

**After the 1995 Swedish
Mental Health Care Reform**

-a follow-up study of a group of severely mentally ill

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ABSTRACT

Arvidsson, H. (2004). After the 1995 Swedish Mental Health Care Reform- a follow up study of a group of severely mentally ill.

Aims: The overall aim of this thesis was to follow up a sample of severely mentally ill persons after the 1995 Swedish mental health care reform and to assess if the observed changes were in accord with the aims of the reform.

Methods: In 1995/96, 602 persons were surveyed and identified as severely mentally ill in a defined area of Sweden. In 2000/2001, 828 persons were surveyed using the same method. The surveyed persons were interviewed and their needs were assessed on both occasions. Study I involved the 378 persons surveyed on both occasions. The results of interviews and assessments of needs from the two occasions were compared. In Study II, the results of the interviews and need assessment in 1995/96 and in 2000/2001 were compared. The subset of the group surveyed in 2000/2001 that also was surveyed in 1995/96 (n=378) was compared to the group that was "new" in 2000/2001 (n=450). In study III the persons surveyed in 1995/96 but not in 2000/2001 (n=224) were investigated with respect to recovery. A small sample also participated in an interview particularly focusing on recovery. Study IV was a case register study, assessing the quantity of psychiatric care delivered during the period 1994-2003.

Results: In general, the results were in accord with the aims of the reform. The number of met needs had increased and the number of unmet needs had decreased. Furthermore, efforts by psychiatric care and social services had increased for the target group of the reform. The objectives of the reform thus seemed to have been effectuated.

There seemed to have been a change in the interpretation and application of the concept severely mentally ill between 1995/96 and 2000/2001. It appeared that the threshold for applying the concept had been lowered on the second survey.

Only 14 % were considered to have recovered from being severely mentally ill between the two surveys.

Conclusions: The findings were in accord with the aims of the reform. Why then is the reform commonly considered a failure in the public debate? The main argument for dubbing the reform a failure may be the fact that the severely mentally ill as a group are still very underprivileged and that they are clearly not afforded opportunities equal to those enjoyed by society at large.

Key words: severely mentally ill, mental health care reform, needs, recovery, prospective study, case register study

LIST OF PUBLICATIONS

This thesis is based on the following studies referred to in the text by their Roman numerals:

- Study I Arvidsson, H. (2003). Met and unmet needs of severely mentally ill persons- The Psychiatric Care Reform in Sweden. *Social Psychiatry and Psychiatric Epidemiology*, 38, 373-379.
- Study II Arvidsson, H. Changes in the group defined as severely mentally ill- five years after the mental health care reform in Sweden. Accepted for publication in *International Journal of Social Welfare*.
- Study III Arvidsson, H., Arvidsson, E. Recovery of severely mentally ill persons- a five year follow-up study after the 1995 Swedish mental health care reform. Submitted.
- Study IV Arvidsson, H., Ericson, B. G. The Development of Psychiatric Care after the Mental Health Care Reform in Sweden- a case register study. Accepted for publication in *Nordic Journal of Psychiatry*.

PREFACE

In the summer and autumn of 2003 serious episodes of violence involving men who had had contact with psychiatric care occurred in Sweden. Contact with care had been in rather close connection to the crime and in one case the person was still in hospital care. Among the victims was the Swedish foreign minister. The crimes set off a wave of harsh criticism in media about the fiasco of the mental health care reform and the total absence of psychiatric care. The reform was accused of closing up the institutions and putting severely mentally ill persons out on the streets, without providing them with any kind of support or assistance. The conviction that the reform was a total failure was held by media, politicians, the general public and by many members of the psychiatric profession. The question was not *if* the reform had become a failure but *why*.

The debate very soon reached the political level and the government was forced to act. The government appointed a co-ordinator of psychiatry with the commission to investigate the conditions of the care of severely mentally ill persons throughout the country and during a period of three years continuously suggest improvements. Money for actions of improvement should be available.

The work on this thesis of course started long before the dramatic events of 2003. However, these events unavoidably will be a background for my thesis, but my hope is that the foregrounding “figure” of the thesis will be the empirical material and my analyses and interpretations of it.

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Introduction

Mental Health Care Reforms

Mental health care reforms and deinstitutionalisation as a world wide process

In recent years, mental health policy documents, programs and mental health care reforms have been implemented all over the world with the aim to improve the conditions of severely mentally ill persons. The contents of the policy documents and reforms may vary between different countries but they all stress the development of community care instead of institutional care.

In Europe several mental health care reforms have taken place in recent years. The countries differ widely in terms of political, economic and health care systems. Still, the mental health reforms have been based on the same key principles (Becker & Vázquez-Barquero, 2001). The principles imply a process of deinstitutionalisation and closing of the traditional mental hospitals, the development of alternative community services and programs, the integration with health services and the integration with social and community services.

In Europe, the closing of mental hospitals and reduction of the number of beds in psychiatric clinics started at different times and progressed with different speeds (Goodwin, 1997; Madianos, 1994). The change has been particularly noticeable in England (Goodwin, 1997; Johnsson, Zinkler & Priebe, 2001) and Italy (Burti, 2001) and less so in countries like Greece (Madianos, Tsiantis & Zacharakis, 1999) and Spain (Vázquez-Barquero & Garcia, 1999; Vázquez-Barquero, Garcia & Torres-González, 2001). In Eastern Europe the process of deinstitutionalisation and development of alternative community based services is still in its cradle (Poloshij & Saposhnikova, 2001; Puzynski & Moskalewicz, 2001; Tomov, 2001).

The number of mental hospitals in Europe was halved during the seventies (Freeman, 1996). In the United States there were 400,000 beds in public mental hospitals in 1970 but fifteen years later the number had been reduced to 100,000 (Grob, 1994).

The closing or downsizing of psychiatric hospitals is only one part of the reform process. The other part is the provision of alternative services (Geller, 2000; Goodwin, 1997; WHO, 2001a), which can be defined as replacement of long-stay psychiatric hospitals with smaller, less isolated community-based alternatives for the care of mentally ill people (Bachrach, 1996; Lamb & Bachrach, 2001). Concepts such as “community care” (Goodwin, 1997; Grob, 1994; Tansella & Thornicroft, 2001) and “community psychiatry” (Szmukler &

Thornicroft, 2001) were created to describe this new kind of care for severely mentally ill persons.

Important early acts and laws urging this development are:

- a. The English Mental Health Act in 1959 with the purpose to abolish the mental hospitals and creating smaller community based units (Goodwin, 1997).
- b. The U.S. Action for Mental Health in 1961 followed by Community Mental Health Centers Act in 1965 with the intention of establishing local health centres and phasing out the number of patients in the mental hospitals (Goodwin 1997, Grob, 1994).
- c. Italian Law 833 and Law 130 in 1978. Besides directions of the development of local community based clinics the Law 130 prohibited new admissions to mental hospitals (Goodwin, 1997). The implementation of reform in Italy was closely related to Franco Basaglia and the left-wing movement *Psichiatria Democratica* (Romanucci-Ross, 1996).

Reforms or policies with similar content have not only started to be implemented in Europe (Becker & Vázquez-Barquero, 2001, Goodwin, 1997) and the US (Goodwin, 1997; Grob, 1994) but also in Australia (Whiteford, Buckingham & Manderscheid, 2002), Canada (Goodwin, 1997), Japan (Ito & Sederer, 1999) and South America (Larrobla & Botega, 2001).

The World Health Organisation (WHO, 2001a) summarises ten recommendations for actions to improve mental health all over the world: provide treatment in primary care, make psychotropic drugs available, give care in the community, educate the public, involve communities, families and consumers, establish national policies, programmes and legislation, develop human resources, link with other sectors, monitor community mental health and support more research. The reasons for providing care in the community are mixed: “Community care has a better effect than institutional treatment on the outcome and quality of life of individuals with chronic mental disorders. Shifting patients from mental hospital to care in the community is also cost-effective and respects human rights. Mental health services should therefore be provided in the community, with the use of all available resources. Community-based services can lead to early intervention and limit the stigma of taking treatment. Large custodial mental hospital should be replaced by community care facilities, backed by general hospital psychiatric beds and home care support, which meet all the needs of the ill that were the responsibility of those hospitals. This shift towards community care requires health workers and rehabilitation services to

be available at community level, along with the provision of crisis support, protected housing, and sheltered employment” (p 110-111).

WHO (2001a) stated that a sound process of deinstitutionalisation demands three essential components: prevention of inappropriate mental hospital admissions through the provision of community facilities, discharge of long-term institutional patients who have received adequate preparation and establishment of community support systems.

WHO (2001a) also described problems in integrating mental health care into primary health care in developing countries, even in countries where pilot programmes have been successful. Brazil, China, Colombia, India, The Islamic Republic of Iran, Pakistan, Philippines, Senegal, South Africa and Sudan are here mentioned. WHO (2001a) summarises: “The past half century witnessed an evolution of care towards a community care paradigm. This is based on two main pillars: first, respect of human rights of individuals with mental disorders; and second, the use of updated interventions and techniques. In the best cases, this has been translated into a responsible process of deinstitutionalisation, supported by health workers, consumers, family members and other progressive community groups..... The idea of community-based mental health care is a global approach rather than an organizational solution” (p 54). The motives behind substituting institutional care with community care have been a mix of idealism and pragmatism (Syterna & Oldehinkel, 1996).

The rationale for deinstitutionalisation contains at least three basic assumptions (Bachrach, 1996, Lamb & Bachrach, 2001): community-based care would be more humane than hospital-based care, community-based care would be more therapeutic than hospital-based care and community-based care would be more cost-effective than hospital-based care. However, these assumptions have not been tested empirically (Lamb & Bachrach, 2001). Community-based care may indeed be more humane and therapeutic than hospital care, but only if adequate resources are provided (Geller, 2000).

Consequences of deinstitutionalisation

Research about the mortality of severely mentally ill persons thoroughly shows a higher risk for the group compared to the rest of the population. For persons suffering from schizophrenia, higher mortality rates have regularly been found both among deaths from unnatural causes, like suicide and accidents, as well as among deaths from natural (somatic) causes (Allebeck & Wistedt, 1986; Brown, 1997; Brown, Inskip & Barraclough, 2000; Simpson & Tsuang, 1996). Ösby,

Correia, Brandt, Ekblom & Sparén (2000a) summarised that a number of studies from different countries for a long time have found a doubled risk of mortality for persons given the diagnosis of schizophrenia compared to the general population, and this increase was still observed. Higher mortality rates for persons with other psychiatric diagnoses than schizophrenia have also been thoroughly reported (Baxter & Appleby, 1999; Hannerz, Borgå & Borritz, 2001; Harris & Barraclough, 1997; Harris & Barraclough, 1998; Joukamaa, Heliövaara, Knekt, Aromaa, Raitsalo & Lehtinen, 2001; Ösby, Brandt, Correia, Ekblom & Sparén, 2001).

There are ambiguous results reported concerning the connection between mortality and deinstitutionalisation. This ambiguity is valid both for natural and unnatural deaths.

Results indicating that increased mortality among severely mentally ill persons could be ascribed to deinstitutionalisation have been reported (Belfrage, 1994; Hansen, Jacobsen & Arnesen, 2001; Mortensen & Juel, 1990; Ösby, Correia, Brandt et al, 2000b) This result was not found by Brown, Inskip & Barraclough (2000), Harris & Barraclough (1998), Leff, Trieman, Knapp & Hallam (2000), Salokangas, Honkonen, Stengård & Koivisto (2001) and Sohlman & Lehtinen (1999).

