

For testing the significance of changes of needs between baseline and the end of the follow-up period, McNemar’s test was used (Norušis, 2003).
Differences in proportions of improvements and deterioration between the two groups of clients at the end of the follow-up were also calculated. Logistic regressions were used to examine which characteristics distinguished clients who had changed their needs from other clients. The method of logistic regression used was stepwise forward (Wald method) (Norušis, 2003). The independent variables were gender, age, a diagnosis of schizophrenia and SOFAS score.

The statistical software used was SPSS for Windows (Statistical Package for Social Sciences, versions 10.0.7 (Paper II), 11.5 (Papers I and III) and 12.0.1(Paper IV). All reported p-values were two-tailed and the levels of statistical significance were set at p<0.05 (Papers I, II and IV), and p<0.01 due to the high number of comparisons (Paper III).
Results and Discussion

The reliability study

Seven raters – all mental health key workers - were used in the reliability study (Paper I). Totally 84 clients were rated. Test-retest was calculated for 77 clients and inter-rater reliability was calculated for 69 clients.

The mean percentage test-retest agreement for the need of support and need of service items taken together was 92.2% (all items ≥ 83.1%), with the corresponding mean kappa of 0.80 (all kappa coefficients ≥0.63).

The mean percentage of inter-rater agreement for the need of support and need of service items was 87.2% (all items ≥76.8%); the corresponding mean kappa was 0.68 (all kappa coefficients ≥0.33). Only two kappa coefficients were in the ‘poor’ agreement range, where both concerned inter-rater reliability in the needs of dental care and mobility service.

Test-retest and inter-rater reliability on items concerning sociodemographic information and present living situation all showed perfect agreement (kappa coefficients 1.00). The mean test-retest reliability and mean inter-rater reliability for the whole questionnaire was 0.86 and 0.78, respectively.

The results from the reliability study, percentage agreements and kappa agreements demonstrate that the NSSQ has acceptable test-retest and inter-rater reliability.

The validity study

In the validity study, information from the NSSQ was compared with information from the CAN (n=529), with the latter as reference standard (Paper I). It was possible to compare 19 out of 33 NSSQ items with corresponding areas in the CAN. Items of sociodemographic information and present living situation (10 items) and three other NSSQ items (buying clothes, taking medication and handling contact with public authorities) had no comparable area of need on the CAN instrument. Further, the item ‘need of psychiatric care’ was not considered meaningful because all of the clients had contact with psychiatric care. In addition, six variables were truncated to be more appropriate to the description of the CAN items.
Good concordance between NSSQ and CAN items was found in the following items: preparing a meal, cleaning and washing, personal hygiene, handling finances, using public transportation and home help service. Less satisfactory concordance was found in several other items. In general, the sensitivity of the individual items was high and increased when the items were truncated. Specificity, on the other hand, was higher in the individual items than in the truncated items, suggesting that the NSSQ managed to identify the same clients as the CAN but that the NSSQ specified the needs of the clients in more detail.

In order to evaluate the clinical significance of the NSSQ LR were calculated for each corresponding item. With few exceptions, areas of need with high specificity and high LR had, in general, high sensitivity. Low sensitivity was noted in needs of assisted care living, trustee, mobility service and to move. One explanation might be that the NSSQ items have identified the needs more precisely in comparison with the corresponding areas of need in the CAN instrument. The item ‘need of assisted care living’ in the NSSQ is more precise than the more general area of need of accommodation in the CAN instrument. This also seems to be true for scheduled activity, job training, occupational rehabilitation and work as compared with daytime activity in the CAN area of need. In most cases the NSSQ items are more specified than the corresponding areas of need in the CAN instrument.

To establish concurrent validity the NSSQ was correlated to the GAF and SOFAS scores. Although not particularly high, negative correlations were found. The correlations between GAF -scores and the number of need of support, number of need of service and the total number of need of support and service were -0.49, -0.32 and -0.47, respectively. The corresponding correlations for the SOFAS were -0.48, -0.26 and -0.45. All correlations were statistically significant (p<0.01). Correlations between the CAN instrument and the GAF and SOFAS scores have been found at the same level (Phelan et al., 1995). It seems that a person could have needs of support and service and still have a moderate level of functioning. Thus, the circumstance that a client does have particular needs of service may not necessarily reflect his or her level of functioning.

The population-based cross-sectional studies

The prevalence of clients with unmet needs in the community

Totally, 1,759 clients were identified. The first cross-sectional study identified 1,261 clients (Paper II) and the second cross-sectional study identified 1,290 clients (Paper III). Table 1 shows the distribution of identified clients in the two cross-sectional studies. It seems as more clients have been identified by staff in social services in the second cross-sectional study in 1999.
Table 1. Distribution of identified clients in the two cross-sectional studies.

