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Everyday Life Experiences Among Relatives of Persons With Mental Disabilities Represented in Basic Documents Governing the Swedish Psychiatric Reform

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Mental disability is one of the most serious health problems facing Europe today. The reform of psychiatric care in Sweden has passed much of the rehabilitation and daily care of these people on to their families/relatives. The aim of this article is to analyze how the psychiatric reform in Sweden has affected everyday life experiences among close relatives of persons with mental disabilities. It is an explorative and descriptive study using inductive qualitative content analysis of 18 individual interviews with close relatives. In order to deepen the understanding of the relatives' situation and the consequences of the psychiatry reform, the relatives' statements are put in a dialogue with how problems are represented in documents that form the basis of the psychiatry reform. The results indicate that the reform of psychiatric care in Sweden has put the solution of problems on the relatives, but for the relatives, there is still no consensus among the different care providers, county council, and municipal and national social services that are involved in treatment. The results further indicate that the relatives feel guilty about not providing enough support for the persons with mental disabilities, and they expressed a need for personal support and a need for better information, consistency throughout the caring process and professional therapy for themselves as well. Children of parents with mental disabilities express a need for assistance, opportunities for participation in care, and information about their parents' illness. Even though there are a lot of bad experiences, all relatives could also relate to positive experiences, i.e., open dialogues, relevant information, timely care, and support given by some hospital staff. We recommend that relatives' experiences should be taken seriously in further reforms of the psychiatric care and that relatives meet in different kinds of supportive networks.

Keywords: mental disability, psychiatric care, qualitative content analysis, family involvement in care, relatives' experiences

Introduction

Mental disability is one of the most serious health problems facing Europe today (Wilhelmsson, 2011a; 2011b). "There is no health without mental health" were the catchwords in 1999 when "mental health" was placed on the European agenda in the EU (European Union). In Europe, the number of mental hospitals was halved in the 1970s (Freeman, Fryers, & Henderson, 1985). The closing of the mental hospitals in Europe started at different points in time and was implemented with varying speed (Goodwin, 1997; Rose, 2001). In

Sweden, practically, all mental hospitals with a total of between 20,000 and 30,000 patients were closed in the course of a few decades (Bulow, 2004). In 1995, when the psychiatry reform came into force, there were 8,400 beds for psychiatric care. The reform of psychiatric care in Sweden has passed much of the rehabilitation and daily care of these people on to their families/relatives. In earlier articles, we have analyzed everyday life experiences among close relatives of persons with mental disabilities living in a district in Northern Sweden with focus on their own responsibilities as caretakers and on the psychiatric health care system (Wilhelmsson, Hällgren Graneheim, Berge, Johansson, & Åström, 2010; Wilhelmsson, 2011a, 2011b). In this article, we relate our data more closely to the psychiatry reform per se. The data consist of state documents that form the basis of the psychiatry reform and inductive qualitative content analysis of 18 individual interviews with close relatives. The analysis highlights three main problems in the process of change: (1) problems with implementing the reform itself linked to how mentally disordered persons were treated in psychiatric care; (2) problems arising during and after the implementation of the reform; and (3) problems arising after the implementation of the reform for relatives of mentally disabled persons. Parts 1 and 2 are based mainly on state documents. When analyzing the state documents related to the psychiatric reform, we were inspired by Carol Bacchi's methodological questions in her publication *Analyzing Policy: What's the Problem Represented to Be?* (Bacchi, 2009). In part 3, we put the relatives' everyday experiences from the interviews in dialogue with state documents that form the basis of the psychiatry reform.

What Is the Problem Represented to Be in the Psychiatric Investigation to Justify a Psychiatric Reform?

Before the reform, the mentally disabled people were classified as not being adapted to society. Seen from a historical perspective, psychiatric care was developed round and marked by old structures based on the legislation of the mental health care in the country, Royal Medical Board that came into force in 1931. The law stated that a "mentally ill" person in need of care could be admitted for treatment in a mental hospital against his/her will as long as there was a need for care. The development towards deinstitutionalization of the mental hospitals and reform of psychiatric care was a lengthy process that started its preparation as early as the 1970s. The aim of the reform was justified by the argument that it was important to normalize the mentally disabled persons' living conditions by increasing their influence on and participation in society. The new concept of "mental disability" replaced the "mentally ill" concept with the entry of the psychiatry reform in 1995.