Bülow (2004) concluded that there is no evident support in the literature concerning increasing death rates following deinstitutionalisation.

An increase in criminal behaviour has been reported as a consequence of deinstitutionalisation (Belfrage, 1994; Kramp & Gabrielsen, 2003; Lamb & Bachrach, 2001).

It is well known that persons suffering from mental disorders are overrepresented in the statistics of violent crimes (Brennan, Mednick & Hodgins, 2000; Hiday, Swanson, Swartz, Borum & Wagner, 2001; Tiihonen, Isohanni, Rasanen, Koironen & Moring, 1997; Wallace, Mullen, Burgess, Palmer, Ruschena & Browne, 1998; Walsh, Buchanan, & Fahy, 2002). However, when controlling for abuse problems and other social factors this overrepresentation becomes small or non-existent (Hiday, 1997; Steadman, Mulvey, Mohanan, Robbins, Appelbaum et al, 1998; Wessley, 1998). Addictive problems are most closely related to violent behaviour (Hiday et al., 2001, Steadman et al., 1998). It is not unambiguously shown that serious violent crimes caused by severely mentally ill persons have increased after deinstitutionalisation began (Angermayer, 2000; Kullgren, 2003; Mullen, Burgess, Wallace, Palmer & Ruschena, 2000; Taylor & Gunn, 1999).

Furtermore, it has been intensely debated whether many of today's prison inmates belong to the group that previously have been confined in mental

institutions. Studies in this area have yielded ambiguous results (Goodwin, 1997; Lamb & Weinberger, 1998; Thornicroft & Goldberg, 2000).

Other negative consequences of the deinstitutionalisation have been reported. Corollaries include homelessness (Brown, 1988; Goodwin, 1997; Salize, Horst, Dillman-Lange, Killman, Stern et al., 2001) and drug abuse (National Board of Health and Welfare, 1999; Ridgely & Johnson, 2001).

Another reported problem is transinstitutionalisation i.e. patients discharged from hospitals turn up in other institutional arrangements like nursing-homes (Goodwin, 1997; Markström, 2003). The director-general of the Swedish National Board of Health and Welfare has sharply criticised the development of transinstitutionalisation as a consequence of the mental health care reform in Sweden (Wigzell, 2001).

Lamb and Bachrach (2001) try to sum up the experiences of three decades of deinstitutionalisation: “Where community services have been available and comprehensive, most people with severe illness have significantly benefited. On the other hand, there have been unintended consequences of deinstitutionalisation- a new generation of uninstitutionalised persons who have severe mental illness, who are homeless, or who have been criminalised and who present significant challenges to the service system.” (p 1039).

Evaluation of mental health care reforms

The process of deinstitutionalisation and the creation of community care have been going on for a long time in Great Britain, the U.S. and Italy.

However, the process of closing the mental hospitals has been moving at a slow pace for a long time in Great Britain. The closing of mental hospitals started in England in the 1980s and the pace of the closing has been even slower in other parts, particularly in Scotland where the process has taken place spontaneously rather than as a result of political decisions (Pullen, 1993). During the 1990s the closing process of the mental hospitals has accelerated. Of 130 hospitals in England and Wales in 1975 only fourteen remained in 2001 and all fourteen had less than 200 beds (Leff, 2001). The major impact of the implementation of the reform is a relatively recent experience (Jones, 2000) and there is as yet little evidence available regarding the long-term outcome for people with severe mentally illness who have been provided care primarily in the community (Reid, Johnson, Bebbington, Kuipers, Scott & Thornicroft, 2001). In the late 1990s there was an intense debate in media about the supposed failure of community care in connection with violent crimes (Thornicroft & Goldberg, 1999; Moon,

2000; Wolff, 2002). In a twelve-year follow up study in London, Reid et al. (2001) found that there was little evidence of significant improvement or deterioration in either social or clinical functioning. However, improvement of social skills was evident. Similar results were reported in studies of 13 years of research, 1985-1998 in the TAPS project (The Team for the Assessment of Psychiatric Services) established with the purpose of evaluating the national policy of replacing psychiatric hospitals with community based services. Psychiatric symptoms and social behaviour problems remained unchanged overall but the quality of life was greatly improved (Leff et al. 2000). Thornicroft & Goldberg (1999) summarised the arguments for and against community care in England: "The case against community care is that across the country wards are overcrowded and 30% of the acute beds are blocked by patients who do not need to be there.... Homicides by those suffering from severe mental illness attract much media attention, with increasing pressure on Ministers to take action. A substantial proportion of the homeless and prisoners are mentally ill.

The case for community care is that it is preferred by service users, and is associated with better social adjustment and fewer chronic symptoms. For those discharged from the old mental hospitals the benefits far outweigh the disadvantages. Care of severely disabled patients in houses in the community is successful, and the results of "home based" rehabilitation are encouraging. Research shows that community care does not increase the burden of carers, and while the overall rate of homicides is rising, those committed by the mentally ill are fairly stable in recent years." (abstract, p 2).

Leff (2001) makes similar comments while trying to explain why many believe that community care has failed despite substantial evidence of success.

In the U.S. the mental health system underwent a substantial change in the 1960s (Grob, 1994). The claim that community care was superior to confinement in mental hospital became an article of faith that shaped the political agenda (Grob, 1994). After the Mental Health Service Act in 1965 there were 700 Community Mental Health centres in 1980 but the ultimate goal was 2000. Their role was declining under the Reagan administration, when the health system was decentralised and there were great cuts in federal taxes (Brown & Cooksey, 1989; Goodwin, 1997). However, there was a rapid expansion of different kinds of residential accommodations, including half way houses and the development of short-term general hospitals and nursing homes of varying quality (Scull, 1985). The combination of a decentralised psychiatric system and the emergence of a new young chronic population, difficult to treat under any circumstances, got consequences (Grob, 1994). The image of deinstitutionalisation portrayed in the public media of violent severe mentally ill adults, using drugs, wandering the

streets and threatening residents, was true, but represented only a subgroup of a much larger severely mentally ill population. Often overlooked were innovative programs for the severely mentally ill, enabled for many to live in the community (Grob, 1994). Also unforeseen developments like the expansion of federal disability and entitlement programs made this possible (Grob, 1994).

It is difficult to get a complete picture of the development of the living conditions of the severely mentally ill persons in the U.S. after the act in 1965. The care system is decentralised, most care facilities are privately owned with little control from federal authorities (Bülow, 2004; Harrington & Pollock, 1998). Of a calculated number of 2.8 million persons considered to be severely mentally ill in 1993, 3 % stayed in mental hospitals. Where the remaining 97 % lived and under what circumstances was not known (Bachrach, 1997).

In 2002 president Bush identified three obstacles preventing Americans with mental illness from getting “the excellent care they deserve” (DHHS Publication, 2003) namely: the stigma that surrounds mental illness, unfair treatment limitations and financial requirements and the fragmented mental health service delivery system. A commission delivered a final report in July, 2003 (DHHS Publication, 2003) with far reaching consequences. The reform prizes recovery instead of simply managing daily symptoms. The commission did not make recommendations on how the states should pay for the reforming of the system. The report came on the heels of a number of high profile criminal cases involving mentally ill persons (Gambrell, 2003).

In Italy the implementation of Law 180 has been geographically uneven. There have been regional differences both as far as the closing of mental hospitals and the establishment of community-based care (Burti & Benson, 1996; Jones, 2000). Twenty years after the reform in Italy, Burti (2001) concluded that the implementation of the reform had been accomplished. The year of 1998 marked the very end of the state mental hospital system in Italy. Instead there is a comprehensive network of in- and out-patient, residential and semi-residential facilities (Burti, 2001). There was still a lack of data on the national level documenting the social and clinical outcome. Barbato (1998) and Girolamo & Cozza (2000), concluded that additional information is needed to understand to which extent the more favourable outcome, shown by the few outcome studies carried out so far, can be attributed to more effective forms of treatment, and to which extent to the elimination of an iatrogenic environment in the mental hospital, or to non-clinical factors, like changes in the socio-economic environment, or increased family support.

The background of the mental health care reform in Sweden

The process of deinstitutionalisation in Sweden is similar to that of most countries in Western Europe. In the late sixties and early seventies there were about 35,000 psychiatric beds. By 1991 the number had dropped to 13,000. By the time of the mental health care reform in 1995 the number was about 8,000 and in the 2001 there were 5,500 psychiatric beds (.6 per 1,000 inhabitants).

Sectorised psychiatric care, with one psychiatric organisation responsible for all adults within a limited catchment area, was reinforced by policy documents from the National Board of Health and Welfare (1980, 1982). In 1985, 135 clinics had been established following the principles of sectorisation according to the National Board of Health and Welfare (Stefansson & Hansson, 2001). The differences between regions were important (Sandlund, 1998). Sectorisation is not a clear-cut concept and it has been blurred with deinstitutionalisation and the concept does not imply any specific structure or content of the services (Hansson, 2001).

Evaluation showed that the sectorisation did not fulfil the needs of social support of the long-term mentally ill persons e. g., those with a diagnosis of schizophrenia (Silverhielm & Kamis-Gould, 2000; Stefansson, Cullberg, Steinholtz Ekecrantz, 1990; Stefansson & Hansson 2001).

The Social Service Act of 1982, implied that municipal social services should be given an increased responsibility in meeting the needs of acceptable housing and meaningful employment of the long-term mentally ill. However, still in the late 1980s the limits of responsibility for mental health care and social services were not obvious, and in 1993 a parliament commission (SOU 1992:73) concluded that the efforts of social services were still largely inadequate. A mental health care reform (The Psychiatric Care Reform) was therefore implemented in 1995. The reform was geared toward individuals suffering from chronic mental illness and its objective was to improve their situations and circumstances in society and quality of life (Swedish government bill, 1993/94).

The reform sought to define the division of responsibilities between social services and mental health care. The role of social services was to make life outside institutions possible for the severely mentally ill, while psychiatric care organisations were to adapt and develop their efforts into adequate treatment methods.

The objective of the reform was to promote social integration and to offer the best life possible for the mentally ill person, and to close the gap in equality separating the severely mentally ill from the rest of the population (National Board of Health and Welfare, 1999).

The target group of the reform was persons with a long lasting mental illness that causes a disability to the degree that it influences daily life. Surveys were made across the country to identify the size and needs of the group. The size of the target group was found to be about 43,000 persons (app .6 % of the adult population, Stefansson & Hansson, 2001).

Evaluation of the Swedish mental health care reform

In the evaluation of the reform, the National Board of Health and Welfare (1999) declared that the size and the needs of the target group of the reform were rather well known. The reform was in progress, but much remained to be done. The reform had contributed to a better life for many. Especially younger persons with severe mental illness who had moved from institutions had got a better standard of living. There were still evident shortcomings concerning daytime activities, of mobile care teams and of social service field teams (National Board of Health and Welfare, 2003a). If anything, the possibilities of rehabilitation in order to join the workforce have decreased, since the implementation of the reform. The social services had difficulties in creating forms of accommodations appropriate for the individual and therefore many persons had to live in institution-like homes far away from their own home town. These problems were greatest in the largest cities (National Board of Health and Welfare, 2003a) and are examples of a process of transinstitutionalisation (National Board of Health and Welfare 2003a; Wigsell, 2000).

In the context of a debate in media in 2003 about the failure of the reform, the National Board of Health and Welfare (2003a) stated that there was need for more resources for acute psychiatry including more psychiatric beds. The number of days of psychiatric hospital care have been reduced from 6 millions in 1987 to about 1.5 million in 2000 (National Board of Health and Welfare, 2003a). During the same period, the number of occasions of care had only been reduced by about 20 percent. The reduction of the days of care is primarily dependent on the reduction of the lengths of the periods of care.

