


## Summary

### THE SWEDISH MENTAL HEALTH REFORM — AMONG BUREAUCRATS, USERS AND PIONEERS.



**T**HE BACKGROUND to this thesis lies in the changes that have occurred in the field of psychiatry during recent decades. Up until the middle of the 1960's, institutional-based care was the dominant form. Following this period, a trend towards deinstitutionalisation has taken hold, which has meant that hospital-based care has diminished and a community-based system for care, support and services for persons with serious psychiatric disabilities has developed.

In Sweden, the process of reforming psychiatry began in the 1970s'. Development proceeded with an emphasis on increased outpatient care, and with psychiatry having renewed its provision of programs in the direction of community-based services. One question, which has held a central position in the great number of government investigations in the field of psychiatry, has been that of what responsibility the social authorities will have in relation to persons with psychiatric disabilities.

In 1990, a government commission was formed with the task of improving care and services to persons with serious psychiatric disabilities. Special emphasis was placed on considering and suggesting measures to delineate the division of responsibility and organisation of services to the psychiatrically disabled. The government bill that resulted from the work of the commission constitutes an attempt to clarify the responsibility of the

municipal social services for residential services and occupational activities for persons with psychiatric disabilities. The government's foremost strategy to support the realization of these recommendations was an economic incentive, which was paid out over a three-year period. The Mental Health Reform came into effect in 1995.

The aim of this thesis is to describe, analyze and critically review the planning and implementation of the Mental Health Reform, and to identify the conditions and choices along the way, which have been meaningful for the ability of the municipal social services to succeed in realizing the intentions of the Reform. The thesis also aims to present the Reform within an historical perspective on caregiving.

The thesis consists of two empirical studies. The first is a case study encompassing five Swedish municipalities and their method of planning and implementing the Reform. The second is a case study of a vocational rehabilitation project for persons with serious psychiatric disabilities, which began in connection with the Reform. In addition to the two component studies, the substance of the report is composed of comprehensive written material. This includes documents which illuminate developments prior to the Reform and experiences following its taking effect. The material includes official investigations from the 1970's and beyond, as well as evaluations and other scientific work in the area.

*Chapter one* also consists of a description of method and procedure. The study of the five municipalities is intended to present thorough descriptions of how they proceeded in the work of the Mental Health Reform. The selection was made based on the principle of distribution, with reference to variables such as size, geographic location, history of psychiatric care, and the level of ambition regarding the implementation of the Reform. The local authorities were contacted and a strategically placed person provided the researcher with existing documentation connected to the local work around the Reform. Following a review of the documentation, visits were made to the communes, where interviews were conducted with the

leaders and planners within the social services, personnel working within the social services and psychiatry, users in the services, and representatives for the users and relatives movement. On average, approximately fifteen interviews were completed in each commune.

The study of the vocational rehabilitation project was intended to illustrate the implementation of the Mental Health Reform by examining the process in the project structure. The project was studied beginning with its start-up and continuing for a little more than two years. The material included interviews with personnel at two points in time, interviews with representatives for similar projects at two points, ongoing interviews with a number of participant's, observation studies and a questionnaire study.

*Chapter two* consists of a review of the central themes and the theoretical starting points for the thesis. The chapter begins with a description of developments within research related to policy and implementation. A perspective on the process of negotiation at the political level is presented, as well as the importance of local actors and the actions of so-called street level bureaucrats. The role of the care-giving organisation in the implementation of socio-political reforms is discussed from a starting point in the New Institutional School within organisational analysis. The organisation is, according to this perspective, dependent on its environment in order to acquire legitimacy and resources, which often implies that it must adapt itself to the normative system that dominates a particular sector. A part of the discussion concerns itself with knowledge regarding the characteristics and functions of the project structure.

The concept of the project is symbolically, positively charged, often dynamic, and can function as a sort of free zone where creative work transcends organisational boundaries. The problem with the project as organisational form lies in the difficulty of transferring knowledge to the mother organisation, as well as in the risk of postponing longer-term decisions. A phenomenon that is also described is that of collaboration, which has been tied to the New Institutionalisms emphasis on legitimacy

as a motive for the organisation to maintain contact with the surrounding world. The chapter concludes with a discussion concerning knowledge and professionalisation in the area of care, support and service to persons with serious psychiatric disabilities.

In *chapter three*, the development of society's services to the psychiatrically disabled is described. The first section represents the Western world, where the portrayal is dominated by a description and analysis of the deinstitutionalization process; the motives and reasons behind the changes, the implementation and result. Another part devotes itself to the developments in Sweden.

*Chapter four* contains a description of the models of thinking that have been meaningful for developments in the area of psychiatry. The first area described is that of normalisation ideology, which has been widely important in the field of handicap. This ideology has not been of decisive importance for the deinstitutionalisation that took place in the field of psychiatric service, but certain basic components, as in the demand for an independent and worthy life outside of the bounds of the institution, were already being promoted during the 1960s'. The concept of handicap is discussed as well in relation to the target group. It is stated that concepts related to handicap have had difficulty in being accepted within psychiatry and the social services in Sweden, despite the new legislation that has been introduced. Finally, rehabilitation is presented as a strategy for achieving the goals that are reflected in concepts of normalisation and handicap.

*Chapter five* consists of a description and critical review of the Commission on Psychiatric Care along with the government bill, which preceded the Mental Health Reform. The work of the Commission took place between 1990 and 1992 and had as one purpose among others, to consider and suggest measures regarding the division of responsibility and organisation of support and care for the psychiatrically disabled. In the analysis it becomes

evident that the result of the Commission is a document characterised by a strong ideology and one that takes a position regarding the questions of division of responsibility and work methods.

