REHABILITATION IN THE HOME – INTERPLAY AND CONFLICTS BETWEEN DIFFERENT PARTIES

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Abstract: In this article an organisational and professional perspective is combined with a user approach to analyse the difficulties and obstacles that arise when rehabilitation takes place in the home. The reason for this is that organisations appear to play an increasingly important role in the implementation of welfare policies such as care, home help services and rehabilitation in step with decreasing stringency of central government steering. This increased leeway also brings the potential for increased autonomy for the elderly and the disabled in need of rehabilitation. The fact that professional groups belong to different organisations, have various administrative procedures and aims for their activities means that the goals of professional helpers are not always in accord with the needs and wishes of the care receiver. The article highlights a number of collisions and difficulties that occur when rehabilitation is provided in a home-setting. It is argued that the opportunities of success in rehabilitation in the home lie in the rehabilitation staff respecting and starting out from the care receiver’s values, preferences, goals and needs. Professionals must increasingly organise their work around the holistic needs of the disabled person rather than around the individual fields of specialists, who are needed to meet these needs.

Introduction

This article describes and analyses the difficulties and obstacles that arise when rehabilitation takes place in the home. This is an attempt to combine an organisational and a professional perspective with a user perspective on the issue in question. The reason for this is that organisations appear to be playing an increasingly important role in the implementation of welfare policy, in step with the decreasing stringency of central governmental control. With an increased degree of freedom in public services such as care, assistance and rehabilitation, organisations take on a more independent role in performing different tasks. Parallel with this development the influence of patients, users and relatives is reinforced, and they now have formal possibilities to influence the forms in which professional help is given. This increased leeway also makes the forms of welfare policy.
more varied, or heterogeneous, as regards cooperation and conflict within and between organisations, but can also bring the potential for an increased measure of autonomy for the elderly and the disabled in need of rehabilitation.

Rehabilitation in the home normally involves several professional groups, belonging to different organisations. These in turn have different rules, administrative procedures and aims for their activities, which means that cooperation is not something self-evident. On the contrary, everyday collisions and difficulties can be counted on. In connection with rehabilitation in the home, the patient and the patient’s relatives often take on a key role alongside the professional rehabilitation staff (nurses, physiotherapists, occupational therapists, counsellors, psychologists, etc.). The fact that professional power and expertise, often in the context of large-scale hierarchic organisations, is not always in accord with the needs and wishes of the care receiver, is an increasingly urgent problem when care and treatment are provided in decentralised forms, and when rehabilitation is increasingly provided in a home setting. These shortcomings often take the form of communication difficulties between the care provider and the care receiver caused by a clash between different types of knowledge, based on different systems of values, needs and fields of interest.

Below, some important theoretical and methodological starting points are stated. Subsequently, there is a description of the parties and organisations operating in the field of "home setting rehabilitation", and of their respective tasks in a Swedish context. A number of significant cooperational and conflict-related dimensions are illustrated with the help of empirical material from the research project in which we have been involved. The article shows that the increased leeway for organisations and professions to shape rehabilitation in the home isolates a number of dilemmas in the interplay between care receivers and professionals. In order to understand the coordinative problems and the possibilities of circumventing them, the parties must be seen in a wider context, from the point of view of the institutional conditions for each organisation and profession.

Organisational analysis and rehabilitation in the home

Within organisational research, it has long been recognised that the connection between the organisation and its environment is central to the form the activity takes. In the so-called New Institutionalism, organisations are perceived as a result of human interaction in different situations (Scott 1995:xv). Organisations, therefore, are social constructions in the sense that they can be perceived as permeated by their surroundings; the surroundings create, rather than influence, organisations and give them certain structural features and operational principles.
(Meyer 1994:32). When the ‘surroundings’, then, are ‘built into’ the organisations, they act as a set of given behavioural traits, modes of action and cultural interpretative models. Care, assistance and rehabilitation are to a large extent incorporated, not only into several different scientific and professional practices, but also into political action plans and legal systems. Instead of regarding organisations as parties that from the start act rationally with given preferences, in the New Institutional perspective there is an emphasis on how the representatives of the organisation perceive the context in which they are, which demands they must adapt to in order to receive support and legitimacy from the environment, and which rules must be followed.