About 10,000 persons from the target group of the reform were staying in different care facilities with 24-hour staffing (hospital care, group homes, nursing homes etc.) in 2001. This total number seemed to be rather unchanged since 1997 but the number of persons in hospital care was reduced (National Board of Health and Welfare, 2003b).

There are no national registers concerning out-patient care, but during one year about three percent of the adult population was in contact with open psychiatric care and there seemed to be an increasing demand for care (National Board of Health and Welfare, 2003a).

The National Board of Health and Welfare (2003a) stated that there still were difficulties in the co-operation between mental health care and social services, especially concerning persons with both severe psychiatric problems and abuse problems. Special efforts should be directed towards persons with the diagnosis of schizophrenia or personality disorders who are also abusing alcohol or narcotics. Methods to assess the risk of violent actions must be developed. According to the National Board of Health and Welfare (2003a) the implementation of the reform differed between parts of the country.

The National Board of Health and Welfare (2003a) made surveys of homeless persons in 1993 and 1999. The group consisted of about 9,000 persons on both occasions, but according to estimates by social service personnel the number of persons in need of psychiatric care had increased from 17 % to 34 %.

An interview study of 60 persons in 2002 (National Board of Health and Welfare, 2003b), seven years after the reform, confirms the development of the physical integration of the group in society. This is particularly true concerning younger persons. But the participation in societal roles was restricted concerning taking part in elections, recreational activities or being a member of an association. Social relations were most common with relatives, staff-members or other clients. About half of the group took part in some kind of daily activity (National Board of Health and Welfare, 2003b).

In an evaluation of the efforts for severely mentally ill persons provided by the municipalities, great shortcomings were found primarily concerning the process of planning of the implementation of the reform. The results had been too dependent on individual enthusiasts. The implementation had been most successful in mid-sized communities (National Board of Health and Welfare, 2003c; National Board of Health and Welfare, 2003d).

Using a method of decision-setting analysis (Larsson, 2000) the conditions of the mental health services in Sweden after the reform was analysed (Malm, Jacobsson & Larsson, 2003). One conclusion was that “in spite of more than a decade of political will and professional efforts to improve current mental health service, the present state of mental health care and social services in Sweden still does not meet evidence based standards...One major problem concerns the unclear distribution of hospital and community resources” (s 63).

The National Board of Health and Welfare also stressed the importance of systematic evaluation and use of evidence-based methods (National Board of Health and Welfare, 2003a).

The reform has put the living conditions of the severely mentally ill on the agenda (Stefansson & Hansson, 2001), but there are still barriers between psychiatric services and social services and it is still difficult for the target group to get support relying on the disability laws. The burden on the families of the severely mentally ill is unacceptably high (Östman 2000; Stefansson & Hansson, 2001).

Bülow, Svensson and Hansson (2002) found signs of a positive development for the group with fewer suicides and less criminality in a 15-year follow-up study during the process of deinstitutionalisation and the implementation of the reform. They suggested that the rather promising results were dependent on the fact that the investigation took place in a municipality with a decent mental health service.

In a dissertation, Magnusson (2003) investigated how the changes in the organisation of psychiatric care has influenced the daily work of the mental health care staff and defined methodological and ethical problems. The reform process created new working situations that the staff was not prepared for (Magnusson, 2003). New duties for the staff require new skills (Malm et al. 2003).

The process of planning and implementation of the reform was treated in a dissertation by Markström (2003). The results of the reform have been described in the media as a fiasco. Markström (2003) remarked that the deinstitutionalisation of the psychiatric care has been in progress since the seventies. The reform of 1995 has been only one late part in this process. It then seems strange that the reform should be evaluated so soon.

Among the difficulties were (Markström, 2003): The reform had no strict target group. The reform demanded great changes both in the health care system and the social welfare system, both systems with long traditions and much prejudice towards each other, and the reform was not strongly supported by the professionals. The reform was also implemented during a period of recession. Markström (2003) concluded that considering these and other difficulties it was rather surprising to find that the implementation of the reform had developed as far as it actually has.

In summarising the evaluation of the reform it seems relevant to conclude that the findings so far vary a lot depending on from what perspective the reform was evaluated. It is yet not possible to conclude if the reform has brought a better life for the target group.

The reform in the investigated area

In the municipality of Jönköping, Sweden, where these studies took place, there were 1,000 beds at the psychiatric hospital in the beginning of the 1970s versus 92 today (2004). The reduction of beds over the years could almost be illustrated with a straight line with a steep slope. The process of sectorisation started in 1980 and three different clinics with a main responsibility for the psychiatric care in a specific catchment area were established. The mental health reform in 1995 implied a reorganisation. The changes that were brought by the reform can be summarised as: a lowered capacity of in-patient treatment facilities (hospitals), new psychiatric field teams primarily directed towards patients with psychosis, new social service field teams also targeting this same group and providing them with home-care and assistance, close co-operation between these teams, the development of more group-homes, the development of day-centres and other facilities for daytime activities.

It appeared that most communities in Sweden at least had initiated changes in this direction.

The concepts of handicap, need and recovery

The concept of handicap

The ICIDH was published in 1980 by the World Health Organisation (WHO) to provide a vehicle of conceptualising the consequences of disease (WHO, 1980). These consequences were described at different levels of experience in terms of impairment, disabilities, and handicaps in a sequential manner. Impairment could give rise to disabilities, which in turn could give rise to the experience of handicap.

The ICIDH has been crucial in developing a frame of reference for the area of handicap, specifically in pointing to the necessity of differentiating between levels of analysis.

The ICIDH has been criticised, and one target of this critique has been the linear model it employs. The model suggests a linear relationship in describing disease and the consequences of disease, a relationship that in reality is much more complex. A lack of consideration for environmental factors, a lack of consideration for demographic differences, a large overlap of the dimensions of the model, and the stigmatising connotation of the concept of handicap are other areas of the ICIDH that have been criticised (Birkenbach, Somnath, Badley & Üstün, 1999; Chapireau & Colvez, 1998; Halbertsma, Heerkens, Hirs, de Kleijn-

de Vrankrijker, van Ravensburg & Napel, 2000; Simeonsson, Lollar, Hollowell & Adams, 2000). The limited use of social and psychological factors in the model is also a weakness (Grunewald, 1999; Sandlund, 1997; Sartorius, 2001). A handicap can also sometimes arise when no impairment can be identified. Panic disorder is an example (Hjelmquist, 2000). In other cases, changes in cognitive capacity can be registered before the onset of the disease (Neuchterlein, Dawson, Gitlin, Ventura, Goldstein et al, 1992; Wiersma, 1986).

A revision of the ICDH has been in progress since 1993 and it has been replaced by the International Classification of Functioning, Disabilities and Health (ICF, World Health Organisation, 2001b). The domains of the ICF can be seen as health domains and health-related domains. These domains are described from the perspective of the body, the individual and society in two basic lists: 1. Body functions and structures and 2. Activities and participation (Grimby & Smedby, 2001).

Functioning is an umbrella-term that covers body function and activity as well as participation. Another inclusive term is disability which denotes impairment, activity limitation and participation restrictions. The ICF also lists environmental factors that interact with all these constructs.

Activity can refer either to the individual's capacity to carry out a task or to that individual's actual performance of the task.

Participation is defined as involvement in life situations and participation restrictions as problems an individual may experience while involved in life situations. Consequently both activity and participation should be described both in terms of actual performance as well as capacity.

One objective of the ICF is to provide a scientific basis for understanding and studying health and health-related states, outcomes and determining factors (World Health Organisation, 2001b). However, it is not obvious that the ICF gives a better scientific ground to understand and study health related problems than the ICDH. The model of the ICF is very complex, but still lacks a classification of personality factors, which makes the model less interesting from the point of view of psychology and psychiatry.

The concept of need

In the psychology of motivation the concept of need is used as a basis for understanding action. Maslow's hierarchy of needs is well known (Maslow, 1968). Basic needs are of two kinds. One kind of needs is caused by deficits or lacks in the human organism. Those needs are physiologically determined and

shared by all people. The other kind of needs is learnt. Action could be explained by the individual's efforts to satisfy unsatisfied needs. Maslow set up a hierarchy of five levels, reflecting, in sequence, needs for physiological functioning, safety, belongingness and love, esteem needs and self-actualisation. The basic physiological needs must be satisfied before "higher" needs could be of interest. If the basic needs are not satisfied there is a great risk for a mental disorder. The Maslow hierarchy of needs is one of the most famous and well known concepts in psychology but seems to have little empirical support (Sopre, Milford & Rosenthal, 1995; Wahba & Bridwell, 1976).

McClelland's theory of needs (McClelland, 1987) and the ERG-theory (existence, relations and growth) of Alderfer (1972) can be seen as further development of Maslow's hierarchy of needs to explain human action. Other identifications of basic needs have been formulated by Nohria, Lawrence & Wilson (2001) and Thomson, Grace & Cohen (2001).

Franken (2001) referred to research showing that a person's explanatory style will modify the list of basic needs. Therefore, it seems appropriate to ask people what they want and how their needs could be met rather than relying on an unsupported theory (Franken, 2001). Israel (1999) similarly criticised the use of the concept of need in motivational psychology. It is a difference of vital importance between stating that *we have* needs and talking about needs *as if* we have them. Israel argues from a relationistic theory of human action that the concept of basic needs can not explain human behaviour and there is little empirical support for the existence of basic needs. A relationistic theory proceeds from what happens between persons and not from the intra-psychic level. It is better to ask what persons need in specific situations than using the concept of basic need, which often results in circular reasoning (Israel, 1999).

In psychiatry the concept of need often is used to inform service provision and plan individual care (Slade, 1994). In this respect, needs are ambiguous concepts for severely mentally ill persons, and there are several approaches to definitions and measurement (Slade, 1994; Hansson, Björkman & Svensson, 1995). Needs (what people benefit from) must be separated from demand (what people ask for) and from supply (what is provided) (Thornicroft, Phelan & Strathdee, 1996). There are similarities between the concepts of the ICIDH and the ICF and one concept of need used in psychiatry (Wiersma, 1986). In terms of mental health services, unsatisfied needs could represent an insufficient supply of particular treatment interventions and interventions from social services. A disability becomes the non-ability to fulfil a need, thus leaving this need unmet (Wiersma, 1986). Needs in this respect are based on cultural and ethical determinants and on the current research agenda (Thornicroft, Phelan and Strathdee, 1996). Relating to the criticism of Israel (1999) this concept of need is based on the

question “what do severely mentally ill persons need?” rather than “which are the physiological and learnt needs of severely mentally ill persons?”

This is illustrated by the Camberwell Assessment of Need (CAN) (Phelan, Slade, Thornicroft, Dunn, Holloway et al, 1995). The needs listed in the CAN reflects a wide range of human needs such as shelter and company as well as needs specific to severely mentally ill persons. The areas of the needs were chosen after reviewing comments by experts and users. The CAN is based on a model of need as a subjective concept (Phelan et al, 1995). Staff and severely mentally ill persons themselves rate needs in 22 different areas, most of them closely related to the domains of disability and handicap according to the ICIDH and to the domains of activity and participation according to the ICF. If a particular need is met (CAN-concept) then the gap between actual performance and capacity for the related activity/life situation is small (ICF-concept). If the need is unmet the gap is larger.

There seems to be an association between high number of unmet needs and low subjective quality of life (Slade, Leese, Ruggeri, Kuipers, Tansella & Thornicroft, 2004).

