The social worker as case manager for persons with mental disabilities

By Barbro Lewin

Abstract: The crown jewel in the modern Swedish disability reform is a special rights law from 1993, the Disability Act. However there is considerable underutilisation of services in accordance with this act, especially among people with mental health problems. This research project was undertaken at a psychiatric clinic in order to activate the social workers of the clinic to motivate their patients to apply for support in accordance with their legal rights under this act. An intervention by nine social workers resulted in applications from one fourth of the patients assessed to be in need of such support according to an earlier follow-up. The results are discussed from a bureaucratic ethics perspective. The study demonstrates that the social workers have shown understanding of the political intentions of the reform, a will to pursue its implementation, and also an ability to act as case managers for those with mental health disabilities, motivating them to use their legal rights to support.

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Introduction

A central starting-point for this research project was the generally accepted fact that the Swedish disability and mental health reforms of the 1990s were not being fully implemented. Statistical reports show that especially persons with mental health disabilities have not benefitted from these welfare reforms to the extent that politicians originally intended. Medical interventions have not been complemented by the social supports considered necessary to achieve satisfactory rehabilitation. It had been estimated that between twenty and forty thousand persons would be eligible for such social supports in accordance with the Swedish Disability Act (Socialstyrelsen, 1999). This special rights law from 1993 is the crown jewel in the modern disability reform in Sweden. It is commonly referred to as the ‘LSS’ in Swedish, an abbreviation that will be used alternatively here. In 1998, about two thousand persons with mental disabilities were receiving such help (Socialstyrelsen, 1999). Some years later, in 2001, the number had only increased to 2,700 persons (Socialstyrelsen, 2002). There thus seems to be a considerable underutilisation of supports for people with mental health disabilities, according to the intentions of the Disability Act.

Political scientists study the conditions necessary for carrying out political re-
forms. The breakthrough for such implementation research came in the 1970s when it was realised that public measures did not always result in better societal conditions (for a literature review, see Rothstein, 1994). When studying the problem of underutilisation of welfare benefits, I have chosen my point of departure from Lennart Lundquist’s work *Implementation steering: an actor-structure approach* (1987). He argues that “will, understanding and ability” are required from those actors responsible for pressing a reform forward and into reality. An important group consists of the bureaucrats and managers at the front line, who might be termed ‘street-level bureaucrats’ (Lipsky, 1980). In this particular instance, these would be the professionals who come into direct contact with persons with disabilities. They might be the civil servants who administer social services, but also specialists within the health, medical and social care sectors such as social workers, psychologists, occupational therapists, doctors and others. Successful implementation of such reforms demands an active approach on the part of all professionals involved or those who should be involved, based on knowledge of socio-political reforms and related new ways of understanding regulations and expectations.

Lundquist discusses the importance of bureaucratic ethics for reform work (Lundquist, 1988; Lundquist, 1991). The professional ethical stance when dealing with a reform such as the LSS is to actively support and strengthen individuals to seek, demand and gain access to what is legally due them, including clarification and information about their rights. This seems to particularly apply to persons with mental health disabilities. A passive bureaucracy which limits itself to a legal approach, for example simply pointing out that the LSS states that it is the individual who is required to request support and that no such application has been filed, risks acting in a manner that can be interpreted as unethical. The socio-political intention of guaranteeing both a voluntary (self-determined) system and ensuring an adequate level of social support, presupposes some sort of action and responsibility on the part of professionals.

This is the background context for choosing social workers (called *kurator* in Swedish) within psychiatric services for this particular research project. The project’s purpose was to encourage the social workers at one psychiatric clinic in the middle of Sweden to motivate their patients to apply for social supports in accordance with the Disability Act (Lewin, 2003). Social workers should or could have an important role and contribution, since medical rehabilitation is to be complemented by social supports in order that persons with mental health disabilities can find it easier to participate and manage in their everyday living. The general aim of this study was to find out if part of the solu-
tion to the problem of underutilisation of social support services could be that social workers should be acting as case managers for persons with severe mental health disabilities, especially and more precisely to motivate them to apply for LSS-support to which they are entitled but are not utilising as intended.