The environment of organisations essentially consists of different institutional settings. The term institution, then, is central to this variant of organisational analysis. Scott (1995:33) suggests that institutions consist of cognitive, normative and regulatory structures and activities that give stability and meaning to social actions. With regard to institutions that uphold welfare policy, not least of all care, assistance and the social services, the cognitive element is reflected in views that are considered self-evident by the expert and the care receiver respectively, the normative element has to do with what is considered good and desirable, and the regulative element concerns which rules should apply and be followed, i.e. the clients in these sectors have a legal right to certain benefits and services as stated in the social welfare law, and professionals have a duty to perform their work according to acceptable medical and caring standards as stated in the Swedish Health and Medical Care Act and its numerous secondary regulations.

An important aspect in this context is that we are dealing with a series of separate institutional sectors that may be in conflict with each other. This is fundamental to our understanding of the conditions under which organisations and professions are operating. As Scott (1991:167) maintains, we must go in the following direction: “from a conception of the institutional environment to one of multiple, alternative institutional environments”.

Friedland & Alford (1991:248) pursue a similar line of thought. Instead of speaking of institutional sectors, they hold that in western society one can distinguish different institutional orders. They argue that society is built up of “multiple institutional logics which are available to individuals and organisations as a basis for actions” (Friedland & Alford 1991: 253). The fact that institutions are potentially in conflict means that they allow individuals and organisations several possible courses of action. Institutions not only set limits for which goals may reasonably be aimed at - they also define which means may reasonably be used. When organisations have similar missions and practices, have roughly similar tasks and work with the same
clients they come to belong to the same ‘organisational field’. According to DiMaggio & Powell (1991:64-65) they "constitute a recognized area of institutional life: key suppliers, resource and product consumers, regulatory agencies, and other organisations that produce similar services or products.”

Rehabilitation in the home setting of the elderly or the disabled is an organisational field in which a number of parties meet, and have much in common, through their working with the same care receivers, and through carrying out parts of the same work process, referring or delegating tasks between each other. It is an area of conflicting driving forces, principles and applications. Belonging to the same organisational field may facilitate cooperation, but it can also be a source of competition. Here it seems appropriate to use the term "organisational domain" with reference to "the claims organizations make with respect to products and services provided and populations served" (Scott 1992:126). Such claims usually relate to a number of other organisations, suppliers and customers, which means that it is an open question to what extent there is consensus over what constitutes the rightful domain of one organisation or the other. A vital domain claim for the rehabilitation staff at the primary health care centre is the right to assess the care-receiver’s capacity for mobility and activity, and to set up treatment and exercise programmes to improve this. In a corresponding way, it is the domain claim of home help services to assess whether the care receiver has sufficient need of help to be given personal service, in the form of practical help in the home, or help in social activities etc. And the care receiver him/herself (together with his/her family) makes claims to managing daily life as far as possible without assistance and to being able to pursue his/her interests.

Work on concrete rehabilitation, practical help in the home through home help services and the user’s own activities are fields in which the domains of several organisations and professions to a large extent overlap. Consequently, it is there that also collisions can occur, leading to the perception that the professional help is less effective. In the next section we shall outline what these conflicting elements are.

The home as an arena for the rehabilitation parties

The home as an institutional setting. The home is the domain of the patient (and the relatives). In the home more than anywhere else, the integrity of the care receiver is respected. The home is not designed to fit in with professional care and rehabilitation. Care and rehabilitation often mean that changes must be made to the patient’s home (thresholds, mats, hoists and other devices). The goals of rehabilitation must therefore be adapted to the patient’s or relatives’ wishes, to a greater degree than if corresponding assistance is given in an institution. The
autonomy that nursing and rehabilitation must refer to therefore becomes complex, because not only the care receiver, but also the relatives, can make a claim on shaping the actions. Autonomy, as a guiding principle in home-setting rehabilitation, presupposes that the professionals re-define their roles, from treatment-provider to information-provider, tutor and implementer of the care receiver’s wishes (Arras & Dubler, 1994; Collopy et al. 1990).

Care and rehabilitation in the home thereby makes demands that the team of professionals co-operate, which is not always the case. The hierarchic and expert-dominated order that characterises institutional care must now be re-defined to achieve an adequate balance between the power blocs, i.e. a kind of partnership between care provider and care receiver. In such a partnership the common dilemma for care provider and care receiver is to construct a common view of the care receiver’s rehabilitation and future life. This presupposes that the individual’s experiences and needs are integrated with professional knowledge – knowledge that quite often is fragmentary, in the sense that each different professional group only knows "its field". The layman’s (care receiver’s) knowledge of illness and health is instead based on the values instilled by the experiences of his/her own life (Fitzpatrick et al., 1984; Helman, 1994). The international debate of recent years has largely been about how to deal with these two worlds that are represented on the one hand by the professionals and on the other by care receivers and their relatives (Clark, 1996; Delbanco, 1992; Gage, 1995; Reiser, 1993).