A person has a mental disability if he or she has considerable difficulties in performing activities in important areas of life, and if these limitations have existed or may be assumed to remain for a lengthy period of time. (SOU (Swedish Government Official Reports), 2006:100, p. 69)

The establishment of the psychiatry reform aimed at giving the mentally disabled persons a more "normal" and therefore "better" life through access to social benefits and extended support (Socialstyrelsen, 1999c, p. 9). One of the goals of the psychiatry reform was that persons with mental disabilities should be able to live as other people in society with the same rights and duties.

What Do Political Processes Form the Basis of the Problem?

The forms of psychiatric care in Sweden underwent several great changes in the latter part of the 20th century. The enlargement of the institutional mental care with a larger number of beds went on up to the middle of the 1960s when it reached its peak. When the responsibility for the mental hospitals was decentralized and

transferred from the state to the county councils in 1967, the idea behind the change was that it would make it possible to integrate the psychiatric care with the other activities in the county councils in a better way. Since the middle of the 1970s, the result was a change from care and treatment in mental hospitals to more non-institutional psychiatric care (Markström, 2003; Estroff, 1989). In the 1980s, one observed problem was that the institutional psychiatric care had both reached an economic pain threshold and signaled that the care did not live up to the development that the rest of society was a part of (Socialstyrelsen, 1980). Other Nordic countries were also affected by similar ideas of how to best handle the situation of patients in need of institutional psychiatric care. The changes and ideas were gathered in the 1980s under the concept of “sectoring” with a clear focus on “non-institutional” care. Special sector clinics and non-institutional care teams were given the overall responsibility in a geographical area (Werne, 2000). The National Board of Health and Welfare’s report *Psykiatri i utveckling (Psychiatry under development)* (Socialstyrelsen, 1988) funded and published by the state showed that the sectoring principles that had been advocated for a long time had gained support from all county councils.

Investigations, ordered by the state (SOU, 1991:88; SOU, 1992:46) discussed different forms of support that were expected to be both “cost effective” and “socially integrative”. This may also be interpreted as an attempt to meet political ideals of decentralization, market adjustment, individualization, and user influence (Barron, Michailakis, & Söder, 2000). The goal of the implementation of the psychiatry reform, which came into force in 1995, was to emphasize and focus on cooperation, planning of care, employment, rehabilitation, dwelling support, and influence of users and relatives. There was also a clear economic aspect that was visualized in the psychiatry reform, which pointed to large costs for the institutional psychiatric care. The focus of decision-makers at the state level was to create good prerequisites in daily life for the mentally disabled persons, and the Swedish Parliament’s unanimous opinion was that there was a need for guaranteeing a safe existence for persons with disabilities. In 1993, the government decided to introduce the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS, 1993:218). The aim was that the mentally disabled persons should be integrated in the handicap reform and included as a part of the rights legislation that was close at hand (Socialstyrelsen, 1997). The text of the Act Concerning Support and Service for Persons with Certain Functional Impairments was established in terms of three different spheres of persons. Persons with mental disabilities belong to the third sphere of persons, which includes persons with severe and lasting physical and mental disabilities involving considerable difficulties in their daily lives and being in great need of support.

One consequence of the changes was that the non-institutional care got a larger area of responsibility. The non-institutional care teams were responsible for both the preventive and the emergency treatment and for the transfer reporting functioning for mentally disabled persons in society. Despite increased efforts to develop sectorized non-institutional care and attempts to improve support and coordination for mentally disabled people, criticism was expressed in the psychiatry investigation (SOU, 1992:73), where it was stated that decentralization had led to deficiencies in coordination and responsibility between municipalities and county councils. The investigation also elucidated that non-institutional psychiatric care disfavors long-term mentally disordered persons and that treatment in non-institutional care was better suited to patients with milder mental illness. The investigation pointed to deficiencies in coordinated support aiming at counteracting social isolation. The deficiencies were related to the lack of venues for activities and social relations, work rehabilitation, and adapted education. This change was regarded as a “problem” because persons with mental disabilities are in

great need of company, adapted activities, and practice in order to develop functions and skills (Topor, 2001). The SOU investigation described that mentally disabled persons were worse off than other groups in society with regard to, e.g., dwelling and economy. Another problem highlighted in the document was the public's negative attitudes to mentally disordered persons. These attitudes needed to be changed in order to normalize the situation and integrate mentally disabled people in society with the same opportunities for influence and participation in society as other groups (Markström, 2003). All these circumstances affected the relatives, a problem also emphasized in the report, which visualized that the relatives' situation is often affected to a great extent when a close family member falls mentally ill. The investigation refers to a study where "35% of the relatives stated that they needed psychiatric support themselves" (SOU, 1992:73, p. 132).

The Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS, 1993:387) was seen as an important cornerstone in the psychiatry reform, aimed at strengthening the support for persons with mental disabilities and intended as a complement to the Health and Medical Service Act (HSL, 1982:453), which was considered not to be a sufficiently effective legislation for providing support and service to persons with disabilities (Proposition, 1992/1993:159, p. 171) and later formulated in the Social Services Act (SoL, 2001:453; SoL, 2009:549).

In connection with the implementation of the psychiatry reform, new types of non-institutional projects started with the aid of public stimulation resources. They included different forms of dwelling, venues for activities and social fellowship, work rehabilitation, adapted education, and personal representatives. The projects used case management methodology which stems originally from the USA and Great Britain in order to attain the goals for decentralization, market adjustment, individualization, and user influence. The chief aim of the methodology was to support persons with mental disabilities to live as independent lives as possible (Smith & Newton, 2007). The state authority Socialstyrelsen has found some positive effects of greater freedom and opportunities for mentally disabled persons to influence their own life situation (Socialstyrelsen, 1997, 1999c; Baron et al., 2000). However, Markström (2003) has evaluated some projects that were based on work-oriented rehabilitation of persons of working age with a mental disability. The work training was permeated by a clear user influence on the individual's own needs and wishes. The evaluation shows problems with achieving continuity of care and support and individualizing the rehabilitation of mentally disabled persons.

Problems Arising During and After the Reform

When the new reform was prepared, there was a period of fairly high prosperity in Sweden, but when the law came into force, Sweden was on its way towards a recession. The process of change in the psychiatric care with a decrease of beds in institutional care and a transfer to non-institutional forms of care did not have sufficient support in the activities and among relatives. This had consequences for both mentally disabled persons and their relatives, who were not prepared for what the transition from an institutional care system to a system with non-institutional forms of care would involve. The report of the National Board of Health and Welfare (Socialstyrelsen, 1999c, p. 9) described the living conditions of people with mental disabilities as a problem in its evaluation of the psychiatry reform. The National Board of Health and Welfare is of the opinion that the aim of the psychiatry reform, which was to promote the living conditions of people with mental disabilities by improving their quality of life and participation in society, has not been attained. The individual's influence was to be strengthened through the reform, but "mentally disabled persons' opportunities

for participation and influence are still neglected” (Socialstyrelsen, 1999c, p. 105). In connection with the introduction of the psychiatry reform, a great part of the responsibility was transferred from the county councils to the municipalities, which hence got greater responsibility for persons with mental disabilities who were not in need of institutional mental care. “The municipalities and county councils were not prepared” (Socialstyrelsen, 1999c, p. 112) for which respective parts they would be in charge of and therefore did not manage to meet the existing needs. Large parts of “the law” were “vaguely formulated” (Socialstyrelsen, 1999c, p. 115). This implied that the law permitted free scope of interpretation for the officials that were to grant or refuse applications that had arrived. According to the evaluation of the National Board of Health and Welfare (Socialstyrelsen, 1998), the outcome showed that there were “few decisions on efforts for precisely the mentally disabled persons” (Socialstyrelsen, 1999c, p. 118). Administrators and officials lacked information and education about how the Act Concerning Support and Service for Persons with Certain Functional Impairments are related to the Social Services Act. The evaluation showed that “decision-makers at the municipal level had insufficient knowledge of how to interpret the new law” and that the application did not correspond to the original intentions of the law. It was highlighted that “the social services only took responsibility for the mentally disabled persons’ daily life and not enough for their treatment” (Socialstyrelsen, 1999c, p. 122).

The National Board of Health and Welfare further stated that the “problems with issues of funding are unacceptable and not enough controlled” (Socialstyrelsen, 1999c, p. 216). The work in county councils and municipalities is to some extent characterized by conflicts of interest between the responsible parties. “There is a gap between institutional and non-institutional care” (Socialstyrelsen, 1999c, p. 221) that is detrimental to patients with special needs. The conclusion was that many mentally disabled persons had fared badly, especially during the process of change. Alternative forms of treatment were not sufficiently developed when the institutional care beds were closed.