As with most other social workers in the overall health care system, they have no mandate or authority for exercising this task. It is the welfare officers (called handläggare in Swedish) in the municipalities and county councils who have this authority and responsibility, including the power to decide if the applicant actually has the right to receive LSS-support and how this support will be designed. The role of the social worker thus is more like that of a counsellor or advisor, while the role of the welfare officer is that of an administrator (Terum, 2003).

Background discussions

*From ‘mentally ill’ to ‘person with a mental health disability’*

Today, we are all more or less equal citizens in the Swedish welfare state. The individual is in the centre, and our relationship to the public sector is regulated in collective norms and confirmed by legislation. In Swedish social politics as well as internationally, certain fundamental values have formed the basis for this system of regulations. The human dignity of each and every individual is recognised, regardless of any real or assumed merit or ability. An individual’s participation in community life and influence over his or her own living conditions are two much honoured concepts in Swedish disability politics. Two longstanding and underlying principles are normalisation and integration, where the aim is that persons with disabilities shall be able to live a life in society like other citizens. The normalisation principle has its roots in Scandinavia in the 1960s, most notably by front figures Bengt Nirje and Niels Erik Bank-Mikkelsen (Nirje, 1992; Bank-Mikkelsen, 1980; Tideman, 2000; Lewin, 1998). Their ideas concerned the intellectually disabled, but have also come into use internationally for others, including people with mental health disabilities (cf. Ramon, 1996; Markström, 2003).

The above sub-heading title indicates that a development is underway in two respects. First, the individual is brought to the fore as opposed to the illness or disability: being a patient or having a disability does not make up a person’s entire existence or identity. And second, there is a move away from a ‘medical approach’ regarding mental illness: the emphasis is consequently not primarily on the diagnosis. Instead, there is a focus upon the consequences that mental illness, as with other impairments, long-term illnesses and many injuries, can lead to: consequences that affect how one copes with everyday living (cf. Hyden, 1998;
Markström, 2003). This tendency is still an emerging one, and has not yet broken through in all its force. It is a development embraced by politicians with a rhetorical commitment to disability issues, representatives of various organisations for disabled people, and by some researchers. It is also recognised by some far-sighted members of the professions. Often however, it seems as if some citizens with disabilities themselves have not come to adopt this way of looking at things (cf. Grunewald, 1999; Hydén, 1998).

This change in perspective also finds expression in the new WHO International Classification of Functioning, Disability and Health (ICF). This marks an attempt to achieve a synthesis of various perspectives on human functioning and disability, making use of a 'biopsychosocial' model. The medical model which views disability as a problem of the person and one which necessitates medical care by professionals, is complemented with a social model of disability. Social models view disability primarily as a socially-created problem which thus necessitates social action in order to modify the environmental conditions and thereby allow for participation of persons with disabilities in all areas of everyday life in their societies (WHO, 2001; Bickenbach, Chatterji, Badley & Üstün, 1999). Such a way of thinking is also totally in line with the ideas of normalisation: it is not the person who needs changing, but rather the surrounding conditions at all levels.

Rehabilitation concerns the entire life situation
The term ‘rehabilitation’ is a controversial concept, as is the term ‘disability’. Today, the concept of rehabilitation is typically extended beyond being simply a matter of health and therapy, and more commonly now means looking at the entire living situation of an individual and in a broader societal context. Thus, a programme of rehabilitation supports and interventions has to be based upon an overall view, where the individual’s own aims and preferences are at the centre, and also taking into consideration his or her rights as a citizen. Often, rehabilitation necessitates the involvement of different sectors of society, and at different levels, placing great demands on cooperation and coordination efforts. The World Health Organisation arranged a global conference titled Rethinking Care in 2001, where one of the recommendations was that the aim of rehabilitation should be “equalization of opportunities for all disadvantaged people” (Hanssen & Lindqvist, 2003). One can recognise this phrasing from The U.N. Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1994).