The welfare policy as an institutional setting. The logic applied by welfare bureaucracies is to fit individual situation-specific needs into such routines and procedures as are compatible with the political mandate and legal framework of the organisation. Each organisation must therefore cope only with categories of clients that clearly fall within its jurisdiction. Such a "compartmentalization of clients’ needs" (Hasenfeld 1992:16) implies that officials specialise by attending to a limited set of client attributes perceived to be within their range. A large proportion of the benefits, social services and treatment under the welfare policy, however, is manifested in the encounter between the client and the welfare bureaucrat. Human service functions performed by formal organisations are usually standardised and fitted into routines, but the administrators who come into contact with the clients are under considerable pressure to individualise the contact. Street-level bureaucrats working in human service organisations often find themselves in a dilemma: on the one hand, they must act according to formal rules and procedures; on the other hand they must investigate, assess and solve problems in a manner that benefits the client (Lipsky 1980, Johansson 1992). Home help managers and community
nurses in the care services for the elderly often find themselves in the dilemma of whether to give each care receiver social service and rehabilitation "of good quality on equal terms", at the same time as they are expected both to follow the set routines of bureaucracy and meet the organisation's budgetary demands. To appraise whether the needs of the elderly and disabled are great and long-lasting enough to be able to merit home help, rehabilitation, early retirement, a disability pension, etc. is a task handled within this sphere.

The logic of the professional form of knowledge. The expansion of scientised professions and professionals in the field of health and welfare policy has been remarkable during recent decades. Professional knowledge is a vital part of the cognitive processes involved in the creation and reproduction of institutions. It shapes social order with the help of a shared conception of the situation and determines one's order within it. The meaning of the term professional is that the occupational group in question has a monopoly on current knowledge on the strength of long theoretical education built on scientific theory, technical skill, relevant degrees, practical experience, diplomas etc. Such occupational skill is considered useful to society, which is thought to justify a considerable amount of autonomy and self-regulation. The medical profession is often seen as a pure model in this context: the authority of the medical profession implies an exclusive right as far as medical decision-making is concerned, i.e. diagnosing and treating patients. An important aspect of this is the recognition of the status that medical doctors are given by laymen. Hence, doctors do not have to accept criticism and judgements from the uninitiated, concerning the definition of quality and adequate treatment (Freidson 1988, Murphy 1987).

When it comes to rehabilitation in a home setting however, the doctor plays a more unobtrusive role. The personnel groups that the disabled and the elderly are most in contact with are community nurses, occupational therapists, physiotherapists, home help managers and home helpers or nursing auxiliaries. These groups do not have the professional attributes mentioned above. Therefore they have instead been referred to as semi or para-professions. Etzioni (1969) contends that they differ from professions owing to shorter training, lower status, less supremacy in communication with the clients, less developed body of specialised knowledge, and less autonomy from supervision. Freidson (1988) considers that the subordination of para-professions within the system of professional dominance has to do with the fact that the social division of labour within the health and medical care sectors has been built up by weight of social and political power. He states the following: "to escape subordination to medical authority it must find some area of work over which it can claim and maintain a monopoly, but it must
do so in a setting in which the central task is healing and controlled by medicine” (Freidson 1988:66).

The work of physiotherapists and occupational therapists is historically given legitimacy by its relationship to the physician’s work. These occupational groups often carry out research in the medical faculty, but their occupational activities are increasingly located outside the hospital walls. They therefore have a base from which they are able to develop their own viewpoint and thereby have certain possibilities of avoiding being controlled by medicine. In this new context they gain their status and legitimacy not principally through being helping hands for the doctors, but through the good they do for the patients.

Home help managers are incorporated in the municipal welfare bureaucracy, where they are decision-makers and gatekeepers of the social rights existing within care for the elderly. They are not directly involved in care of the elderly, but instead have managerial prerogatives vis-à-vis the home helpers who come into direct contact with the care receivers. Neither do they have any formal professional knowledge, but rather have intimate knowledge of social welfare laws and organisational skills. The home helpers have the most subordinate position: they lack a base of knowledge founded on science, and also have a subordinate position as employees in the organisation. The negotiating base that in other occupational groups is reinforced by professional knowledge, then, is very weak in the case of home helpers (nursing auxiliaries); they do not carry much weight if on a collision course with the other professional groups.