The non-institutional care was under development, but according to representatives of the municipalities, “the winding up of the mental hospitals was too rapid” (Socialstyrelsen, 1999c, p. 225). The responsibility was unclear regarding new forms of dwelling for mentally disabled persons. It is also evident in the investigation that the psychiatric care and the municipalities’ social services were and are far apart as regards knowledge and outlook and there is some uncertainty as regards areas of responsibility.

Who Is Responsible for the Problem? What Basic Assumptions Underlie the Problem?

At the same time, as the psychiatry reform came into force, there was extensive work on reconstructing the public finances which had consequences in the form of smaller subventions to municipalities and county councils (Socialstyrelsen, 1999c). There was lack of planning for how to implement the reform at different levels. In practice, there were no strategies for how the work should be conducted at the local level and there was an unclear overarching central coordination function (SOU, 2006:100, p. 22). In addition, the officials did not use new directives, because the old Social Services Act (SoL, 1980:620) was already in existence, which the officials felt secure with. In addition, the target group’s special needs were not sufficiently known, because the Act Concerning Support and Service for Persons with Certain Functional Impairments and the LSS (1993:387) efforts were too vaguely formulated. One part of the reform that has proved to be difficult to interpret and implement is the change of perspective from being mentally ill to being mentally disabled. A consequence of this was that the municipalities, which were given the main responsibility for coordinating efforts and making an inventory of needs, did not attain the goals that were stated in the psychiatry reform

(Socialstyrelsen, 1999c, p. 34). As a result, there were difficulties in precisely defining the concept of mental disability, which consequently influenced the administrators in their judgment of needs, according to the Final Report by the National Psychiatric Reform (SOU, 2006:100, p. 24).

Is It Basically a Political Problem? How in That Case? How Is the Selection of the Problem Described?

As we have stated earlier, the psychiatric reform was originally based on a political shift and deinstitutionalization of people. "Mentally ill" persons became "mentally disabled" and the political aim was to increase these individuals' influence on and participation in society. Individuals' free choices of how to live their lives were key words in the political strategies. These mentally disabled persons were to become full citizens through special support from society and their close relatives. However, when it comes to how to describe problems with the reform, the political ideology per se is not challenged. As we have shown, it is not the political strategy per se but its policy documents and administrative processes that have been described as problems and in need of becoming more distinct. The staff working within the framework of the psychiatric reform is also described as a problem, because the staff has not left old routines to a sufficient extent. Consequently, the staff also has to become more updated and educated. Thus, the main problems are described not as political problems but as problems with "co-operation", "collaboration", and "co-ordination" (SOU, 2006:100, pp. 22ff). In line with this description, "the government decided to call in a national psychiatric coordinator with the commission to look over problems with working methods, collaboration, resources, staff and competences within medical care, social care and rehabilitation of mentally ill and mentally disabled persons" (SOU, 2006:100, p. 1). A common political strategy in Sweden was thus to continue to investigate the situation through "a prolongation of the state investigation" (SOU, 2006:100, p. 1).

State Intentions and Relatives' Experiences

What Are the Effects of the Representation of the Problem?

As we have mentioned earlier, the reform was expected to be both "cost effective" and "socially integrative". Even though state representatives assert that the reform's goal fulfillment of the government's intentions, seen from an economic perspective, has been successful (Socialstyrelsen, 1999c), state evaluations discover flaws in the reform. The principal intention had not been fulfilled, according to the final report by the National Psychiatric Reform (SOU, 2006:100) of closing down institutional psychiatric care by transfer of the main responsibility to the municipalities for coordination and inventory of needs among the group of mentally disabled persons in society, in accordance with the Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS, 1993:387). Another problem is that the law is vague to some extent and leaves free scope of interpretation to administrators and officials. The change of perspective of the reform from being "mentally ill" to being "mentally disabled" has also made it difficult to exactly define the meaning of "mentally disabled". If the concept is unclear, the judgment of needs is consequently difficult to handle and implement for the administrators. Here, a third field of problems appears. Even though the Social Welfare Board is to support the relatives according to the act, alternatives of treatment have not been developed to such an extent that they could provide for the needs of the mentally disabled persons, in reality giving relatives too many caring responsibilities (SOU, 2006:100).