<table>
<thead>
<tr>
<th>Study</th>
<th>Psychiatric care only</th>
<th>Both organizations</th>
<th>Social services only</th>
<th>All clients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>(%)</td>
<td>n</td>
<td>(%)</td>
</tr>
<tr>
<td>Study I</td>
<td>1996</td>
<td>671 (53.2)</td>
<td>204 (16.2)</td>
<td>386 (30.6)</td>
</tr>
<tr>
<td>Study II</td>
<td>1999</td>
<td>636 (49.3)</td>
<td>233 (18.1)</td>
<td>421 (32.6)</td>
</tr>
</tbody>
</table>

The prevalence rate of clients with long-term mental disabilities meeting the inclusion criteria was 5.7/1,000 inhabitants of the population of persons 18 years or older (Paper II). A statistically significant difference was noted between the prevalence rates of clients living in urban (6.4/1,000 inhabitants) and in rural areas (4.5/1,000 inhabitants). Clients living in the urban area were older, more frequently male and more often had a diagnosis of schizophrenia. All differences were statistically significant. This calculated prevalence rate corresponds well to the results from studies on similar clients (Halldin, 1984; Widerlöv et al., 1989; Widerlöv, Lindström & von Knorring, 1997).

Conditions of life

A large proportion of the clients (77.0%) lived independently without a family. Nearly half of the identified clients (43.5%) did not take part in any activity during the day. One third of the identified clients were reported to participate in social and scheduled activities, 11% were employed or studied and 10.7% received occupational rehabilitation or took part in a job-training programme (Paper II).

Differences in living conditions were observed between clients living in urban and rural areas. For clients to live without a family or to live in assisted care accommodation was more common in the urban area. Clients living in a rural setting more often had a primary educational level of less than 10 years and more frequently had children living at home.

Clients identified by staff in psychiatric care only differed from the other clients in living with a partner and having children living at home under 18 years of age (Paper III). These clients also had a higher level of social and occupational functioning and a rehabilitation allowance more often than the other clients. Clients identified by staff in social services only were older, more frequently had assisted care living (i.e. sheltered housing) and less often a secondary school education. They also had more frequently a diagnosis of substance-related disorder and less often a diagnosis of other psychoses than the other groups. Clients identified by staff from both organizations had a disability pension and a diagnosis of schizophrenia more often than the other clients. The clients identified by the different groups of staff did not differ in gender, country of birth or living in urban or rural areas.
As in earlier studies (Borgå et al., 1992; Middelboe et al., 2001) examining conditions of life for patients with long-term mental disabilities, our data demonstrated that many clients lived on their own.

Needs of support in activities of daily living

More than half of the identified clients needed support in everyday activities. The most frequent needs of support concerned contacts with public authorities, interpersonal skills, cleaning and washing, handling finances and taking medication (Paper III).

Clients living in an urban area had more needs of support with personal hygiene ($\chi^2=13.04$, df=1, $p<0.001$), cleaning and washing ($\chi^2=15.79$, df=1, $p<0.001$) and taking medication ($\chi^2=5.30$, df=1, $p<0.05$). Clients living in a rural area had more needs of support with interpersonal skills ($\chi^2=15.53$, df=1, $p<0.001$) and using public transportation ($\chi^2=25.40$, df=1, $p<0.001$) (Paper II).

Clients identified by staff in social services only had more needs of support than the other groups in using public transportation, using a telephone and in to move. Clients identified by staff from both organizations had more needs of support in interpersonal skills and in contact with public authorities. In general, increasing age led to an increase in need of support. The differences among the clients remained even after controlling for age, except for the youngest group (i.e. 18-30 years of age).

The mean SOFAS for identified clients was 51.40 (sd=14.03). Significant differences were reported between males (mean=49.65, sd=14.40) and females (mean=53.10, sd=13.45), F=16.57, df=1, $p<0.001$.

Clients living in urban areas had lower levels of function (mean=50.53, sd=14.22) than clients living in rural areas (mean=53.31, sd=13.41), F=9.26, df=1, $p<0.002$. Significant differences were also noted between age groups, where clients 65 years of age and older (mean=44.91, sd=18.90) had lower levels of function than clients 18-30 years of age (mean=53.82, sd=12.87) or clients 31-44 years of age (mean=53.27, sd=13.23), F=11.63, df=3, $p<0.001$.

Clients with a diagnosis of schizophrenia had lower levels of function (mean=48.38, sd=14.18) as compared with clients with affective psychosis (mean=54.94, sd=14.18) or neurotic disorder (mean=55.57, sd=12.46), F=7.25, df=6, $p<0.001$.

The mean number of needs of support in activities of daily living reported by care and service providers was 4.2 (sd=3.5). Almost a third of the clients were reported to have more than 5 needs of support of a maximum 10. Most needs of support were related to interpersonal skills, taking medication, handling finances, and cleaning and washing.

Statistically significant differences were observed in the number of needs of support among the different groups (F=133.83, df=2, $p<0.001$). Clients identified by staff in psychiatric care only (mean needs 3.48, sd=3.18) had
less needs of support in all activities in comparison with the other groups. The corresponding means for clients identified by staff in social services only and clients identified by staff from both organizations were 6.38 (sd=4.05) and 7.09 (sd=3.27), respectively.

Staff in psychiatric care and social services found that the clients had several pressing needs of support in everyday activities. Most needs were reported for interpersonal skills and taking medication. Overall, staff in both psychiatric care and social services reported females to be better functioning than males in regards to daily activities.

In addition, clients identified by staff in both psychiatric care and social services had more needs of support in activities of daily living, including interpersonal skills and contact with public authorities.