The mental health care reform in Sweden and the concept of handicap

The mental health care reform calls attention to the suitability of using the concept of handicap to describe the lives of severely long-term mentally ill persons. Even though it has long been recognised that psychiatric illnesses bring about enduring disabilities, the concept of handicap is not a traditional one in psychiatric terminology. When long-term mentally ill patients were living in institutions, the concept of handicap was not relevant (National Board on Health and Welfare, 1999). There has also been reluctance to the concept because of its supposed negative connotations. The concept of handicap has furthermore been associated with low ratios of successful treatment and recovery (National Board on Health and Welfare, 1999).

The introduction of the concept of handicap denotes a demand for organisational and legal changes adapted to the situation and needs of the handicapped person, as well as a change in the content of psychiatric care and services. This concept reflects a shift in perspective, with the intention of securing a stronger position in society for mentally disabled people.

Handicap is suggested to be an ideal concept in describing the problems brought about by life outside the institutions (National Board of Health and Welfare, 1999):

“A mental disability arises as a consequence of an illness and constricts important life spheres. The handicap is a function of both the disability itself and outside factors. Inadequate support from people and organisations surrounding the ill person contribute to her or his handicap. Thus, a handicap can be ameliorated or even cease to exist, but may also be exacerbated depending upon the support one receives or how the people in one’s life act. Social, psychiatric and medical assistance must be seen as equally necessary components and interacting therapeutic agents. They are elements that make it possible for the mentally ill individuals to return to a life that is as normal as possible.” (p 281). The view of severe mental illness as a handicap developed in preparation for the reform emphasised the poor living-conditions of the severely mentally ill. To a great extent, these conditions were caused by prejudices and by the limited capacity of society to adapt its efforts to the actual needs of the group (Markström, 2003; Sandlund, 1997). The concept of handicap described in the reform is based on the concept in the ICIDH (World Health Organisation, 1980). Impairment and disabilities may disadvantage the individual by limiting or preventing the fulfilment of important survival roles. When this happens, the social disadvantages constitute a handicap (Birkenbach, Chatterij, Badley & Üstün, 1999). A severely mentally ill person could get rid of or at least significantly reduce the handicap with the help of proper efforts from society (Sandlund, 1997).

In 1996 and 1997, 85% of the municipalities in Sweden (corresponding to 93% of the population) were surveyed by social services together with psychiatric organisations in order to identify severely mentally ill persons living in society as well as their needs (Stefansson & Hansson, 2001).

The definition used in the surveys to identify “severely mentally ill persons “ i. e. the target group of the reform, was “persons with a mental illness that causes a disability to the degree that it influences daily life (social consequences), and where this handicap is estimated to be long-lasting” (National Board of Health and Welfare, 1998, p 34).

The target group of the reform is described as a group of persons with handicaps caused by mental illnesses and societal deficiencies (Markström, 2003).

The mental health care reform was implemented at the same time as a general handicap reform regarding certain legal rights for some groups of persons with handicap, the Law of Support and Service (LSS, Swedish government bill 1993:387). The possibilities for the severely mentally ill to benefit from these rights was unclear when the two reforms were implemented (Markström, 2003). The National Board of Health and Welfare concluded some years later that LSS

did not apply to the severely mentally ill (National Board of Health and Welfare, 1999).

Markström (2003) described the concept of handicap as the “stumbling block” for the implementation of the reform. The shift of perspective had not yet taken place. There were expectations of a new area of knowledge, new resources and a new language. This change of perspective, from illness to disabilities and handicap, is the part of the reform that has been most difficult to carry out (Markström, 2003). The reason for this failure is a combination of factors such as vague and inconsistent ways of acting as formulated by the authorities and too few initiatives of developing knowledge of disabilities and handicaps related to psychiatric and psychological conditions. The institutionalised habit of describing psychiatric problems from a perspective of illness is hard to change. It is easier when developing competence to ask for existing knowledge instead of developing new areas of knowledge. There are also difficulties with different views among the mental health staff and the social services staff. The expert knowledge of the mental health staff is more attractive than the general knowledge of the social services handicap care staff (Markström 2003).

Recovery from severe mental illness

The mental health care reform emphasised the suitability of a perspective of handicap to describe the lives of the severely long-term mentally ill. With the right kind of help a person could get rid of the handicap but the impairment is conditioned by biological factors and is still existing (Grunewald, 1997). From this point of view the possibilities of recovery is limited. A handicap-view and a view of recovery in studying severe mental illness could be difficult to unite. This antagonism is illustrated by the final report of the Bush-commission (DHHS Publication, 2003) that prized recovery instead of simply managing daily symptoms.

But in the Swedish reform, it was stressed that the handicap perspective used in describing the target group should not be interpreted to mean neither that changes in the conditions of severely mentally ill persons are rare, nor that their disabilities are static (National Board on Health and Welfare, 1999).

Scientific interest in persons who recovered from severe mental illness has been limited over the last twenty years (Torgelsboen, 1999). However, in the research that has been presented, the importance of taking the recovered persons' own experiences into account has been increasingly stressed (Chadwick ,1997;

Corrigan, Giffort, Rashid, Leary & Oeke , 1999; Topor, 2001; Torgalboen, 2001).

Harding (1988) summarised five large longitudinal studies of recovery of persons with a diagnosis of schizophrenia. Between half and two thirds of the groups investigated were found to have made a total or at least a considerable recovery.

Shephard, Watt, Fallon & Smeeton (1989) observed clinical improvement in about half of the persons after five years, with better results for women than for men. A meta analysis (Warner, 1985) of 87 studies between 1919 and 1979, shows how the number of persons who made a total or considerable recovery varies over time. The number of recovered persons was higher during periods with a positive economical climate in society and during periods of optimism in treatment (Topor, 2001). On average, the proportion of socially recovered persons was between thirty and forty percent and the proportion of totally recovered between ten and twenty percent.

Yet another meta analysis (Hegarty, Baldessarini, Tohen, Waternaux & Oepen, 1994) shows similar percentages. In this study the number of recovered was connected to the criteria of diagnoses applied during different periods of time. The stricter the criteria, the fewer the number of recovered persons.

Harrison, Hopper, Craig, Laska, Siegel et al. (2001) reported a WHO-study with 1600 patients from nine countries. Follow-up studies were made after two, five, fifteen and twenty-five years. About half of the survivors were improved after twenty-five years but the numbers varied between different countries. Between fifteen and twenty per cent were recovered to the extent that they did not need any treatment. The most important predictor was the amount of symptoms during the first two years of the illness; the less time with psychotic symptoms the better the prognosis.

In an interview-study, Torgalsboen (1999) compared seventeen persons who were fully recovered from schizophrenia to thirty-three persons with persistent symptoms. Torgalsboen had the following hypothesis for differences between the groups which also could be seen as a summary of research on factors predicting good recovery: a good pre-morbid adjustment, no presence of auditory hallucinations or illusions, precipitating events at onset and female sex were all factors that suggested a good possibility for recovery. Women had a better pre-morbid functioning than men and thus a more favourable prognosis. According to the results early positive symptoms predicted poor chances of recovery. Poor pre-morbid function did not significantly predict a poor outcome but the results were in the expected direction. Women reported better pre-morbid functioning and a more favourable psychosocial functioning than did men (Torgalsboen, 1999).

Sullivan (1994) interviewed forty-six formerly severely mentally ill persons about activities, attitudes and behaviour among themselves or among other persons important to their process of recovery. Factors associated with a successful recovery were medication (71 %), support from society (67 %), own willpower (63 %), work and school (46 %), spiritual dimension (43 %), knowledge about the illness (35 %), support from user-organisations and friends (33 %), important relatives (30 %).

Torgalsboen & Rund (1998) conducted a study based on an earlier study of eighteen totally recovered persons (Rund, 1990). Factors like willpower and a supportive family were discussed as positive contributors in the process of recovery.

Denhov (2000) studied the importance of the health care staff in the process of recovery. Time and relations were the important concepts. Staff-members who appeared to be important had stood by the patient in different phases of the illness. Dehov (2000) stressed the fact that the patient him/herself was an engine in his/her own process of recovery.

Topor (2001) stressed the importance of the patient's own efforts in the recovery process.

Holzinger, Müller, Priebe & Angermeyer (2002) interviewed thirty-one persons with a diagnosis of schizophrenia and their relatives concerning their view of the possibility of recovery with the conclusion that their views were rather realistic. They did not see themselves as victims but thought there was a possibility to influence the development of the illness through treatment and own efforts.

It is problematic to compare the results from different recovery studies. The criteria of inclusion differ. Persons who are considered to be severely mentally ill could have different diagnoses though the diagnosis of schizophrenia is most common. It seems that there are no fundamental differences as far as the process of recovery between groups with different diagnoses (Topor, 2001; Young & Ensing, 1999). But even in a group of persons diagnosed with schizophrenia it is not certain that the diagnoses are comparable. Earlier, it was easier to get a diagnosis of schizophrenia in the U.S. than in Europe, with the consequence that the recovery rates were higher in the U.S. (Hegarty et al, 1994; Warner, 1985). During the last twenty years the criteria of diagnoses have become stricter, but still differ from country to country and from doctor to doctor (Warner, 1985).

Other difficulties in comparing studies involve different operationalisations of the concept of recovery and the length of the follow-up period. However, the results for some patients unanimously show that recovery can be rather complete. The probability of this recovery was more difficult to estimate.

Summary of the Studies

Aims

In order to improve care and quality of life for severely mentally ill persons a mental health care reform went into effect in Sweden in 1995.

The overall aim of this thesis was to follow-up a sample of severely mentally ill persons after the reform and to analyse and discuss if the changes observed could be expected given the aim of the reform.

The aim of Study I was to describe the development after the reform of met and unmet needs in important psychological and social domains, and of activity and participation in a sample of severely mentally ill persons.

The aim of Study II was to investigate changes in the population of severely mentally ill five years after the reform as well as changes in the way the staff of mental health organisations and social services apply the concept “severely mentally ill”.

The aim of Study III was to follow-up a group of persons who was considered to be severely mentally ill at the time of the reform but not so five years later, and generate knowledge about the number of persons recovered and the process of recovery.

The aim of Study IV was to describe the changes of the quantity of psychiatric care during the implementation period of the reform.

The changes are discussed in view of the aim of the reform and concerning the local changes in the mental health organisation brought about by the reform.

Methods

Surveys and interviews

During the Swedish mental health care reform in 1995, surveys were performed in order to estimate the number of severely mentally ill persons and their needs. 85 per cent of the municipalities in Sweden (corresponding to 93 per cent of the population) were surveyed (Stefansson & Hansson, 2001). The definition of “severely mentally ill” used by the National Board of Health and Welfare (1998)

was a person with a mental illness that causes a disability to the degree that it influences daily life. Only persons over 18 years old were included. The handicap should remain during at least six months. Persons with mental retardation and age dementia were excluded.

The municipality of Jönköping has approximately 120,000 inhabitants. In 1995/96 the Department of Psychiatry at the County hospital of Ryhov and the Department of Social Services co-operated in a survey with the purpose of identifying and listing severely mentally ill persons in the municipality using the National Board of Health and Welfare (1998) definition. The staff of the mental health care services and the social services went through their lists of clients and identified the severely mentally ill according to this definition. The staff consisted of doctors, psychologists, social workers, psychiatric nurses and occupational therapists. Two persons co-ordinated the reports and made the final list of the persons defined as severely mentally ill. Staff at the social insurance offices and interest groups, were also involved and were given the opportunity to add names of persons unknown to mental health care and social services. In this way, 602 severely mentally ill persons were identified and listed.