Some people with long-term mental health problems will come to spend much of their lives in various parts of the chain of psychiatric care facilities. But important developments have taken place during the second half of the 20th century. Perhaps most notable is the
process of deinstitutionalisation in the Western world and the move towards community-based services, including for people who need psychiatric care. Part of this pattern in Scandinavia, which is especially noticeable during the last twenty years and very much influenced by normalisation ideas, is the shift of responsibility from the health care sector as single provider to the generic municipal authorities when it comes to social support. This recognises peoples’ fundamental needs as fellow human beings, emphasising stable housing and housing support, meaningful daily activities and employment, improvement of the capacity for everyday activities, and prevention of loneliness by supporting leisure and social opportunities. However, results of actual achievements thus far show that living standards and level of living conditions and welfare continue to be low (Söder & Sandvin, 1998; Brunt, 2002; Markström, 2003; Hansson, 2003).

**LSS and other relevant Swedish legislation**

The Social Services Act together with the Health and Medical Care Act are two main pieces of Swedish universal legislation, and all citizens are entitled to interventions and supports according to these acts. But Sweden has also experienced a substantive effort concerning the ‘special’ needs of people with disabilities, and the Disability Act known as LSS supplements these two other acts and is especially intended to better meet the needs of citizens with more severe disabilities. It stipifies ten enumerated types of support. The local municipality is responsible for all except one of these. Examples of measures are help from a personal assistant, residential arrangements with special service, contact person, and daily activities. However, persons with the most severe physical or mental health disabilities are not legally entitled to the LSS-measure known as ‘daily activities’. The reason given is lack of financial resources. The county administration is responsible for one support measure called ‘advice and personal support’, i.e. higher level expertise support from the county health care system. Such support must not involve ‘treatment’, and if that is the case the support must be decided and provided in accordance with the Health Care Act.

The individual person must apply for LSS-support him/herself. The support is voluntary, meaning that it is chosen and self-determined. Those legally entitled to support according to LSS legislation are those with intellectual disabilities, physical or mental health disabilities. It is considered that the mere existence of a diagnosis of intellectual disability means that there is need for some kind of support and service from society. However, to be eligible for support when having other forms of disability, the diagnosis becomes one of minor importance. Instead, certain other criteria must be met: the disability must be long-lasting; not due to normal aging;
cause considerable difficulties in daily life; and lead to extensive need for support and service.

Regarding the LSS-measures that the municipality is now responsible for, the same type of measures can also be provided in accordance with the previously enacted Social Services Act. There are some decisive differences however. The most important concerns the high level of ambition with regard to quality and influence. The aim of LSS is ‘good’ living conditions, not just an ‘acceptable’ standard of living, the latter being the target of the earlier Social Services Act. The idea is that LSS-support should fulfill the person’s individual, psycho-emotional, physical and social needs, often in complementary or supplementary ways. Care and support can consist of direct practical assistance or be of a more advisory nature, entirely dependent upon the individual’s needs, wishes, and possibilities. Of particular relevance for people with mental health disabilities is the observation that help may be necessary for planning and structuring everyday life, even though the individual may be capable of physically carrying out the task itself (Socialstyrelsen, 2003).

The Swedish Government clarifies the concept “acceptable standard of living” according to the Social Services Act as an expression for certain minimum demands for measures concerning quality (Prop. 2000/2001:80). Support provided in accordance with LSS in order to achieve good living conditions, means that the individual can demand support on a greater scale and that the support is individually planned in another way than that required by the Social Services Act.

The Social Services Act to a limited extent intends to provide citizens with certain rights, including the right to appeal decisions. The Disability Act (LSS) however offers support as an unconditional right if there is a need. Necessary resources must be made available. This means that the welfare officer of the responsible authority is not able to reject an application on account of a shortage of resources, often described as ‘short-term insufficient funding’. LSS is thus a very strong law in specifying specific rights, and a law that gives priority to particular groups. This means that the LSS gives priority to particular conditions affecting people with severe disability, rather than (for example) old people with the same conditions (Lewin, 1998). Finally, LSS-measures are free-of-charge, whereas some fees may be charged for support and care supplied according to the other two previous laws.