Unmet needs of service

Staff in psychiatric care and social services reported that almost half of the clients had needs of social or scheduled activities that were not fulfilled. This group of clients did not differ from the rest in age, gender, psychiatric diagnoses or living area.

Clients living in urban settings had more often unmet needs of home help services ($\chi^2=10.48, df=1, p<0.001$) and of a trustee ($\chi^2=4.21, df=1, p<0.05$) in comparison with clients living in rural areas. Conversely, unmet needs related to work in the open market ($\chi^2=6.92, df=1, p<0.01$), job training ($\chi^2=18.76, df=1, p<0.001$), and dental care ($\chi^2=7.26, df=1, p<0.01$) were more often reported for clients living in rural areas (Paper II).

Clients identified by staff from both organizations were reported to have more unmet needs of service (mean=3.21, sd=1.97) than the other clients (F=33.75, df=2, p<0.001). The corresponding means for the clients identified by staff in psychiatric care only and clients identified by staff identified in social services only were 2.21 (sd=1.73) and 2.00 (sd=2.01), respectively. In four areas (social activity, scheduled activity, home help service, and assisted care living) clients identified by staff from both organizations were reported to have a greater frequency of unmet needs than the other clients identified by one organization only.

After controlling for age, some of these differences remained. Older clients (65-92 years of age), identified by staff in social services only, had less unmet needs of home help service than the other clients of the same age. Clients identified by staff from both organizations had more unmet needs of assisted care living than the other clients, except for the oldest (65-92 years of age) clients identified by staff in psychiatric care only and clients younger than 45 years of age identified by staff in social services only. Moreover, clients identified by staff from both organizations had more unmet needs of social activities and scheduled activities than the other clients, except for
clients 18-30 years old identified by staff in psychiatric care only and clients younger than 45 years of age identified by staff in social services only.

A larger number of needs of assisted care living that were not met were reported in males in comparison with females ($\chi^2=6.31$, df=1, p<0.01). In addition, clients having a diagnosis of schizophrenia or a dependency disorder were reported to have more unmet needs of assisted care living ($\chi^2=15.09$, df=7, p<0.05). Males had more unmet needs than females in work ($\chi^2=10.83$, df=1, p<0.001), especially sheltered work ($\chi^2=20.59$, df=1, p<0.001). Furthermore, males had more needs of home help services that were not fulfilled ($\chi^2=9.62$, df=1, p<0.002). Clients in the oldest age group had more unmet needs of psychiatric care as compared with the other age groups ($\chi^2=18.73$, df=3, p<0.001).

The staff–staff comparison study

Staffs in psychiatric care and social services were asked to identify clients with needs of support and service in order to improve care, support and service (Paper III). However, the difference in perspectives between the two organizations (i.e. the public health care sector and the community social services sector) may influence the identification and assessment of such needs.

Three main findings were obtained in this study. First, the staffs from the psychiatric care and the social services only partly identified the same clients (18.1%). Second, clients identified by the staffs in both organizations had more needs of support and service. Third, the staffs in the psychiatric care and the social services demonstrated high agreement regarding the presence and type of needs, but poorer concurrence in pairwise agreements at the individual level.

The best pairwise agreements were in the activities using public transportation and cleaning and washing, where the kappa values were 0.67 and 0.65, respectively. Moderate agreements were found in five areas, to move, buying food, buying clothes, personal hygiene and preparing a meal. Fair agreements were found in three areas, handling finances, taking medication and using a telephone. In only two areas poor agreements were found. In addition, separate indexes of positive and negative agreements were calculated. In general, positive agreements on the presence of a need of support were higher than negative agreements, i.e. agreement of the absence of a need.

Agreements on identified unmet service needs also corresponded well in number of unmet needs and in need areas. However, the pairwise agreements were low. A moderate agreement (Cohen’s kappa coefficient 0.50) was found in one area (assisted care living) only. Fair agreement (0.21–0.30) was found in four areas (trustee, home help service, work and job training) and only slight agreements were found in five areas.
There were also differences between staffs’ ratings in the two organizations on whether the client had a met need of service provided by the public sector. A substantial agreement of a met need was found in the areas of need of a trustee, work, assisted care living and mobility service (Cohen’s kappa 0.63–0.72). Moderate agreement (0.52) was found in home help service. Fair agreement (0.27–0.40) was found in job training and scheduled activities, and poor agreement (-0.03–0.16) was found in four areas. In general, agreement on the presence of a met need of service was higher than the agreement on the presence of an unmet need of service.

Clients identified by staff in social services only were older than the other clients, which may partly explain some of their more frequent needs than the clients identified by staff in psychiatric care only. The clients identified by staff in social services had a lower level of social functioning, including more frequently assisted care living. All clients identified by staff in social services had had contact with psychiatric care. Clients identified by staff in psychiatric care had a higher level of functioning than the other groups and more often a rehabilitation allowance. This difference in socio-demographic characteristics between clients identified by staff in psychiatric care only and clients identified by staff in social services only seemed to be a factor that influenced their needs of help and service.

Good agreement between the organizations was found in the assessment of number of needs of support and unmet needs of service. However, individual pairwise agreement between staffs in psychiatric and social services was at a lower level. The kappa values were higher for needs of support than for unmet needs of service.