A new survey using the same method and definition of severely mentally ill was conducted in 2000/2001. This time 828 persons were identified and listed.

After both surveys the identified persons were interviewed.

The same interview procedure was used in the two surveys. One staff member from social services and one from psychiatric care together conducted the interview with the participant.

The interviews consisted of one questionnaire, designed by the National Board of Health and Welfare for use in surveys related to the mental health care reform. It included items on age and gender, housing, employment and income, activities and social relations, addictive problems, needs of support from the community in different areas, ratings of needs of care and needs of activities and housing, satisfaction with the amount of care provided, psychiatric diagnosis (ICD 10, World Health Organisation, 1996) and the Global Assessment of Functioning Scale, GAF (American Psychiatric Association, 1994). The GAF is a measure of symptom severity and social disability. It is widely used throughout the world as it is considered to be a fast and accurate measure of overall psychosocial functioning. Score range from 1 to 100 where a higher value indicates better functioning. The reliability and validity of the GAF has been assessed in a sample comparable to that of the present (Jones, Thornicroft, Coffey & Dunn ,1995). The GAF-rating was made by the interviewer(s) immediately subsequent to the interview.

For the purpose of this study, the psychiatric diagnosis were grouped into six groups according to ICD 10; F 10-19 (addictive disorders) ; F 20-29 (schizophrenia or similar diagnosis); F 30-39 (mood disorders); F 40-48 (neurotic, stress-related or somatoform disorders); F 60-69 (disorders of personality and behaviour) and one group for remaining psychiatric diagnoses. When referring to persons with a diagnosis of schizophrenia in this study, the whole group, F 20-29, is included.

Pragmatic considerations steered the choice of questionnaire used in the studies. The questionnaire, designed by the National Board of Health and Welfare, was a standard instrument developed to facilitate data collections for assessing living conditions and needs of severely mentally ill in the nationwide surveys conducted during the implementation of the reform. However, since no data on the reliability or validity of this questionnaire were available, the validity of inferences drawn from the generated data may be questioned, especially regarding the assessments of needs. Therefore, the questionnaire was supplemented with the Camberwell Assessment of Need (CAN), the second major instrument in the study. The CAN is a widely used instrument intended to measure the needs of severely mentally ill persons and designed for use by psychiatric and social personnel after some practise (Phelan, Slade, Thornicroft, Dunn, Holloway et al.). The CAN assesses needs in 22 different areas: accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information about treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, child care, basic education, telephone, transport, economy and social benefits. Assessments of each of these areas include the views of both the client and the staff.

The interviewee's CAN ratings were obtained during the interview conducted by an employee from social services together with an employee from psychiatric care. The participant indicated his/her ratings to the interviewers who then recorded the values. Following the interview, the interviewers jointly recorded their own CAN ratings. At least one of the interviewers was trained in the CAN and had had prior experience using the instrument.

Summary scores of the total number of needs, met needs and unmet needs were computed (Appendix).

Test-retest and inter-rater reliability of assessment of needs made by staff and patient was investigated by (Phelan et al., 1995). Test-retest and inter-rater reliability of the patients' assessment of needs were investigated in a five-nation European study (McCrone, Leese, Thornicroft, Schene, Knudsen et al, 2000). The inter-rater reliability of the Swedish version of the CAN has been

tested by Hansson, Björkman and Svensson (1995). They concluded that the CAN has good inter-rater reliability, even when used under routine conditions and without specially trained administrators.

Arvidsson (2003) assessed test-retest reliability of the Swedish version using the same method for obtaining ratings as was used in these studies and concluded that the summary scores generally are reliable over time using this method.

The overall primary purpose of the two surveys was to elicit information to assist the departments of social services and psychiatry in planning their future efforts for the severely mentally ill. Since the aims of the studies comprising this thesis were not central to the purpose of the surveys, we were able to exercise only limited influence in the choice of study methods and instruments in the first survey. In the second survey, we attempted to replicate procedures used in the first survey as closely as possible, especially regarding the identification and listing procedure, interview methods and instruments.

Samples of the studies

Table 1 Identified and listed number of severely mentally ill persons in the surveys

		Identified and listed in 1995/96		
		Yes	No	
Identified and listed in 2000/2001	Yes	378	450	828
	No	224		
		602		

Study I

The 378 persons identified in 1995/96 and again in 2000/2001 constituted the sample of Study I, i.e. a sample of persons identified twice. ¹⁾

Study II

All persons identified on the first occasion and the persons identified on the second occasion constituted the sample of Study II (the 602 persons identified in 1995/96 and the 828 persons identified in 2000/2001).

Study III

The 224 persons identified in 1995/96 but not in 2000/2001 constituted the sample of Study III.

Study IV

Study IV was a case register study of persons in contact with in-patient and/or out-patient care provided by the Department of Psychiatry at the county hospital of Ryhov during the period 1994 to 2003.

¹⁾ Because of a mistake when Study 1 was performed, the results of the study only included 377 persons.

Statistical levels of significance

In this summary of the studies the p-values for each testing procedure are generally not to be found in the text. If the text in the result-section speaks about changes or differences between groups the largest corresponding p-value is .05.

Design and specific methods of the four studies

Study I

Design

The results from the 1995/96 and 2000/2001 interviews with the persons identified on both occasions (the 378) were compared.

Statistical analyses

Paired t-test was used to analyse differences in CAN scores and GAF-scores. For dichotomous variables, the sign-test was used.

Study II

Design

a. In a cross-sectional study, the results of the interviews of the persons identified in 1995/96 (the 602) were compared to the results of the persons identified in 2000/2001 (the 828).

b. Considering the interviews conducted in 2000/2001: The results of the group of persons that also was identified in 1995/96 (the 378, “the old group”) were compared to the group of persons that were “new” in 2000/2001 (the 450).

Statistical analyses

Descriptive statistical methods were used in comparing the samples from the surveys in 1995/96 and in 2000/2001.

A group of 378 persons was identified as severely mentally ill in both surveys (Table 1). Since the samples from the two surveys were thus not independent, two independent sub-samples were created. The 378 persons who were identified in both surveys were randomised to just one sub-sample. Of the total 1995/96 sample, 224 persons were identified as severely mentally ill only in that survey (Table 1). Given the possibility that systematic differences existed between this group and the group that took part in both surveys, it was deemed important to maintain the original ratios of these two groups in the sub-sample. Consequently, the group of 224 persons who took part only in the 1995/96 survey was randomly halved to 112 persons. The same procedure was used for

the 2000/2001 sub-sample. Thus, 225 of the 450 persons who were identified in only the 2000/2001 survey were randomly selected.

The Student's t-test was used to analyse differences in CAN scores. A stepwise logistic regression analysis was used to identify differences between the 1995/96 and 2000/2001 sample.

Differences between the group of persons that was considered to be severely mentally ill in both 1995/96 and 2000/2001 (old group) with the group that was 'new' in 2000/2001 (new group) were tested using the Student's t-test for CAN scores and GAF-values. For dichotomous variables, the Fisher's exact probability test was used. The Mann-Whitney's U-test was used to test between-group differences for the variable social isolation.

A stepwise multiple logistic regression analysis was used to identify variables that discriminated the new group and the old group.

Study III

Design

The group of persons identified in 1995/96 but not so in 2000/2001 was investigated concerning their recovery. The recovered group was compared to a group who still was considered to be severely mentally ill. A subgroup of the recovered persons was interviewed.

Usage of registers

The number of visits to outpatient facilities, the number of occasions of inpatient care and days of inpatient care were calculated via the case-register used in the psychiatric clinic.

The national registration register was used to identify persons who no longer were in contact with psychiatric care in order to determine if they had moved from the area or if they were deceased.

Who was considered as recovered?

In the definition of the target group of the reform used in the surveys in 1995/96 and 2000/2001, "severely mentally ill persons" were defined as persons with mental illnesses that caused disabilities that had become handicaps. Persons who were identified as severely mentally ill in the survey in 1995/96 but not so in 2000/2001 were considered to have recovered from being severely mentally ill and estimated to have recovered in the sense that their illness no longer caused handicaps. One problem of definition was that some persons were not considered as severely mentally ill in 2000/2001 because their care had been transformed from psychiatric care to other organisations or authorities e.g. somatic care, dementia care, or care of

elderly persons. Their disabilities did not seem to have decreased; they had simply changed care provider. These problems were naturally more significant for the older part of the sample. For the elderly subjects it was also problematic to determine if their psychiatric problems actually were the main reason for their care.

Therefore, a somewhat arbitrary age-limit was imposed in the present study. Persons aged 65 or above at the time of the 2000/2001 survey, were excluded.

Persons in this study who were defined as recovered from being severely mentally ill were those who were surveyed in 1995/96 but not so in 2000/2001, had an age of 64 or below in 2000/2001. They were still living in the county in 2000/2001 and did not belong to the care of any other provider than psychiatry or primary care.

The persons recovered in this sense could still be in contact with psychiatric care.

The persons in this study defined as “still severely mentally ill” are those who were surveyed in *both* 1995/96 and in 2000/2001 and had an age of 64 or below in 2000/2001.

In trying to gain knowledge about the recovery process the intention was to interview persons who had recovered from being severely mentally ill and who had no contact with psychiatric care. However, it appeared that this sample was practically non-existent. Seven persons, recovered from severe mental illness, and with at most three contacts with psychiatric out-patient care during the last two years, were identified and interviewed.

Statistical analyses

In analysing the results of the interviews in 1995/96, t-tests were used to study differences in age, CAN and GAF value, between individuals who had recovered from severe mental illness and those who were still considered to be severely mentally ill in 2000/2001. When studying differences between those groups, when variables were discrete, the χ^2 -test was used.

A logistic regression analysis was also performed to find variables that discriminated between these two groups

Interviews with the recovered persons

The planning, performing and analysis of the interviews was based on methods described by Kvale (1996).

Seven interviews were conducted.

The aim of the interviews was to identify variables that were of importance in the process of recovery. The interview schedule was based on a study by

Topor (2001) and could be described as semi-structured. The following areas were investigated in depth concerning their contribution to recovery (Topor, 2001): own contribution, type of treatment, medication, hospital care, out-patient care, contacts with personnel in psychiatric and social services, family, friends and other people, contacts with user organisations or persons in private practise and the social situation.

The categorisation of sentences in the present study was based on the areas identified in the interviews as significant to the process of recovery.

The categories found were similar to the areas in the interview-schedule. Another category found in the analysis that seemed relevant was similar to the concept "locus of control" formulated by Rotter (1966).

Locus of control refers to the extent to which individuals believe they can control events affecting them. Individuals with high internal locus of control believe that events result primarily from their own behaviour and actions. Those with high external locus of control believe that powerful others, fate or chance primarily determine events. An assessment was made as to whether the interviewed persons had a mainly high external or high internal locus of control of their view of the reasons for their psychiatric disorders. Those with high external locus of control seemed to find the reasons for their illness mainly in circumstances beyond their control and those with high internal locus of control thought that they could influence their disorders.

Study IV

Design

Considering the department of psychiatry the changes in the total care and the care directed towards the inhabitants of the municipality of Jönköping was studied during 1994-2003.

During the same period the care provided by the department of psychiatry and the social services geared towards persons in the municipality of Jönköping with a diagnosis of schizophrenia was studied.

Usage of registers

Case registers were used to describe the changes in the psychiatric care concerning the number of patients, the number of occasions of hospital care, the number of days of hospital care and the number of visits to out-patient care facilities. Information about the number of severely mentally ill persons living in different kind of group homes and institutions and the number of persons in contact with social service field teams were collected from the registers of the social services.