It should also be mentioned that there has been a reform of special relevance for mentally disabled people. The 1995 Swedish Mental Health Reform follows the international pattern to normalise living conditions for these individuals. According to The Municipal Financial Responsibility Act, local municipalities
must pay for discharged patients that are deemed by a psychiatrist as fully medically treated. This was supposed to facilitate integration into the community by stimulating the municipalities to develop new forms of housing supports, supported employment, etc. The act was complemented by state subsidies to facilitate such a process.

In connection with this reform there was also an experimental programme of case management, which resulted in an increased number of LSS-measures and a decrease in the need for health care measures (Björkman, 2000). There are different varieties of case management, such as models that integrate clinical care with care in the home by a team, or an independent case manager. The Swedish choice is in effect an expression of the so-called ‘strengths model’, where the case manager works as a representative for an individual. In order to help the individual achieve his or her goals, the manager supports the individual and functions as a go-between and mediator to try to facilitate support from other sources and care-providers. The model focuses on the individual’s self-determination, choice and resources (Mueser, Bond, Drake & Resnick, 1998).

Methods

This section describes the research project, including a discussion of ethical aspects and methods of data collection and analysis of findings. The project consisted of two parts. The first part was a preparatory in-service training programme for the social workers attached to a Swedish psychiatric clinic (dealing with ‘psychosis and rehabilitation’), conducted by myself as the project leader. The second part was interventions carried out by these social workers, with the aim of increasing the number of applications from ‘patients’ registered at the clinic, in accordance with their right to seek supports under the Swedish Disability Act. The project ended at the point decisions were made, and did not follow up any possible consequences or effects of the support.

Project part 1: In-service training for social workers

The in-service training programme started with a postal survey questionnaire to all (N=10) social workers working at the clinic. The intention was to document and explore their opinions about the LSS and on their own work in relation to this legislation when compared with the previously-enacted Social Services Act. The response rate was 100 per cent. Respondents were asked to take a stand on the following statements:

- LSS-measures are suitable for some of my patients;
- It is important that some of my patients apply for LSS-measures;
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- It is part of my job to motivate some patients to apply for LSS-support;
- I believe that support in accordance with the Social Services Act is sufficient for my patients;
- There is no need for a complementary legislation such as the LSS;
- My patients know of the LSS but they do not want to get support in accordance with "a handicap act";
- It is no use to encourage my patients to apply for LSS-support as they will not be granted such support.

The structured response alternatives were scaled as followed: Agree completely; Agree partially; Do not agree; No opinion.

Responses to this survey were then used as a basis for the content of the in-service training, with a focus on bureaucratic ethics. Eleven discussion seminars were held under the theme: What are the ethical boundaries for our actions? The seminars started in September 1999 and continued during the intervention year 2000 until November. The ten social workers were encouraged to raise questions about what they considered to be ethical problems in their daily work. The statements of the survey were also continuously brought up by them, as well as by myself. Together we discussed the problems in the framework of Lennart Lundquists works on bureaucratic ethics. A special focus was put on the specific ethical dilemma faced by bureaucrats generally in the caring sector: the conflict between the principle of respecting the integrity, self-determination and autonomy of the individual and the principle of giving good care. These two principles are prescribed by law in the LSS and the Social Services Act.

Project part 2: Intervention by the social workers

According to two follow-up reports of the mental health reform in 1999 and 2000, it was estimated that between 150 and 400 persons (out of a total of just over 1,500 patients registered at the clinic) ought to be eligible for LSS-measures. The higher figure emanates from assessments made by staff in psychiatric care settings (Jansson, 2000), the lower from a renewed assessment of the same population made by the social workers of the clinic (Engberg & Lovén, 2002). During the intervention year 2000, nine of the originally ten social workers included patients consecutively in their normal professional activity. The inclusion criterion for the intervention was need of LSS-support that was not being met according to the follow-ups.