There were frequently more positive decisions than negative decisions on the presence of a need of support. Concerning unmet needs of service, however, agreement on the absence of an unmet need occurred more frequently. Accordingly, the kappa values were lower for unmet needs of service as compared with met needs of service. It seemed easier to identify a need as met than a need that was unmet.

The client–staff comparison study

In all, 406 clients (204 males and 202 females) of 921 (44.1%) agreed to participate in the client-staff comparison study and returned the questionnaire (Paper II). The majority of these participating clients (67.7%) were living in the urban community. The distributions of sociodemographic variables and psychiatric diagnoses were similar to those obtained for all identified clients.

Clients and staff in psychiatric care reported the needs of the clients in the same areas; however, clients reported a fewer number of needs than did the staff.
Information provided by both staff and clients showed that the total percentage of agreement ranged from moderate to high (i.e. 60-88%), although the kappa values were considerably lower because of a skewed distribution. The results indicated that staff and the clients identified most needs of support in the same domains. Staff identified more needs of support than the clients; staff also identified more needs of support for male than for female clients.

In the pairwise comparison of reported unmet needs of service between staff and the clients the total percentage of agreement was found to correspond well across all variables (i.e. 62-92%).

However, in comparison with the staff, the clients reported fewer unmet needs. Comparable results have been found in at least one other study (Hansson et al., 2001). Low levels of agreement have mostly been reported in studies comparing assessment of client needs by staff and the clients themselves (Crane-Ross, Roth & Lauber, 2000; Lasalvia et al., 2000; Middelboe et al., 1998, 2001; Slade et al., 1996; Slade et al., 1998). Staff identified more needs (Slade, Phelan & Thornicroft, 1998) or needs in life areas different from those identified by psychiatric patients (Slade et al., 1999).

Both staff and the clients reported the unmet need of accommodation; however, staff more frequently reported the unmet need of assisted care living, whereas the clients more frequently asked for independent living. Further, staff reported the unmet need of job training and occupational rehabilitation more frequently than the clients. The clients, on the other hand, reported the unmet need of work more often. It seems as though the staff and the clients agreed on the presence of unmet needs, but could not agree on how to solve these unmet needs.

Most of the agreements between staff and the clients were on the ‘no need’ or ‘met need’ categories, which helps to explain the low kappa values. Staff and clients identified social and scheduled activities as the most salient unmet need, followed by the unmet needs of work, housing and dental care.

A comparison of reported unmet needs across diagnostic groups indicated that clients with a diagnosis of schizophrenia reported fewer needs than either staff or the clients with other diagnoses. These differences were most pronounced in the domains of accommodation and needs of support in activities of daily living. These findings are consistent with quality of life (QoL) studies (Katschnig, 2000) in which schizophrenic clients living in the community report lower expectations and achievements and are therefore satisfied with their QoL and well being.

The prospective follow-up study

In a population-based prospective study, 792 clients were followed during a period of 3.5 years (Paper IV).
Three main findings emerged from this study. First, a majority of the clients with an unmet need of service at baseline had their need met at the 3.5-year follow-up. Two-thirds of the unmet needs of service were met during the 3.5-year period. Improvements for clients with schizophrenia were evident in need of psychiatric care, a trustee, mobility service and occupational rehabilitation. For non-schizophrenic clients, most improvements were in the areas of mobility service, a trustee, dental care and assisted care living. In addition, these clients more frequently had reductions of needs of support than clients with schizophrenia.

Second, new unmet needs were identified at the end of the follow-up. The most frequent unmet needs included social activity, scheduled activity and psychiatric care. Clients with schizophrenia more frequently had changes to new unmet needs as compared with non-schizophrenic clients. Moreover, clients with schizophrenia had new needs of support more often than non-schizophrenic clients. Clients with schizophrenia required assisted care living more often and had a disability pension more frequently than non-schizophrenic clients. It seems as if clients with schizophrenia had a course of deterioration during the follow-up period. This observation is in line with a worse prognosis of schizophrenia in comparison with other psychiatric diagnoses (Kelly et al., 1998; Tsuang, Woolson & Fleming, 1979; Tsuang & Dempsey, 1979). However, non-schizophrenic clients had more new unmet needs of job training than clients with schizophrenia. On first inspection, this finding seems in contradiction to the higher level of functioning in non-schizophrenic clients. However, the high level of functioning may have made it more apparent that job training could help these clients.

Third, the results demonstrated important differences in changes of needs between schizophrenic and non-schizophrenic clients. Changes from no need to a new need of support were more frequent among clients with schizophrenia as compared with non-schizophrenic clients. Clients with schizophrenia, in comparison with non-schizophrenic clients, had more frequently new needs in preparing a meal (p<0.001), personal hygiene, cleaning and washing, buying clothes, handling finances (all p<0.005), buying food (p<0.01), interpersonal skills and using a telephone (p<0.05). Non-schizophrenic clients had reductions in needs of support more frequently than clients with schizophrenia concerning preparing a meal, buying food, cleaning and washing, buying clothes, taking medication (all p<0.001), handling finances and interpersonal skills (p<0.01).