Statistics

The data of Study IV concerned different measures of the consumption of psychiatric care in the municipality of Jönköping. Descriptive statistics were used.

Ethical considerations

Ethical risks exist in collecting data on severely mentally ill persons. The group is exposed to prejudices and therefore it is important that care is exercised in handling the data. At the same time, much still needs to be learnt in order to improve the conditions of this group.

In the first survey (1995/96), the identified persons were simply asked if they were willing to participate in an interview concerning the needs of the severely mentally ill persons, identified or unidentified. Naturally, they also had the option to decline.

In the second survey (2000/2001), obtaining consent for participation was more complicated. For example, even if a person was willing to participate in an interview concerning the needs of the severely mentally ill, this did not necessarily mean that he/she would also be willing to take part in a research project or that he/she would allow the comparison of the results from the interview in the first survey with the results from the interview in the second survey. Due to ethical considerations, permission had to be obtained for specific kinds of participation and consequently consent forms became a bit elaborate and complicated. From an ethical point of view, the advantage to this procedure was that the interviewee became very aware of what he/she consented to. However, it is possible that this procedure resulted in a larger refusal rates in the second survey.

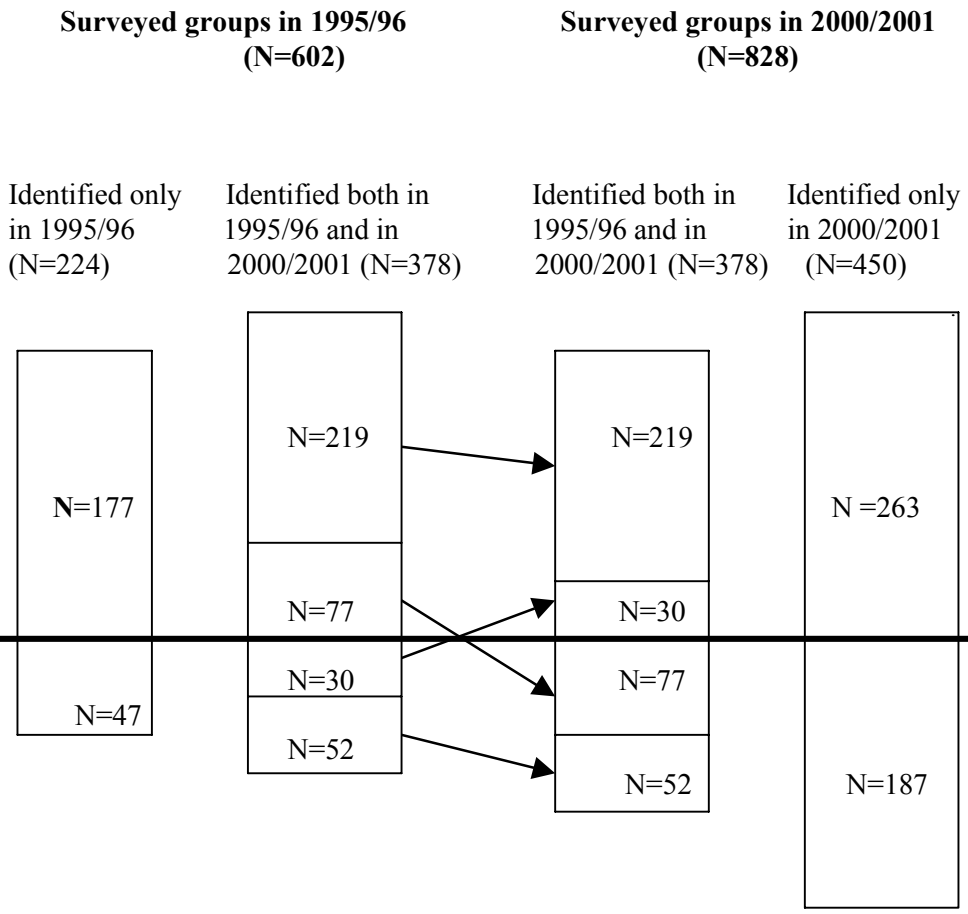
There were further ethical problems with the interviews of the supposedly recovered persons. These problems concerned both contacting persons who had no actual contact with care and the treatment of data. Only persons who participated identified in the first interview were available for a contact. The interviewed persons signed a separate admittance form.

The studies were reviewed and approved by the Research Ethical Committee, Linköping Health University on three separate occasions (Research Ethical Committee, Linköping Health University 00-175, supplements in 2002-03-25 and 2002-05-28).

Figure 1

Interviewed groups and attrition groups of persons identified in the surveys in 1995/96 and 2000/2001.

Interviewed groups are found above and attrition groups below the thick line.



Results

Samples and attrition of the 1995/96 and 2000/2001 interviews.

In the 1995/96 survey, 602 persons were estimated to be severely mentally ill (0.67 % of the population older than eighteen years of age).

In 2000/2001, a total of 828 persons were identified as severely mentally ill (0.90 percent of the adult population). Of these 828, 378 persons had also been identified in 1995/96 (Figure 1). Of these 378, 219 persons were interviewed on both occasions, 77 were interviewed on only the first occasion, 30 on only the second occasion, and 52 refused to be interviewed on both occasions (Figure 1).

The 77 participants who were identified on both occasions but did not participate in the 2000/2001 interviews were compared with the 219 persons who were interviewed on both occasions based on the results from the 1995/96 interviews. A multiple logistic regression analysis showed that more women (OR 1.92, 95% CI 1.05-3.45) and more participants with fewer met needs (staff-ratings, OR 1.20, 95% CI 1.05-1.37) belonged to the group that took part only in the 1995/96 interview.

No differences were found between the 30 persons who took part in the interview in 2000/2001 but not in the interview 1995/96 and the 219 persons who took part in both interviews.

No differences were found between the 52 persons who were identified on both occasions but did not take part in either interview and the 219 who took part in both regarding gender or age (the only possible comparisons).

Of the 602 persons identified in 1995/96, 224 persons were not identified in 2000/ 2001 (Table 1). Of these, 47 were not interviewed in 1995/96 (Figure 1). There were no significant differences between the group that participated in the interviews and the group that refused to participate regarding gender, but the attrition group was younger (mean age 50.0, SD 17.7 compared to 60.0, SD 16.0).

Of the 828 persons identified in 2000/2001, 450 persons were not identified in 1995/96 (Table 1). Of these, 263 persons were interviewed and 187 persons declined the offer to participate (Figure 1). There were no significant differences between the group that participated in the interviews and the group that refused to participate regarding age and gender (the only variables available for comparison).

Study I

Changes in needs between 1995/96 and 2000/2001

Generally the average number of met needs had increased and the number of unmet needs had decreased between 1995/96 and 2000/2001 concerning assessments made by staff as well as by clients.

The sum of unmet needs had decreased independently of gender and age concerning both assessments made by staff and by clients, but generally the clients assessed the decrease to be somewhat smaller than did the staff.

There were differences in the sum of met needs between men and women. Men had increased their met needs significantly. This was not the case for women. The group below 50 years of age increased the sum of met needs but there were no such result for those who were above 50. These results were valid for both men and women. The differences between men and women as far as met needs seemed to primarily depend on the differences in age between men and women in the sample.

In ratings for individual needs, there were significant drops in unmet needs in the following CAN domains:

Accommodation (patients and staff ratings), food (staff), looking after the home (patients and staff), self-care (staff), daytime activities (staff), psychotic symptoms (staff), psychological distress (patients and staff), company (patients), economy (staff). The number of unmet needs had not increased in any domain.

There were significant increases in met needs for:

Accommodation (patients and staff), food (patients and staff), looking after the home (patients and staff), physical health (patients and staff), psychological distress (patients), transportation (patients and staff), economy (patients and staff). The number of met needs had not decreased in any domain.

Accommodation, activities and social relations

In 2000/2001, the number of persons living on their own was equal to the number recorded in 1995/1996. A greater number received support from social services in their homes on the later occasion. Furthermore, in 2000/2001 a greater number of persons lived in group homes etc.

There were no significant changes in daily activities, area of work, income and support or social isolation between 2000/2001 and 1995/96.

The interview contained questions focusing on present assistance received and the need of assistance from psychiatry, primary health care, and social services. In 2000/2001 fewer persons indicated a need for more help from psychiatry and social services compared to 1995/96.

Study II

Comparison of the groups from 1995/96 and 2000/2001

The average age of the group was lower in 2000/2001. This was true for both women and men. In 2000/2001, 19 % were cohabiting with a partner (11 % in 1995/96), 11 % lived together with children below 18 years (5 % in 1995/96), 13 % had a mother tongue other than Swedish (8 % in 1995/96) and 47 % had diagnoses other than schizophrenia (54 % in 1995/96).

According to staff ratings, the clients had fewer needs in 2000/2001 than in 1995/96. These results primarily owe to a drop in the numbers of unmet needs. In contrast, client ratings showed no differences between the total number of needs between the two occasions, but there was a significant increase in met needs.

Comparisons between the old group and the new

The group of persons identified on both occasions is referred to as 'the old group' and the group of persons identified only in 2000/2001 is referred to as 'the new group'.

A higher percentage of subjects in the new group were in need of more assistance than presently received from social services, psychiatry, primary health care, employment services, social insurance offices and dental care compared to the old group.

The persons in the new group were less isolated and they had a higher mean GAF-value.

The new group had fewer total needs, fewer met needs and more unmet needs, both with respect to staff and client ratings.

A logistic regression analysis was performed to identify variables that discriminated the new group from the old one. Conditions that significantly differentiated the new group from the old group were female gender, younger age, cohabitation with a partner, non-native Swedish speaker, no

schizophrenic diagnosis, existence of abuse-related problems and a fewer met needs.

Study III

Quantitative analysis

Fourteen percent of the identified sample in 1995/96 below the age of 65 were considered recovered in 2000/2001 to the degree that their illness did not cause disabilities that constituted handicaps.

Group of diagnosis was the only significant variable in a logistic regression. Those not given the diagnosis of schizophrenia were more likely to be considered recovered than persons with the diagnosis of schizophrenia.

Qualitative analysis

Seven persons, five female and two male, were interviewed. None had been treated in in-patient care for the last four years. Six persons still had little but regular contact with open psychiatric care or primary care for their psychiatric problems and medicated. The number of contacts with care was lower than twice a year.

All seven persons described a huge difference in their psychiatric health status and quality of life at the time of the interview in 2002 compared to the time of the 1995/96 survey. However, only one person described herself as totally recovered. She had no contact with psychiatric care and described her psychiatric problems as a part of her history.

Support from others, medication and care were important factors in the recovery process. However, the contribution to the process of these factors was complex and sometimes contradictory.

All seven persons described own contributions to their process of recovery. However, the nature of these activities differed a lot depending on whether they had a mainly high internal or high external locus of control (Rotter, 1966) of their view on the reasons for their psychiatric disorders.

Three persons were estimated to have mainly an external locus of control. These three persons seemed to have chosen a strategy of recovery in which they have adjusted their expectations of life to their problems and tried to avoid situations provoking agony.

These persons had a close relation to a person of the opposite gender, but seemed to live rather isolated with few friends and social activities. None of them was employed.

Three other persons had a mainly internal locus of control of their view on the reasons for their psychiatric disorders. Their strategy was more of a fight against the restrictions of life caused by their illness and they described closer contacts both to friends and to society compared to persons with a more external locus of control.

As for the seventh person, the only one who was estimated to be completely recovered, there seemed to be a balance between internal and external locus of control.