The social workers documented the initiating and motivational work in a special appendix in the individual’s medical record file. This appendix was constructed jointly by the social workers...
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and me as project-leader during the in-service training. The content of the appendix ranges from questions on demographic data for the LSS-persons, who initiated the talk about application for LSS-support, the persons knowledge of LSS, etc., to questions on what measure was applied for and the resulting decision. During the preparatory stages of the appendix, together we came to an agreement that the social workers should raise the question of LSS-support in at least four meetings with their clients before one could regard the intervention as closed. After each occasion, the social worker would mark on a diagram the person’s attitude – as judged by the social worker – with regard to applying for LSS-support. The alternatives were: The person wants to apply for LSS-support; the person might want to apply for LSS-support; the person is not interested in applying for LSS-support; the person does not want to apply for LSS-support.

Descriptive data on included patient participants
During the year of intervention, fifty-four patients were included through their meetings with nine social workers. The average age was 44 years (40 years for men and 48 for women). Other descriptive data concerning demographic and clinical background for the participating patients can be seen in table 1.

Table 1. Sex, highest level of education completed, present daily activity, diagnosis, duration of symptoms for subjects, according to sex (n=54; valid percent given when data is missing).

|                                      | Men | Women | Total |
|--------------------------------------|-----|-------|-------|
|                                      | Number | %    | Number | %    | Number | %    |
| Sex                                  | 30    | 56    | 24    | 44    | 54    | 100  |
| Completed basic secondary education   | 15    | 54    | 12    | 50    | 27    | 52   |
| No present daily activity             | 25    | 83    | 18    | 75    | 43    | 80   |
| Diagnosis of schizophrenia            | 16    | 53    | 14    | 58    | 30    | 55   |
| More than 10 years duration of symptoms | 20    | 67    | 19    | 79    | 39    | 72   |
There were slightly more men participants (56%) than women (44%). Half of the subjects had completed nine-year compulsory school, while only one had completed a university education. Only one-tenth had anything meaningful to do during the day-time. More than half had a diagnosis of schizophrenia. Among the others, nine had an intellectual disability or autism and related conditions. Almost three fourths had suffered from their condition for more than ten years.

Within the framework of the project, it is not possible to indicate how representative the 54 subjects are for the entire-group (150-400 persons considered eligible for LSS-measures) in regard to sociodemographic and clinical backgrounds.

**Ethical aspects**

The in-service training and the interventions can be considered to be within the framework of normal professional activities of the social workers. For the patient participants, the project was an integral part of the clinic’s own quality assurance work regarding its ambition to help patients acquire support from society other than purely medical help. The appendices (copied for the project) to the medical record files contained no confidential information such as name or personal identity number. Any invasion of personal integrity was therefore considered minimal. The expected benefits for future patients at the clinic as well as for other persons considered to have severe disabilities were deemed greater than the use of personal information and possible invasion of privacy for the patients whose medical record appendices were analysed. The questionnaire sent to the social workers contained no personal details, and thus presents no ethical problems for them either.

**Assessment of the results**

Political scientist Evert Vedung points out the importance of assessing activities of public administration. Assessment may serve as a learning goal and be of use for future decision making and other activities (Vedung, 1998). The results of this project have been assessed from two different angles.

First, the impact of the intervention was assessed by answering the following question: Did the persons with a mental health disability, considered to be in need of LSS-measures in the follow-ups, apply for such measures?

As Vedung points out it may not be sufficient to look only at the goal of the intervention, in this case the number of applications for LSS-measures. If we want to learn something useful for the future, it may also be of interest to evaluate the quality of the intervention work carried out by the social workers. This second task means that the actions of the social workers were discussed from the perspective of bureaucratic ethics. The following questions were put to the material: Had the social
workers understood the political intention that also severely mentally disabled persons should benefit from the Disability Act (LSS)? Using terms from Lundqvist’s previously mentioned writings; did they have the will and ability to pursue the implication of the Act?