Overall, these two groups of clients differed in the mean number of needs of support reported at baseline and at the end of the 3.5-year follow-up. The mean number of needs of support for schizophrenia clients at baseline and at follow-up was 5.07 and 5.59 (t=-3.39, p< 0.001), respectively. The corresponding mean number of needs of support for non-schizophrenia clients was 3.56 and 3.68, respectively.
A significant difference between the two groups of clients in SOFAS score was also noted (p<0.005). Clients with schizophrenia had a lower level of SOFAS, both at baseline (48.1) and at the end of the follow-up period (48.4). Corresponding values for non-schizophrenic clients were 53.1 and 51.5, respectively. However, there was no statistically significant change on the SOFAS score at the follow-up.

The logistic regression revealed that clients who had reduced their needs of support at follow-up were younger and had higher SOFAS scores at baseline. A reduction of interpersonal skills and handling medication was more often noted in female clients. A new need of cleaning and washing and buying clothes was more frequent among male clients.

Clients with schizophrenia had significantly more unmet needs of mobility service (p<0.005), home help service (p<0.005), scheduled activity (p<0.05), and assisted care living (p<0.05) at baseline than non-schizophrenic clients.

There were significant changes in the clients’ needs of service during the follow-up period. Clients with schizophrenia had significantly changed their needs of service. Changes from unmet need to a met or no need of service ranged from 31.2% (social activity) to 92.3% (psychiatric care). There were also new unmet needs of service reported at follow-up in all areas. The frequency of these new needs ranged from 4.1% (mobility service) to 55.7% (social activity).

Non-schizophrenic clients had significantly changed their needs of service. Changes from an unmet need to a met or no need of service ranged from 43.2% (social activity) to 100% (mobility service). Changes from a met or no need to an unmet need ranged from 4.3% (mobility service) to 45.1% (social activity).

There were statistically significant differences in the frequency of changes of needs between the two groups of clients. Clients with schizophrenia changed more frequently from a met or no need to an unmet need of home help service and social activity (p<0.01) and dental care (p<0.05). Non-schizophrenic clients changed their unmet need of scheduled activity to a met or no need more frequently than clients with schizophrenia (p<0.05). Non-schizophrenic clients also changed more frequently from a met or no need to an unmet need of job training compared (p<0.05).

Overall, needs of service had increased during the follow-up period in all clients. The mean number of unmet needs of service reported at baseline and at the end of follow-up for clients with schizophrenia was 1.37 and 2.14 (t=-7.79, p<0.001) respectively. The corresponding means for non-schizophrenic clients were 1.22 and 1.93 (t=-6.44, p< 0.001), respectively.

The logistic regression showed that clients who had their unmet needs of social activities, job training and a trustee met or reduced were older than the other clients. Younger clients often had their needs of mobility service met more often at follow-up. Clients who had changed their met or no need to an
unmet need of scheduled activity, job training, occupational rehabilitation and work were younger than other clients. Clients who had new unmet needs of mobility service were more often older. New unmet needs of dental care were noticed in clients with lower SOFAS scores.
General Discussion

Two hundred years after Philippe Pinel, had removed the chains from the patients, in the French institution Bicêtre, the mental health care reform was implemented in Sweden. The deinstitutionalization process in psychiatry during the 1970s in Sweden and other European countries was more complicated than expected and changed the view on need for care and service among clients with long-term mental disabilities. The presented studies are a part of the evaluation of the implementation of the mental health care reform in Uppsala County.

Methodological considerations

One issue of methodology is the new instrument, NSSQ, which was developed to provide professionals in psychiatric care and community social services with a tool to assess needs of support and service in mentally disabled clients. In order to provide adequate interventions more specific information on the clients' needs of support and service than could be obtained from existing instruments (e.g. the CAN instrument), was requested from the psychiatric care and community social services organizations. One important advantage of the NSSQ is that staff in both psychiatric care and social services could use it without any formal training. The instrument is intended for use by professionals in social services as well. It should be noted that while the instrument is thought to be useful to persons within the social services, reliability and validity were only measured for professionals in psychiatric care. Nevertheless, the results from the test-retest and inter-rater reliability study as well as the validity study demonstrate that the psychometric characteristics of the NSSQ are satisfactory. This means that the NSSQ can be used for planning services, both at a population level to design a service in a geographical area and at an individual level for developing individual plans of care, support and service.

Another methodological issue pertains to the fact that there is no consensus about the definition of need. There is also a lack of consensus as to who should assess the needs of clients. Some argue that need can only be assessed by professionals (Mooney, 1986), whereas others (Bradshaw, 1972) claim that individuals can assess their own (‘felt’ and ‘expressed’) needs accurately. An ongoing debate in the literature is whether clients with long-
term mental disabilities can reliably report their needs (Corrigan, Buican & McCracken, 1996; MacCarthy, Benson & Brewin, 1986). An individual’s needs are in large part value judgements and hence cannot be objectively defined. It is therefore important to include a care provider perspective in addition to a client view. Assessment of unmet needs provided by care and service providers can be significantly distorted by their limited information of the clients’ conditions of life. It is plausible that clients are likely to have the most current information about their life situation. This is particularly probable in community settings, where care providers have less opportunity to observe the behaviour of clients. Another possible complication could be that the clients’ unmet needs fall outside the care providers’ particular area of expertise (Lockwood & Marshall, 1999). One example of this phenomenon is the high frequencies of the response alternative “unknown” that was observed in certain domains such as dental care.