Study IV

The total care provided by the psychiatric clinic in Jönköping

Between 1994 and 1998/1999 the number of days of care was reduced by about 40 percent. The number of visits to outpatient care facilities increased by about 10 percent. Between 1999 and 2003 there were only small variations in the total number of days of inpatient care and visits to outpatient facilities.

The number of unique persons in inpatient care during each year and the number of care episodes were rather constant during the investigated period of time.

Psychiatric care provided for the inhabitants of the municipality of Jönköping

The total sum of unique persons in contact with in-patient and/or out-patient facilities in the Department of Psychiatry in the year of 1996 was 3,850 (.043 of the population with an age of 18 years or older). The corresponding sum in the year of 2003 was 4,444 persons (.048).

The number of days of inpatient care for persons with a diagnosis of schizophrenia had decreased by about 74 percent from 1994 to 2003. During the same period of time, the number of days of care for persons with other diagnoses had decreased by 26 percent.

The number of visits to out-patient care facilities provided by the clinic had somewhat increased for persons with the diagnosis of schizophrenia and somewhat decreased for persons with other diagnoses.

Summarising different care facilities provided by the department of psychiatry and social services with 24-hour staffing, the number of persons with the diagnosis of schizophrenia, staying in those facilities, was rather unchanged during the time period 1994 and 2003.

The change to new social service field teams targeting persons with severe mental illness and providing them with home-care and assistance, started in 1996. In 2001 these teams helped 180 persons and in 2003 they helped 200 persons.

Discussion

General conclusions

In order to improve care and quality of life for severely mentally ill persons a mental health care reform was implemented in Sweden in 1995.

The overall aim of this thesis was to follow-up a sample of severely mentally ill persons after the reform and to analyse and discuss if the changes observed could be expected given the aim of the reform.

Interviews were performed with samples of severely mentally ill persons in 1995/96 and in 2000/2001 and a study concerning the use of psychiatric care in the years 1994-2003 using case registers was performed.

In general, the findings of Study I conformed to the expectations in view of the aims of the reform. The total sum of unmet needs and unmet needs in important need-domains had decreased on the occasion of the second interview.

The decrease in the number of unmet needs could be interpreted as a decrease in the development of handicap (ICIDH) or as a decrease in activity limitations and participation restrictions (ICF). The number of met needs had increased.

The degree of effort by psychiatric care and social services seemed to have increased considering the target group of the reform. A greater number of persons received assistance in their home in 2000/2001 and more persons lived in group homes and similar alternative housing. There was a decrease in the number of persons who indicated a need for a better housing/ accommodation situation or more help from services. This was true for both psychiatric health care and social services.

Data from a register study (Study IV) supported claims that the intended changes of the reform had in fact taken place. The number of days of in-patient care for persons given a diagnosis of schizophrenia had been drastically reduced, but this reduction was quantitatively compensated by an increased staying in different kind of group homes with 24-hour staffing. The number of persons staying in nursing homes had also decreased. There was no sign of a transinstitutionalisation in the investigated area. The work of new psychiatric field teams primarily directed toward patients with psychosis, new social service field teams also targeting this same group and providing them with domestic care and assistance seemed to have been implemented.

Only five persons of the target group of the reform in the investigated area in 1995 were still living in the area without contacts with care-providers because of

their psychiatric problems five years later (Study III). The severely mentally ill did not seem to have been abandoned.

The target group

During the implementation process of the reform the target group was broadened (Markström, 2003). In the beginning the actual target group of the reform was persons with schizophrenia (National Board of Health and Welfare, 1996). When the surveys were made to gain knowledge of the needs of the target group, the definition of the group was based on a view of handicap and not on diagnoses (National Board of Health and Welfare, 1998). The size of the group was then about doubled.

The results of Study II show that the interpretation of the definition of the target group of the reform is not very stable. Many more persons were included in the group in 2000/2001 and it seemed like the group had broadened. The changes in the number of persons considered to be severely mentally ill between 1995/96 and 2000/2001 could have many explanations. The threshold considering being identified as severely mentally ill seemed to be lower at the second occasion. Changes in the mental health status of the population and methodological difficulties were other possible explanations to the differences.

Many organisations and persons were involved in the two surveys. Efforts were made to repeat the same procedure on the two occasions. However, there were differences, and the mental health care reform had implemented new organisations and new methods to care for the target group of the reform. Especially in the field of social services, staff had become better educated in 2000/2001. It is possible that the higher number of severely mentally ill reflects the increased sensitivity to severe mental illness as shown by a better educated staff.

Another possibility is that the number of surveyed persons reflects a desire on behalf of the staff involved to show their amount of work, and the need of resources to be allocated to their workplaces. However, it was difficult to explain why this factor would be more important in 2000/2001.

The new group of persons surveyed in 2000/2001 were on average younger, had proportionately more persons who were cohabiting with a partner and had children at home, was less isolated, had a higher GAF-value and fewer needs. Although the new group thus appeared to be healthier than the old group in some respects, they received less support for their problems. The new group had a larger total number of unmet needs and more unmet needs in areas such as physical health, psychological distress and alcohol abuse related problems. They were in need of more assistance than they received from social services,

psychiatric services, primary health care, dental care, social security offices and employment services compared to the old group. These results may simply reflect the fact that persons in this new group had not been known by services long enough for appropriate support measures to be instituted. The design of the study did not make it possible to compare the new and the old part of the sample in 2000/2001 to the new and the old part of the sample in 1995/96.

However, it is quite probable that the new group of persons need strategies distinct from those needed by the old group to deal with their handicaps. It is also possible that the new group contains sub-groups of persons with psychiatric problems that received a lot of attention in the late debate i. e. persons with personality disorders combined with addictive problems, potentially dangerous to themselves and others.

The changes in care as a consequence of the mental health care reform in the investigated area were specially directed toward persons with schizophrenia (Study IV). The priority of care for the persons with schizophrenia combined with cuts in health care budgets during a period of recession may have had negative consequences for the psychiatric care of other groups of persons within or besides from the target group of the reform.

It seemed possible that the shift in the target group of the reform described by Markström (2003) is a continuing process and continuing analyses of the needs of the severely mentally ill persons are necessary. Furthermore, new interventions and strategies demanding recourses are necessarily following these analyses. Using this perspective, the evaluation of the reform is never finished, but a continuous process. Consequently the three-year perspective of implementation and evaluation set by the government has contributed to an unsatisfied eagerness by politicians, mass-media, researchers and the public to get a quick answer to the question "How did it go?" instead of asking the more relevant question "How is it going?" (Markström, 2003).

The target group and the concept of handicap

The importance of introducing the concept of handicap concerning severely mentally ill was stressed in the implementation of the reform (Grünewald, 1999; National Board of Health and Welfare, 1999).

The introduction of the concept of handicap reflects a shift in perspective and denotes a demand for organisational and legal changes adapted to the situation and needs of the handicapped person, as well as a change in the content of psychiatric care and services.

Markström (2003) concluded that the introduction of the concept of handicap so far has failed and called this failure the stumbling block of the reform.

The results of Study III indicated that the increase in the target group during the implementation of the reform may be one reason for this failure. In Study III, there were significantly more persons with diagnoses other than schizophrenia that recovered in the sense that they were no longer considered to be handicapped at the time of the second survey. The stability of the group is important in consideration of the shifts in perspectives on handicap regarding treatment and legislation. One conclusion of Study III was that the concept of handicap was probably relevant concerning persons with the diagnosis of schizophrenia but more dubious for persons with other diagnoses.

The increase of the group defined as severely mentally ill from 1995/96 to 2000/2001 (Study II) and the characteristics of the new group in 2000/2001 may be a predictor of an even larger group recovered in this sense in the future. The group defined as severely mentally ill might be more fluid in the future.

Nowadays, there is a general agreement about schizophrenia as a long-lasting, mostly lifelong illness causing cognitive deficiencies. In approaching these problems and their consequences the concept of handicap and the consequences of this shift of perspective seem to be very relevant. The constructs in ICIDH and ICF also seem to be applicable.

Concerning persons with certain other kinds of psychiatric problems included in the definition of severely mentally ill e.g. persons with diagnoses like asperger and autism, the concept of handicap also seems relevant. However, concerning some other groups the concept of illness or just psychological or social problem may be more relevant in the approach to treatment.

The more inclusive the concept of severely mentally ill, the more difficulties in implementing the concept of handicap.

Recovery

Even if there are great problems in defining the concept of recovery in such a way that it is possible to compare the results from different studies (Harding, 1986; Topor, 2001) remarkably few persons in Study III were considered recovered. Just one person was considered to be totally recovered and fourteen percent were estimated recovered in the sense that their disabilities no longer constituted handicaps. In the group diagnosed with schizophrenia, only six percent were considered recovered in this sense versus about twenty percent of the persons with a different diagnosis.

The definition of the concept severely mentally ill could be one explanation for the relatively low rates of recovery compared to other studies. The most important factor in defining the present sample was not diagnosis but rather disability and handicap. Although the persons in the sample had different

diagnoses, the inclusion criterion was that the illness had caused a handicap. However, a handicap may appear many years after the illness debuts. Early cases of recoveries are than missed in the present kind of study.

One conclusion from the interviews was that there were varied paths to recovery. Each person described a way different from the others. Support from others, medication and care were important factors. However, the importance of significant others to the recovery process were complex and sometimes contradictory. Persons described important contributions to recovery from relatives and friends but also that they sometimes had contributed to their illness. Even when the interviewees reported unreserved support from relatives and friends the relations could be complicated and ambivalent often with the occurrence of guilt feelings.

The contributions from hospital care were described as side-effects rather than intended effects, i.e. the opportunity to escape from an intolerable situation seemed more important than the actual treatment in the hospital.

Medication was mentioned as important but the side effects were often described as very problematic.

In out-patient care the attitudes from the staff persons seemed more important than methods and that they sometimes could make efforts beyond what could ordinarily be required of them seemed important.

Although the direction and the aims of the efforts differed, the importance of the active role of the persons in their own recovery process (Topor, 2001) was confirmed in this study.

There seemed to be two major strategies in the recovery process among the interviewed persons. One was to adjust one's expectations of life to one's disabilities. People using this strategy had a high external locus of control and believed that their ability to influence the consequences of their illness were limited. They had "accepted" their disabilities, they lived together with a domestic partner but otherwise lived rather isolated lives.

The other strategy was to struggle against the consequences of the illness. The persons who used this coping strategy had an internal locus of control and could be described as believing they could significantly influence the consequences of the illness through their own behaviour and actions. They lived in close contact with other persons and society. They did not "accept" their disabilities. Naturally, there were also examples of mixed strategies. Interestingly, the only person who seemed fully recovered showed such a strategy possibly suggesting benefits of balancing acceptance and struggle. Neither the victimising attitude of acceptance nor the "it's all up to me"-attitude of struggle may be most effective in the process of recovery.

Methodological issues

The studies exhibit a number of methodological limitations.

The gaining of information for social services and department of psychiatry to plan their future efforts for the severely mentally ill was the primary purpose of the two surveys. Therefore, there were limited possibilities to influence the choice of instruments and methods. The efforts from the research project in the second survey were aimed at making the methods as similar as possible those in the first survey to make results comparable.

Concerning the interviews in 1995/96 and 2000/2001 systematic findings were evident among the dropouts. The analyses of the dropouts that were possible to perform, did not disqualify the main conclusions of the studies. Still, the attrition groups was large and we cannot entirely discount the possibility of other systematic effects of the attrition in the study.