Results

Opinions of the social workers before the intervention

Results from the initial survey showed that 70% of the social workers agreed completely that LSS-measures were suitable for some of their patients, and 30% agreed partially. The statement about the importance for some of the patients to apply for LSS-measures resulted in the same figures. One social worker did not give an opinion on the statement that it was part of the job to motivate some patients to apply for LSS-support. For the remainder, 89% (N=8) social workers agreed completely and one (11%) agreed partially with that statement. However, there was a certain ambivalence, both with regard to their opinions about how appropriate the LSS was, and to the work of motivation which was considered necessary in order to get the patients to apply for LSS-support. For the remainder, 70% agreed partially with the statement that their patients knew of the LSS but did not wish to receive support in accordance with “a handicap act”. Finally, a majority (60%) of the social workers partially agreed that it was no use to encourage the patients to apply for LSS-support for fear that the applications would be rejected. 40% did not agree at all.

These quantitative results were confirmed in the following seminars, especially the earlier ones preceding the intervention phase. A recurrent topic was the question of integrity and autonomy. Some of the social workers expressed frustration about motivating their patients out of fear that this might violate an individual’s integrity and autonomy.

LSS-work by the social workers before the intervention

During the years preceding the intervention, 1994-1999, the social workers had been involved in just over 60 applications, on average about ten cases a year. Variation among the social workers was considerable: between one and thirty cases. This means that on average, a social worker has about one such case a year.

Initiation of the application process for LSS-measures

The social workers actively recruited the participant patients on the basis of the follow-ups mentioned earlier (Jansson, 2000; Engberg & Lovén, 2002). In a few cases another member of staff, a relative or other closely involved person such as an appointed administrator (a type of guardian or citizen advocate, called god man in Swedish), raised the question. Commonly expressed additional motives for initiation of the application process were ongoing plan-
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ning work or actual needs, for instance leaving the hospital to live in one's own home. To the knowledge of the social workers, not a single application process was initiated by the patients themselves. Knowledge of LSS was extremely limited among the participating patients: only eight persons (15%) were familiar with LSS.

Applications for LSS-measures
During the intervention year, the nine social workers were involved with 54 individuals, or in other words an average of six individuals per social worker. The number of applications was 44, from 36 patients. Nineteen of these had a positive attitude to applying for LSS-measures from the very beginning. An originally positive attitude could turn into a negative attitude before finally ending up as positive again. In some cases, two LSS-measures were applied for, which explains why the total number of applications exceeds the number of applicants. This means an average initiation of almost five applications per social worker.

Thirteen participating patients experienced an application process that had not yet led to an actual application to the municipality welfare officer. In this category, motivational work had been going on during the intervention period, but for various reasons had not led to a decision. The social workers discontinued the motivational work with five individuals due to continuously negative attitudes.

Table 2. Number of LSS-applications according to measure, if application is approved, application rejected, and no decision reached.

| LSS-measure                                      | Number of applications | Approved | Rejected | No decision |
|-------------------------------------------------|------------------------|----------|----------|-------------|
| Advice and support                              | 2                      | 1        | 1        | -           |
| Personal assistant                              | 1                      | 1        | -        | -           |
| Personal contact                                | 19                     | 9        | 5        | 5           |
| Short stay away from the home                   | 2                      | 1        | -        | 1           |
| Residential arrangements with special service   | 20                     | 14       | 5        | 1           |
| Total                                           | 44                     | 26       | 11       | 7           |
Table 2 shows the results of 44 applications from 36 individuals during the intervention year. The Disability Act offers ten different measures. However, only five of them were applied for: Advice and other personal support; Help from a personal assistant; Help from a personal contact; Short stay away from the home; and Residential arrangements with special service for adults.

If we take a closer look at the figures, we can see that the LSS-measure most frequently requested was “residential arrangements” (20 applications), followed by “contact person” (19 applications). Twenty-six of the applications were approved, eleven were rejected, and seven had not been decided upon at the end of the intervention period.