In this thesis, however, staffs in either psychiatric care or in community social services assess the clients’ needs. Clients were invited to participate in a study to compare assessments made by staff and clients. The results from that study indicated that both staff and clients identified the same types of needs. However, the clients reported fewer needs than the staff. Several studies have shown that staff and long-term mentally ill clients differ in their assessments of needs (Hansson et al., 2001; Slade et al., 1996; Slade, Phelan & Thornicroft, 1998; Slade et al., 1999; Wiersma et al., 1998). What is consistent in these studies is that clients in general report fewer needs than the staff. These findings are in line with quality of life studies in which clients with schizophrenia living in the community report lower expectations but are satisfied with their QoL and well being (Katschnig, 2000).

A great number of the clients who were invited to participate in the staff-client comparison study could not manage to participate or chose not to take part in the study. For that purpose, a survey of the type used in the present studies is indispensable in providing adequate care, support and service in both psychiatric care and community social services.

Not all clients identified at baseline were identified at the end of the follow-up. Thus, this may have influenced the results of the follow-up study. These clients had higher scores on the SOFAS, less often a diagnosis of schizophrenia and fewer needs of support and service at baseline as compared with the follow-up clients. This could indicate that the non-follow-up clients had a better outcome and could have led to an underestimation of the interventions done by the two organizations.

Assessments were in most cases not performed by the same staff at baseline and at the end of the follow-up. Differences in assessments between baseline and at the end of the follow-up period may be due to varying perspectives on the assessment of their clients. The clients unmet needs may also fall outside the particular area of expertise of the staff, including a lack of knowledge of each professional area. Moreover, there might be differ-
ences in how well the staff knew their clients. To which extent this factor has influenced our study is unclear. However, the validity of staff ratings finds support in that the inter-rater reliability was relatively high. All these factors may have influenced the results of our study.

Cohen’s kappa coefficients were calculated in order to compare the agreement on support and unmet needs between staff in psychiatric care and social services and between staff in psychiatric care and the clients. In some instances, there were high percentage agreements but low kappa coefficients. Because of low endorsement frequencies yielding a skewed distribution the kappa values are not valid for its purpose; in fact, they may be misleading. This seemingly contradiction with high agreement and low kappa values may be explained by the symmetrical imbalance in the marginal totals of the 2 x 2 concordance table that can convert a high agreement into a much smaller value of the kappa (Feinstein & Cicchetti, 1990). However, no single omnibus index will describe the evaluation assessment process satisfactorily (Cicchetti & Feinstein, 1990). To provide a more complete description two separate indexes of proportionate agreement in the staffs’ positive \( p_{\text{pos}} \) and negative \( p_{\text{neg}} \) decisions were calculated. This analysis indicated that there were frequently more positive decisions than negative decisions concerning the presence of a need of support. Regarding unmet needs of service, however, agreement was more frequent on the absence of an unmet need. Accordingly, the kappa values were lower for unmet needs of service as compared with met needs of service. It seemed easier to identify a need as met than a need that was unmet.

Discussion of the findings

Prevalence

The two cross-sectional studies were intended to be population-based studies; however, it is not known to what extent all clients meeting the inclusion criteria were actually identified. The fact that a large number of care and service providers were involved in the investigation and reported many cases may suggest an efficient case-finding procedure and one in which the systematic bias in the selection process was counterbalanced. However, care providers may have overlooked clients because of any subjective procedure they may have used. Consequently, the possibility of missing cases cannot be ruled out.

The prevalence of clients with a mental disability, according to our definition, was 6.4/1,000 inhabitants 18 years of age or older in the urban and 4.5/1,000 in the rural area.
According to Swedish epidemiological studies of mental disorders, the 1-year prevalence rate of schizophrenia-like psychosis is estimated to vary between 3.4 and 7.3/1,000 inhabitants (Halldin, 1984; Widerlöv et al., 1989; Widerlöv, Lindström & von Knorring, 1997). The prevalence rate of schizophrenia is higher in urban than in rural communities. When urban and rural areas are compared in European studies, prevalence rates of 4 and 2 schizophrenic patients per 1,000 inhabitants, respectively, have been reported (Jablensky, 1986; Torrey, 1987). Corresponding rates of clients with a diagnosis of schizophrenia in our study were 2.8 (urban area) and 1.4 (rural area). Further, it is noteworthy to consider that the inclusion criteria employed in the present studies (i.e., the duration of the disability for at least 6 month and at least one need of support or one unmet need of service) were specifically chosen to identify clients most in need of intervention. It is reasonable to suggest that the inclusion criteria chosen will influence the size of the study group. Therefore, one could say that the cross-sectional studies have identified a fair estimate of the number of clients with a mental disability that requires care and rehabilitation.