Two main problem fields are highlighted: One is of an administrative nature; the other is about vague acts. The transfer has been impaired by serious shortcomings and deficiencies in the administration of these issues

and there is no clear distribution of responsibility between municipalities and county councils (SOU, 2006:100). Already in the report (Socialstyrelsen, 1999c), it is highlighted that it is of the utmost importance that resources are allocated early and coordinated. This is especially important, since there has been an increase in the number of persons with mental problems since the 1990s. It is established that the relatives have been given too large an area of responsibility, especially since the mentally disabled persons' needs for nursing, supervision, care, treatment and rehabilitation are not sufficiently provided for (SOU, 2006:100). Over time, especially children of mentally disabled persons are described as a neglected group with insufficient support (Socialstyrelsen, 1999b, 1999c; Socialstyrelsen, 2010b). State evaluations claimed that relatives' efforts must not be regarded as an alternative to diminished care, but rather as a valuable complement that with no burden of formal responsibility (SOU, 2006:100). These claims resulted in the implementation of a statute in the Social Services Act aiming at making the situation easier for relatives who care for and support persons with mental disability. The Social Services Act (SoL, 2001:453) was in 10§ strengthened and now stipulates that the Social Welfare Board "should" (SoL, 2009:549) provide support to make life easier for a relative who has a long-term illness or supports a disabled relative.

How Do the Relatives Experience the Effects of the Psychiatric Reform?

Society's view of relatives' role and their participation in the psychiatric care has changed over time: From being someone with no influence at all on the medical care and sometimes even being accused of causing a "mental illness" to be a relative with responsibility to look after a "mentally disabled" person. The relatives are conscious about their increased responsibility and they confirm state evaluations on deficiencies in the coordination between municipalities and county councils. Even though they are thankful for those in the medical staff who listen and try to understand their situation, they still feel excluded from medical insights in the disability per se. They express a feeling of not being well prepared for these obligations, and therefore, they ask for more education and support (Socialstyrelsen, 2005a; 2005b).

The analysis of the interviews visualizes two themes of experiences: not only the relatives' "fighting against powerlessness", but also their "seeing glimmers of hope". Relatives experience powerlessness and think that the medical care does not live up to good quality. This has led to decreased confidence and trust in health care as a whole. A daughter summarizes her situation in this way: "I'm terribly disappointed in everything". There are expressions of disappointment in: medical staff with insufficient competence that makes bad judgments, limited resources, unclear areas of responsibility in county councils and municipalities concerning prevention, planning, and rehabilitation. A common complaint was about lack of clear information about plans of further treatment. The relatives express a feeling that the medical staff does not take integrated responsibility, which results in the aid not being provided.

A husband describes the situation in this way: "It was too late. They did not do anything about it in time then, so the mental problems have become even worse now". Others explain bad treatment as being caused by a lack of competence in some areas, a lack which according to the relatives was also confirmed by persons in the staff. One of the participants expresses a feeling that the staff was "taken directly from the street". "A dwelling with staff, that's in accordance with LSS, so there were no particular demands on the staff, you know".

They describe deficient and unclear information and lack of advice on action strategies and needs of help and support. They experience uncertainty about the future, since many of them have no safety net. A mother said, "I have no relative's allowance, but I take care of a relative round the clock" (SOU, 2003:127;

Socialstyrelsen, 2010a; 2011). Some of the relatives say they did protest when experiencing that they were not met with respect and were only sent to different authorities with their questions. They mean that those who threatened to report the situation to a higher authority were thereafter met with greater respect.

Even though the relatives confirm those weaknesses in the medical care that state representatives also express in state documents, and even though everyone has had moments of fighting against powerlessness, they all express glimmers of hope. They describe moments of constructive meetings with some staff members who helped them to cope with their daily life as a relative of a mentally disabled person. “They listened to me. Yes, they did. I think so. I do”. There have been moments of open dialogues and relevant information given by the staff—information that helped the relatives to handle the pathological state. Moments of support and relief eased their burden. “Yes, they have helped me they are terribly good, because they have always been willing to help”. “He has this fantastic contact person who at the same time is his old friend and I’m very happy about that”.

Recommendations for the Future

We have presented problems when implementing a psychiatric reform in Sweden both from state documents and relatives’ experiences. State representatives are aware of the problems but they seem to be difficult to be solved in reality. Previous routines in the medical care, inadequate education of both staff members and relatives, unclear distribution of responsibility between municipalities and county councils, and unclear state intentions and state acts seem to put obstacles in the way. The next step in the research process could be action research (Berge, 2001) in local network groups suitable both for medical staff and relatives. In such a context glimmers of hope and creative ideas based on local experiences from both relatives and staff members could be put in dialogues aiming at finding strategies to overcome some of the obstacles.

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