In the interviews and assessments of the CAN following the 1995/96 and 2000/2001 surveys one problem was the interview method. First, the interview was conducted using the questionnaire designed by the National Board of Health and Welfare, then the subject's needs were assessed according to the CAN. Finally, after the client had left, the assessment of needs was performed by the staff. The assessments of needs made by clients and by staff were thus not made independently but in a negotiation-like situation (Arvidsson, 2001). In addition, at least one of the interviewers knew the person he/she was interviewing which also may have affected the results. However, the same interview method was used both in 1995/96 and in 2000/2001. There was no reason to believe that the interviewers had affected the results systematically different on the two occasions.

About 500 interviews were conducted on each survey occasion and 219 persons were interviewed on both occasions. For practical reasons (the form of admittance to the interview accepted by the ethical committee) the interviewers in 2000/2001 knew if the subject also participated in the 1995/96 interview. However, they were not aware of the results of this interview.

The follow-up of the 219 was no main objective and it is not likely that the resulting assessment was due to contamination by the interviewers' expectations.

Many interviewers were involved and the participants were generally interviewed by different interviewers on each occasion. However, the interrater reliability of the CAN has been thoroughly investigated (Hansson, Björkman & Svensson, 1995).

Raters who also took part in the 1995/96 ratings did not assess the existence of more needs in 2000/2001 than those raters who were new in 2000/2001. The decrease in needs between the sample in 1995/96 and in 2000/2001 did not seem dependent on the change of raters between the two occasions.

When considering the follow up of the 219 persons, one has to keep in mind that they had aged five years in 2000/2001 compared to 1995/96. Most of them were diagnosed with schizophrenia and the consequences of the disease can change over five years. It is conceivable that the course of the disease *per se*, has caused the decrease of the sum of unmet needs. But the number of unmet needs in similar samples tended to increase over time (Wiersma, Nienhuis, Giel & Slooff, 1998).

Another problem in drawing conclusions about the reform is the vague definition of “severely mentally ill” and how the listing procedure took place in the surveys. There must be persons who were not listed by the applied method, on one, or on both occasions, who should have been listed. There are most certain also “false alarms”, persons listed, who should not have been listed.

Collecting and comparing data from different registers are problematic. The sources of errors are many concerning the conclusion that the figures for different years were compatible, that they were defined in the same way, and related to the same geographical areas. However, it is the major trends rather than the exact numbers that are important in Study IV. It is unlikely that the trends were systematically biased.

One further methodological problem is the possibility of generalising the results outside the municipality of Jönköping. Although the number of the persons identified as severely mentally ill corresponded reasonably well with the national sample (Stefansson & Hansson, 2001), the characteristics of our 2000/2001 sample appeared to be more similar to those of the 1995/96 national sample. The National Board of Health and Welfare found large differences between areas, but stated that the implementation of the reform had been most successful in mid-sized communities (National Board of Health and Welfare, 20003c; National Board of Health and Welfare, 2003d) like Jönköping. The municipality of Jönköping has many characteristics common of a mid-sized municipality in Sweden as far as the organisation of mental health care and the implementation of the mental health reform brought about the same changes in care in many places in Sweden. Still, there are problems with generalising the results of these studies to other parts of Sweden.

The definition of recovery in Study III differs from other studies of recovery and makes generalisations problematic. The difficulties in generalising the results are articulated in the qualitative study in Study III. Only seven persons were interviewed.

Study IV was a descriptive study of the use of psychiatric care in the municipality of Jönköping. The study was based on a population and the results can only be related to the implementation of the reform in Jönköping. It is not possible to generalise the results to other parts of Sweden.

The main results and the debate following the violent incidents in 2003

It seems that the main results of these studies shows a rather favourable post-reform development for the severely mentally ill persons, away from the conviction held by media, politicians, the general public and many members of the psychiatric profession. The debate following the violent incidents in the autumn 2003 concerned the question *why* the reform was a failure and not the question what the actual results of the reform were. Researchers and politicians think that everybody agrees that the reform is a failure (Sjöström, 2000; Markström, 2003). It seems relevant, as did Leff (2001) in the British debate about deinstitutionalisation, to ask why care in the community is perceived as a failure when there is substantial evidence of considerable success.

Firstly there are some conceptual confusion complicating the discussion. In the debate the reform is equated with deinstitutionalisation. It is a common misunderstanding that on the first day of the reform, the mental hospitals were all closed and the patients were left in the community without any care. But the process of deinstitutionalisation had been going on for some thirty years in Sweden like in many other countries, and in the investigated area the reform did not seem to accelerate this process. Rather, the reform can be seen as one consequence of deinstitutionalisation. The ongoing process of deinstitutionalisation demanded a stricter division of responsibility between mental health agencies and social services. However, the Swedish reform, as well as other reforms targeting the severely mentally ill (Becker & Vázquez-Barquero, 2001), was at least implicitly, build on deinstitutionalisation and the development of care in the community. This said, the consequences of deinstitutionalisation are relevant in the study of the outcome of the reform. However, when summing up research about the outcome of deinstitutionalisation the results seem rather favourable for the severely mentally ill (Bülow, 2004; Kendell, 1998; Thorndike & Goldberg, 2000).

Another conceptual confusion is the issue of the target group of the reform. The group was not defined very strictly during the implementation process (Markström, 2003), and appeared even more diffuse as the debate about violence and psychiatry intensified in 2003. It seems very doubtful that most of the ill persons focused in the discussion concerning violence and homelessness really were part of the target group of the reform. In fact, the debate has been more a debate concerning psychiatric care in general and about social problems in general, than about specific points at which the reform has succeeded or failed, or about the target group of the reform.

Deinstitutionalisation has made the poor living conditions of the severely mentally ill visible to the general public. This may be one reason for the conclusion of the failure of the reform. However, the conclusion of this thesis is that the conditions of the group do not seem to have worsened in the investigated area since the reform, rather the contrary.

The main reason for dubbing the reform a failure may be that little progress has been made thus far in achieving its asserted objective to close the gap in equality separating the severely mentally ill from the rest of the population. One finding of Study I was that the total sum of unmet needs and unmet needs in important need-domains had decreased at the second interview. Even if statistically significant differences were found on the group level, this may not necessarily reflect a significant degree of change for the individual. Indeed, statistical and clinical significance may differ. In contrast, Study I revealed no significant improvements in important areas such as daily activities, income and support, and social isolation. Similar results have been reported elsewhere (Bülow et al, 2002; National Board of Health and Welfare, 2003a). The burden on the family of the severely mentally ill is still unacceptably high (Stefansson & Hansson, 2001; Östman, 2000).

Five years after the reform, mortality rates of the severely mentally ill were still nearly double those found in a standard population in the investigated area (Arvidsson, 2004). This findings is in line with those of Ösby et al. (2000a) in a number of studies spread out over a long period of time and made in different countries. General life conditions and the life styles of severely mentally ill persons obviously contribute very heavily to the high mortality rates in this group (Arvidsson, 2004). It is important to note that severely mentally ill persons as a group are still very underprivileged and disadvantaged.

Conclusions

One objective of the 1995 Swedish mental health care reform was to improve the quality of life of severely mentally ill persons by decreasing the development of impairments and handicaps (ICIDH) and increasing the levels of activity and participation (ICF). Our results suggest that this objective has been accomplished. At the time of the second survey, the number of met needs had increased and the number of unmet needs decreased. However, methodological limitations of the studies restrict our ability to draw wide-ranging conclusions from our data. A conservative interpretation of the findings could be that the situation for the sample did not worsen over these five years in the investigated area. Efforts by psychiatric care and social services seemed to have increased for the target group of the reform. More people received assistance in their homes in 2000/2001 and more lived in group homes with 24-hour staffing. Fewer people indicated a need for a better housing/accommodation or more help from either psychiatric care or social services. Data from a register study supported claims that the intended changes of the reform were in fact carried out. Drastic reductions were observed in the number of days of in-patient care for persons with a diagnosis of schizophrenia, but this reduction was offset by increases in the stay at different kinds of group homes. Moreover, the number of persons residing in nursing homes had also decreased, arguing against the presence of transinstitutionalisation in the investigated area. New psychiatric field teams, focussing primarily on patients with psychosis, and new social service field teams, providing this group with domestic care and assistance, were introduced.

In public debates, the reform has been accused of closing down the psychiatric institutions and putting the severely mentally ill persons out on the streets to fend for themselves without any kind of support or assistance. However, five years after the reform only five persons in the group targeted by the reform in 1995 had no contact with care-providers for help with their psychiatric problems. In the present sample, the severely mentally ill did not seem to be abandoned. On the other hand, few persons had recovered from their severe mental illness. Only one person was considered to be totally recovered and 14 % were considered to have recovered in the sense that their disabilities no longer constituted handicaps. Of the latter, only 6 % with diagnosed schizophrenia and about 20 % of those with another diagnosis were considered to have recovered. But even if recovery was rare, it sometimes occurred. There were different roads to recovery, but it seemed like coping strategies were dependent on whether the person had an internal or external locus of control.

Between 1995/96 and 2000/2001, a change seemed to have occurred in the interpretation of the concept severely mentally ill, i. e. the target group of the reform. It seemed that the threshold for applying the concept had been lowered. The definition proposed in the reform was rather vague and left room for different interpretations, causing difficulties both in evaluating the reform and in introducing the concept of handicap. The consequences of a shift to a perspective of handicap considering treatment and legislation seem to be very relevant as far as persons with schizophrenia are concerned.

Why then is the reform considered a failure when conditions for the target group, at least in the investigated area, seem to have improved? The National Board of Health and Welfare found large differences between different areas in Sweden, but stated that the implementation of the reform had been most successful in mid-sized municipalities, such as Jönköping. There are problems associated with generalising the results to other parts of Sweden.

Probably the main reason for considering the reform a failure thus far is that the severely mentally ill are as a group still very underprivileged and that they do not share opportunities equal to those enjoyed by society at large, which runs contrary to the goals of the reform.

Current debate has centered more on psychiatric care and social problems in general and less on evaluating and discussing the impact of the reform on the target group. Even so, the debate has reflected important challenges to psychiatric care organisations, social services and other societal areas. It is also possible that the new group surveyed in 2000/2001 includes persons with psychiatric problems that were given a lot of attention in the debate, i. e. persons with personality disorders combined with addictive problems who are potentially dangerous to themselves and others. In the investigated area, the priority of care for persons with schizophrenia combined with earlier cuts in health care budgets may have had negative consequences for the psychiatric care of other groups of persons.

In order to follow changes in the needs of the severely mentally ill and the development of care, a third survey is planned for 2005/2006. This survey will also enable us to gain a better understanding of the stability of the interpretation of the concept of severely mentally ill used in defining the target group of the reform.

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Appendix

Camberwell Assessment of Needs (The CAN)

The CAN is designed to be used by psychiatric and social personnel with some practise. The CAN assesses needs in 22 different areas (accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information about treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, child care, basic education, telephone, transport, economy and social benefits).

Each of these areas includes the views of both the client and staff and each area has four sections as follows:

1. Severity of need, no problem=0; no problem or moderate problem due to continuing intervention (met need)=1; serious problem (unmet need)=2
Summary scores of the total number of needs (the number of 1s and 2s), the met needs (the number of 1s) and the unmet needs (the number of 2s) are computed.
If there is no problem in the particular area the next area in the schedule is rated. If there is a problem the process proceeds with section 2-4.
2. The current help received from friends or relatives (none=0, low=1, moderate=2, high=3)
3. The current help from local services (scaling as above)
The current need of help from local services (scaling as above).
4. The adequacy of help received (no=0, yes=1) and satisfaction with the type and amount of help received (no=0, yes=1)

There is also a “do not know” alternative in all sections.

Only the first section was used in this study.