Living conditions
Several studies have focused on the living conditions of long-term mentally disabled clients who live in urban and rural settings. The general findings indicate that urban individuals are more often living alone, less likely to be married, have poorer accommodation and more frequently excluded from the labour market than are individuals in rural areas (Blazer et al., 1985; Borgå et al., 1992; Middelboe et al., 2001; Sommers, 1989). Care providers have reported that the most frequent needs of support for patients are the handling of medication and personal finances, as well as the need for individual counselling, psychotherapy and case management (Ford et al., 1992). Problems with daily living skills involve personal hygiene, household chores, interpersonal relationships, social and scheduled activities, and employment (Anthony & Liberman, 1986).

Our data confirm these general findings, showing that most of the clients were living alone and lived independently. A major portion of the clients (63%) had a disability pension, whereas relatively few had a salary or rehabilitation allowance (11%).

Significant differences were found between clients living in urban and rural settings. Clients living in urban areas were more frequently male, older and more often had a diagnosis of schizophrenia. Clients in urban settings needed more support with personal hygiene, domestic chores, taking medication, home help service and assistance in finding a trustee. The most prevalent unmet needs were social and scheduled activities. Clients living in rural areas needed more support with job training and finding work.
In accordance with other studies, more males than females lived in urban communities and males were more likely to have a diagnosis of schizophrenia, regardless of living area (Dottl & Greenley, 1997; Freeman, 1986; Widerlöv et al., 1989; Widerlöv, Lindström & von Knorring, 1997). That more males were living in the urban area and that the mean age was higher in the urban area, could account for some of the differences between urban and rural areas.

Staff–staff perspective

The public health care and community social services are two important organizations that serve to improve the conditions of life for long-term mentally disabled clients. It is, however, unclear how the staffs in psychiatric care and social services judge the various needs of clients.

This is one of the first studies to compare assessments of needs provided by staffs of both psychiatric care and social services. The identification of needs of support and service in clients with long-term mental disabilities is usually not done by staffs from both psychiatric care and social services. Yet, such a process seems necessary if adequate psychiatric care and social services are to be made available to mentally disabled clients.

In this study, we found that staffs of psychiatric care and social services have reasonable agreement in the evaluation of the number of needs, but differ in their pairwise assessment of needs of support and unmet needs of service for the individual client. The results also demonstrate important differences between clients identified by the two organizations. Clients identified by staff from both organizations seem to be more vulnerable than clients identified by staff from one organization. For instance, more than 50% of these clients had a diagnosis of schizophrenia and a disability pension. They also had more unmet needs of service, especially in social activities, scheduled activities, home help service and assisted care living. Clients identified by staff in psychiatric care only had fewer needs of support and fewer unmet needs of service.

Follow-up study

Long-term effects of community-based mental health care are a poorly researched area with important implications for evaluating the efficacy of helping clients with mental disabilities in the community (Mason et al., 1995; Kelly et al., 1998). Moreover, longitudinal studies of needs of support and service in these clients are rare.

The follow-up study showed that the public organizations were able to help the mentally disabled clients in several respects. However, there were still problems in rehabilitation programmes for social and scheduled activities. It seemed as if the services were not appropriate to cover such needs. It
was also obvious that it was more difficult to help the clients with schizophrene. Higher age as well as schizophrenia was found to lead to a greater need of support. This observation is supported by a recent study on needs in elderly people with schizophrenia (McNulty et al., 2003).

It is well known from assessments using the CAN instrument in psychiatric care that needs are frequent in clients with a diagnosis of schizophrenia (Slade et al., 1996; Slade, Phelan & Thornicroft, 1998; Hansson et al., 2001).

The study demonstrated that the clients with unmet needs at baseline generally had their needs met at follow-up. There were reductions in unmet needs of job training, occupational rehabilitation and work.

In accord with our results, Reid et al. (2001) found some increase in levels of unmet as well as met needs. Arvidsson (2003a) found that the number of unmet needs decreased and the number of met needs increased during a 5-year follow-up. Similarly to our study, drops in unmet needs in accommodation, food, looking after the home, self-care, daytime activities and economy were reported. However, for 19% of the clients, the sum of unmet needs was increased. Noteworthy, Bengtsson-Tops & Hansson (2003) also reported reductions in the total number of needs, as well as increases in met needs. However, no changes regarding unmet needs were reported. In a 17-year follow-up study, 12% of the schizophrenic clients changed from unmet to no need and 28% suffered from new unmet needs (Wiersma et al., 1998). However, 22% of the clients had no needs during the follow-up period.

The discrepancies in results between our study and others may, to some extent, depend on differences in inclusion criteria. There is also a problem to compare studies because of the use of different measurement instruments.

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Our population-based studies on assessment of needs nicely illustrate the conditions of life of mental disabled clients. Our data are supported in the literature. Ruggeri et al., (2004) have in a model identified the profile of clients with higher needs of care by using demographic, clinical, social and service variables. She found that being male, unemployed having low functioning and high symptomatology are associated with higher levels of need. The most urgent problems in our studies concern daily activities, where 60% of the identified clients had no meaningful daily activity. There is, accordingly, a great need for support programs, particularly within areas of work, job training, occupational rehabilitation and leisure time activities. Vocational rehabilitation programmes are an essential part in the treatment of clients with mental disabilities (Reker et al., 2000). Crowther et al., (2001) have also found that supported employment is more effective than prevocational training at helping these clients.