Analysis of the results

The outcome of the intervention
The outcome of the intervention was 44 applications by 36 persons. The earlier mentioned follow-ups estimated that between 150 and 400 patients in the catchment area would benefit from LSS-measures. Which assessment of needs is correct? Maybe it is not even possible to get a correct figure of what can be called ‘potential rights holders’ (Lewin, 1998). As mentioned earlier, the higher figure (400) emanates from the regular staff and the lower figure (150) from the social workers. The concept of need is a fundamental and much disputed concept (Bradshaw, 1977; Brunt, 2002; Culpitt, 1992; Eriksen, 2001; Lewin, 1998). Additionally, these are expert estimates, not the service users own views. There may of course be others of the total of just over 1,500 patients in the catchment area that could also be considered as potential rights holders. Another problem when assessing the results of this project is that the social workers have not been asked whether the included participating patients belonged to the smaller population, assessed by them, or to the larger population, assessed by the regular staff.

With these considerations in mind, for the following discussion of results of the intervention, I have chosen the estimates of the social workers themselves as the reference population. The results then show that approximately one fourth of these persons applied for such support. One interpretation is that the intervention was not very successful. A more positive interpretation is that every LSS-application is a ticket that maybe will lead to better living conditions. The two most commonly granted support measures were residential arrangements with special support service and a contact person. Hopefully those measures will assist in improving everyday life, in areas such as housing and housing support, lessen loneliness, and maybe enhance the capacity for greater participation in society, a more ‘normal life’ like that of other citizens. Thus, a small number might be considered some sign of success, and in ac-
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cord with legislative intentions. Some of the other LSS-persons, with whom the motivational work started late in the intervention year, may also eventually have applied for such support. We also do not know how many applications were made in a different manner, directly to the municipal or county administration welfare officers.

The social workers and welfare officers - from the perspective of bureaucratic ethics

Has the social workers behaviour been characterized by activity or passivity? In this study project, there is not a single incidence of the affected individual taking the initiative towards considering an application for LSS-support. For a variety of reasons, about which one can only speculate and are beyond the scope of this study, the participating patients have been passive. This passivity may be interpreted as being an expression of the fact that they are not able to utilise their rights. A vital condition for a successful implementation of the LSS is thus missing for this important group of actors (Lewin, 1998). Mikael Sandlund describes how a lack of awareness of one’s own condition or illness as well as other factors contributes to a reduced ability to make decisions (Sandlund, 1999).

In contrast, the social workers have shown a considerable motivational activity during the intervention period. Previously, they only had on average about one LSS-case per year (or 60 cases for the whole professional group for the whole period 1994-1999). During the year 2000 they have had an average of almost five LSS-cases. Evidently the social workers have manifested a will to pursue the intentions of the LSS-reform.

This will seems to have been strengthened during the project. As mentioned earlier, responses showed a frustration about motivating patients because of fears of violating an individual’s integrity and autonomy. Others indicated a reluctance to encourage applications out of fear that they would be rejected. Some answers demonstrated an opinion that the patients did not want to get support in accordance with “a handicap act”.

The other answers, on the other hand, showed that the social workers seemed to understand the political intentions behind the LSS. They could also be considered to have the necessary professional competence, an ability that was supported by the positive attitudes of their superiors to more actively promote an increase in applications from their patients.

The ethical dilemma of respect for the self-determination of the individual contra the insight that good support from society is beneficial to rehabilitation turned out in reality not to be a concern during the intervention phase. The participating patients had positive
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and constructive attitudes towards applying for LSS-support. And in those instances where there was a dilemma, the social workers seemed to have had the ability to deal with this in a manner that is acceptable from the perspective of bureaucratic ethics by using a ‘mild paternalism’, for example by raising the question of LSS-support on repeated occasions, allowing them the whole time to respect the autonomy and choice of the individual.

Whose judgement won?
Of the 44 applications from 36 subjects, approval was granted to 26, seven applications were still being dealt with (at the end of the intervention), and eleven were rejected. The fears of the social workers that applications might be rejected by the welfare officers of the responsible authorities were thus realised in some instances. The reason given for rejecting an application was usually that the person applying for support did not belong to the target-group for the Disability Act. This is also the reason that the National Board of Health and Welfare has found to be common for people with mental health disabilities (Socialstyrelsen, 1999).