The Commission's problem lies in difficulties it faces in delineating and defining the target group that will be the recipient of the measures. This creates an uncertainty concerning the many recommendations: How many people are affected? What will it cost? The result of this uncertainty constitutes a great deal of the reason why the Commission's suggestion to strengthen the legislation in the area has not been realised. Instead, the government chose to invest in a time-limited economic contribution, with the aim of stimulating the development of community-based activities within the social services.

In *chapters six to eight*, experiences from the implementation of the Mental Health Reform are presented. In addition to the results from the commune-studies and the study of a project, results are also included from other national studies and follow-ups.

The Reforms implementation was characterised during its initial period by uncertainty and delays. The surveys by the municipal social services contributed to the picture of the psychiatrically disabled and their needs as something that could be made clear. The estimates showed that there were 40,000-50,000 people in Sweden with serious psychiatric disabilities. The majority live in their own residence, but of the group of ex-patients who had been cared for in mental hospitals during an extended period, approximately half continue to reside in institutions. Despite the fact that many new programs have been put into place, a large proportion of the target group has no regular daily activity.

There remain wide differences with reference to the level of ambition and the results of the implementation of the Reform by the municipal social services. The principles of the change process and the new programs put into place have often been the result of innovations by personnel and other key actors. They have had a great deal of room in which to act. The limits

of responsibility between the social services and psychiatry have become clearer, but grey zones continue to exist in the areas of rehabilitation and outpatient care. The implementation has further involved a development of new methods of working and program structures within the local authorities. The majority of the experiences have been positive, but the large number of projects has led to certain difficulties, characterised by the lack of a foothold in the mother organisation and the lack of long-term planning.

There has been no high status professional group that has driven the Reform. The personnel in the social service programs consist primarily of individuals with a lower level of formal education, which contributes to the continuing lower level of legitimacy of the organisation itself within the field. Investments in developing competence have often consisted of the transference of knowledge from psychiatry, either through education or recruitment of personnel. However, there has also been a tendency towards new professional domains in the area of rehabilitation and the case management role. Consumer and family organisations have, in connection with the Reform, advanced their positions. They have built up and developed their activities with help from the incentive funding provided by the state. Experience has shown how an alternative knowledge base has developed in relation to work with the psychiatrically disabled. Problems lie in the fact that many associations are heavily depending on a few individuals, and in the uncertainty that characterises the project structure as the form chosen most often for implementing activities.

One of the policy goals of the Reform was to introduce and incorporate a viewpoint that included the target group in a handicap perspective. In such a way, the social services would begin to see more clearly their responsibility for people with serious psychiatric disabilities. This incorporation has taken time and is difficult. One reason for the lack of success is the application of the handicap legislation, which has led to exceedingly few of the psychiatrically disabled receiving services.

The study of the five municipalities confirmed many of the experiences from the national follow-up. Few local politicians, and a very small part of

the local administration had been involved in the implementation of the Reform. Responsibility for both the local “reform ideology” and the direction in programs has rested with certain key individuals. The incentive funding provided by the State has contributed to important discussions and decisions being pushed forward. The best results are considered to have come through specialised organisational models where programs for the target group and training for personnel have been gathered under one leadership. Personnel express uncertainty, as they are unclear as to the expectations of the organisation. They are most interested in seeking a functional method of working, through study visits and the exchange of concrete experiences. The personnel who were recruited from psychiatry often feel degraded and insufficiently utilized.

The study of the project illustrates the implementation and conditions in the lives of the projects that have become common in connection with the reform. In these, a great deal of room to act, a high tempo and an engaged spirit was found. There is an original model that becomes important to imitate in order to maintain a high level of legitimacy within the immediate environment. In this situation it is even important to identify established, institutionalised notions that have contributed to sluggishness in implementation. Finally, the description of the process clearly illustrates a painful effort directed towards “translation”, where those in the project must reshape both the goals and methods of working in order to develop a program that is adapted to the actual conditions.

In the *concluding chapter*, the results of the thesis are discussed, as they are related to the theoretical starting points. It is established here that the responsibility of the local authorities for persons with psychiatric disabilities has been under inquiry since the 1970's. Yet the transformation from the identification of the problem to concrete recommendations and an actual change has been slow-moving. The result of the Commission on Psychiatric Care is judged to be an ideologically ambitious document, but one that is deficient in its stringency with regard to delineating the target group.

These deficiencies contributed to the fact that the recommendation by the government lacked an authoritative legislative steering mechanism. The most important steering forms became instead the transfer of norms and the economic directives.

Taken as a whole, the Mental Health Reform stands as a reform heavily dependent on a few individuals. If the community-based work is to develop further it will require that a greater part of the social services organisation increases its knowledge and engagement in the process. The project structure has both advantages and disadvantages. The broader space within which to act, and the freedom from older institutionalised notions, offers the possibility to attempt new methods of working. At the same time, they can have a weakened foundation within the mother organisation. Despite the temporary structure, it is emphasized that many of the ideas, which will likely characterise the field in the future, have been born as a result of the Reform's investment in projects. The implementation has not been driven forward by certain strong professions, and many educational contributions have been short and consisted of "old" knowledge. Nevertheless, there are many signs that a new body of knowledge has been established. Some of the most interesting ideas come from services run by user organisations. The Reform has signified a more distinct responsibility for the municipal social services, but there are still areas where the delineation of responsibility remains unclear and where certain actors try to avoid carrying out certain tasks. The conclusion is that the implementation of the Reform has been difficult, but that it is far from being classified as a unilateral failure. There are just too many positive experiences. However, much of the progress must be attributed to the incentive funding by the state. The long-term discourse will be decided primarily by how enduring the early initiatives prove to be.



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