Most important, however, are support programs for social and scheduled activities. Interaction and integration of programs between social services and psychiatric care are of central significance as means to integrate the cli-
ents in society. Because the clients do not participate in social or scheduled activities, they miss the opportunity to engage in diverse activities and to establish meaningful relationships with other people. To establish and offer clients with long-term mental disabilities meaningful social and scheduled activities could be an effective goal in psychiatric rehabilitation.

Harding & Keller (1998) analysed the literature on social functioning and schizophrenia, which describes poor premorbid adjustment, deterioration during illness, feelings of isolation and estrangement, disordered emotional responsibility, bizarre behaviour and speech that can drive friends and family away and the symptom of blunted affect, which increases social isolation. The long-term studies revealed that social functioning is most often restored and even undergoes further development after a schizophrenic psychosis. Many of the studies found that this effect occurred with greater frequency or correlated highly with improvement in psychological functioning.

Another important vulnerability factor for clients with schizophrenia is social impoverishment. Research on factors such as social skills (Hoffman et al., 1998) suggests that people with schizophrenia often have trouble with the necessary cognitive, behavioural and emotional skills that are necessary in developing adequate social resources. Substantial evidence exists suggesting that the social networks of younger individuals with schizophrenia are smaller and less reciprocal than those of other adults with or without psychiatric illness (Cohen & Sokolovsky, 1978; Meeks & Murrell 1994). There is also evidence of an association between social networks and functional outcome. Larger social networks are associated with higher levels of functioning (Howard, Leese & Thornicroft, 2000; Evert et al., 2003). Strauss and Carpenter (1974) have showed that the best predictor of working is past work experience. Furthermore, diagnosis and symptoms did not predict work or social functioning or outcome across 5 years of follow-up. Previous social functioning did cross over to help predict work functioning.

Nyström (1999) found that severely mentally ill clients instinctively try to avoid thinking about the possibility to change. The perspective they use to interpret their world is constant throughout their whole lives. The author remarks, consequently, that severe mentally ill people always meet with people who want them to change.

Why are unmet needs not met?

The fact that a need is defined does not mean that it can be met. For example, some needs may remain unmet because other problems take priority or because the person in need refuses treatment or to participate in the intervention, i.e., there is a problem to motivate the client. There could also be shortages in the care and service organizations. An effective method may not be available locally, or there could be differences in perspectives between the staff personnel. Another possibility is that an unmet need could be over-
looked. It is also possible that community social services provide the service or intervention for other clients than those clients who are most in need of help. Furthermore, it can happen that a need is detected that earlier had not been identified or was overlooked. However, fulfilling all the needs of the clients may be problematic because of economic consequences in relation to other political priorities.

Long-term disability is a relatively common course of illness and should lead to services organized to offer long-term treatment and care if needed. In addition, high unemployment rates among persons with long-term disability should lead to specific programmes for vocational rehabilitation.

Interventions from the community social services might not influence schizophrenia clients in the same way as non-schizophrenia clients. An insufficient allocation of resources may be one of the contributing factors to this development. Obviously, there is a need to develop new methods to help these clients in their daily life activities. Co-ordination of resources is an essential condition to improve the situation of the clients. It furthermore gives a more obvious tool to elucidate the needs of the clients.

There is a need of better co-operation between psychiatric care and community social services. This co-operation also comprises primary health care, the regional social insurance office and the local employment agencies. A better allocation of the total resources, including finances and in-service training, is necessary.

Markström (2003) concluded in his study that, taken as a whole, the mental health care reform heavily was dependent on a few individuals. If the community-based work is to develop further, it will require that a greater part of the social services organization increases its knowledge and engagement in the process. His conclusion was that the implementation of the reform has been difficult, but that it is far from being clarified as a unilateral failure.

Let’s hope that we do not end up finding that the circle now is closed. We started with the de-institutionalization process and now we finish it with the re-institutionalization process.

This thesis brings knowledge on the living conditions and needs of support and service in clients with a long-term mental disability living in a defined catchment area of Uppsala County. The results suggest that different perspectives must be complimentary, and for that purpose, a survey of the type used in the present thesis is necessary to be able to provide adequate care, service, and support in both psychiatric care and social services. One other thing to consider is whether a combined unitary organization may be more optimal to help mentally disabled clients living in the community.
Conclusions

In summary, the main findings of the present thesis are:

- Staffs from both psychiatric care and community social services are necessary if the case finding of clients with a mental disability living in the community is to be effective. Staffs from both organizations only partly identify the same clients.

- The NSSQ can be used to identify clients with needs of support and service. It can also be used for planning services, both at a population level to design a service in a geographical area and at an individual level for developing individual plans for care, support and service.

- Staffs in psychiatric care identify more needs in the clients than staff in social services, except for needs of social activities, scheduled activities and occupational rehabilitation.

- In general, there is high agreement between staff in psychiatric care and the clients regarding the clients’ number of needs of support and their unmet needs of service. However, at the individual level, agreement between client and psychiatric care providers is lower.

- Interventions from psychiatric care and social services can change unmet needs to met needs.

- Needs of support and service are a dynamic process and assessments of these needs should be evaluated on a regular basis over time.
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