On the occasions where an application has been rejected, one “expert opinion” (that of the social worker in psychiatric care settings) in combination with the personal opinion of the applicant, has been contrasted with another “expert opinion” (that of the welfare officer who grants or rejects the applications). Whose opinion is correct, in the sense that it is in agreement with the intentions of the law-makers? It is my view that the political intention has been clearly expressed both in the preliminary work for the legislation and in official advisory documentation from the National Board of Health and Welfare. A government report on “disability, welfare and justice” states that support measures shall be based upon the needs that the individual concerned considers should be urgently met. Needs are placed on an equal status with interests: throughout, it is stated that the content of various LSS-measures and their planning shall be based upon the interests of the individual (SOU 1991:46). When this bill was presented to parliament, it was formulated in a similar manner (Prop. 1992/1993:159). Such expressions of intent can be interpreted as implying a very strong emphasis on the self-determination of the individual. For the participating patients whose applications were refused in this study project, it is apparent that their voices did not have a decisive role. The welfare officers have evidently considered themselves better able to judge the needs of the applicants, better than both the affected individuals themselves and the social workers, as well as the psychiatrists who have in some cases supplied certificates.

Even if the intention of the LSS is to minimise discretion in needs assessment and decision making, different judgements thus seem inevitable. It is
possible to differentiate between positive and negative discretion. Positive discretion is related to professional autonomy: to decide in what way a given goal is realised in the best way. It is also called professional or clinical discretion and is a way to find out what is the right action in a given situation. This autonomy presupposes insight in the situation, theoretical knowledge and practical experience. Negative discretion puts focus on norms that restrict and define the discretionary space (Terum, 2003; Alvsvåg, 2002).

Considering the social workers as the main actors in this project, they could be said to have exercised their professional or positive discretion in their assessment of needs, but they did not have any mandate to use negative discretion. The consequence of their discretion was motivational activity. The situation for the welfare workers was more complex. Not only did they exercise positive discretion in the assessment of the applicants needs. They also used negative discretion in their exercise of authority to grant or reject LSS-measures to the applicants. This sometimes resulted in a negative end result from the point of view of the individual person with mental health problems.

Welfare officers as gate-keepers?

One welfare officer is claimed by a social worker to have said that he/she simply did not approve any LSS-measures at all to persons with mental health problems. If this is true, such action is totally unacceptable from both legal and ethical positions. A person has a right to apply for LSS-measures and to have that application properly considered, and this includes people with mental health problems. Any other response means that the rule of law is not being applied, particularly in regard to access to the law (Frändberg, 1986). Such findings support the claim that welfare officers can act as ‘gatekeepers’ for LSS-measures. One can ask oneself whether they consider such a role as a matter of loyalty towards their superiors and municipal politicians, or whether it is some personal belief or interest. The result in any case is that they may ‘ration’ access to LSS-measures, with no legal basis for doing so (Lipsky, 1980; Lundqvist, 1991).

A report from the National Board of Health and Welfare confirms the conclusion of imperfect bureaucratic ethics. Welfare officers tend to consider the ambition of LSS no higher than that of the Social Services Act. They also find it difficult to apply the different criteria for eligibility such as “enduring” disability, and also express lacking knowledge about mental illness and its consequences (Socialstyrelsen, 1999). Thus, welfare officers do not always seem to manage their discretion in correct ways. Or with Lundquist’s words, they do not always understand the political intentions with the LSS or always have the ability needed to realise them (Lundquist, 1987).
Conclusion

A central conclusion is that one professional group, the social workers, among the many different categories of experts that come into contact with people with mental health disabilities has succeeded in bringing about an increase in the number of applications for support in accordance with the Disability Act. They have acted as counsellors or case managers and succeeded in increasing the awareness of their patients about their rights and also how to make use of them. Such awareness needs to be dispersed among other staff groups. The system of municipal case managers, or personal representatives, which is now permanent, will also presumably be of importance in increasing the frequency of applications. Finally, the results from this study may provide various disability interest groups with arguments in their continued efforts to encourage individuals and relatives to learn about and claim their legally-entitled rights.

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