Irrespective of professional group, the professional form of knowledge is based on scientifically acquired knowledge and proven experience. In such a tradition of knowledge, great weight is given to theoretical reasoning, strict rules and scientifically tested methods (Helman, 1994). Regarding rehabilitation, the professionals know that goals for the activity must be set, and suitable methods must be chosen to attain those goals (SoS 1993:10). Both the goals and methods used in the home setting are often similar to those practised in institutional care. The goal of rehabilitation often revolves around how to restore the bodily balance disturbed by illness, and to help the afflicted person to manage daily activities. The methods used are exercise of the reduced functions and/or re-learning of movements. The system of values on which professional knowledge rests is strictly goal-rational, unlike the layman’s knowledge, which is concrete, subjective and holistic.

Organisations, rules and interested parties

An important reason why rehabilitation in the home is not easy is that the different organisations operating in this area have different sets of regulations, administrative boundaries and procedures for decision-making, as well as
different purses. The county council’s hospital care and local authorities’ assistance for the elderly and disabled are the most important organisations.

According to the Swedish Health and Medical Care Act, HSL, (§ 3a) the county council shall not only offer those living in county council’s area good health and medical care, but good training, rehabilitation and devices for the disabled. When a patient is no longer deemed to be in need of the somatic care provided in the hospital or other care institution, i.e. is judged by the doctor to have "finished the medical treatment", it becomes the duty of primary care to perform whatever actions are needed thereafter. This is usually done through doctors, nurses and physiotherapists and occupational therapists etc. linked to the care centre.

If being in the home is not possible, then according to the Social Services Act, (SoL, § 20, paragraph 2a and §21, paragraph 3) the local authority must offer the elderly or disabled person another suitable form of accommodation. Examples of such special forms of accommodation are homes for the aged, service apartments, nursing homes or collective accommodation. The relevant form of accommodation is decided after an application from the individual and an investigation by the social services. The local authority is responsible for ensuring that these people receive the health and medical care that is needed, including training, rehabilitation and devices (HSL § 18a) – but not doctor’s treatment however, which is provided by primary care. This means that in the municipality there is a parallel organisation of nurses, physiotherapists, and occupational therapists with similar duties to the corresponding professional groups in primary care – the difference being that the municipal staff only gives its expert help to those occupying special accommodation. According to the guidelines of the Social Services Act (§ 40), the local authorities shall also, after suitably testing the need, provide for the elderly and disabled to live at home and keep in touch with others through the mobility service, help in the home, service and care, as well as daytime activities.

The perspective and field of interest of the different professions

None of those professional groups who work with nursing and rehabilitation in the home is a profession in the strict sense of the word. Through their less developed body of scientific knowledge and unclearly defined professional and subject-matter limitations, they represent semi-professional occupations under development (Bellner, 1997; Heyman, 1995; Sim, 1985). However, they refer to themselves as professionals and we too shall henceforth use the term profession with reference to them in this article.

Nurses are not directly involved in rehabilitation, but their duties related to care and treatment are often
important preconditions for the successful rehabilitation of the care receiver. Nursing includes such tasks as making qualified judgements, planning and acting, but also such emotional aspects as having empathy, showing respect and creating confidence. There are then two dimensions to care – one aimed at tasks and one aimed at relations (Heyman, 1995). The task-oriented activities comprise care and treatment, medication, taking care of wounds and bandaging. Part of the nurses' domain is to secure that the patient and the nurse's lay associates comply with doctor's orders, for instance concerning medication. Nurses may take over where the medical model fails or ceases, as with the long-term or chronically sick. The claim of nurses is to reach an understanding of the full circumstances of a patient, to build a relationship to adjust the environment and the care plan and to establish a therapeutic environment that may facilitate the patient's recovery and to maintain the integrity of the patient as a human being (Carpenter 1993:98-102; Davies 1998: 129).

Physiotherapists are the professional group primarily associated with rehabilitation. The physiotherapist's is the occupational group that enjoys a relatively high professional status. In their professional strategy they have had the doctor's profession – the profession par excellence – as a model (Sahlin-Andersson, 1997) and are also considerably more medically oriented than the other professional groups. As regards rehabilitation in the home, they are infrequent in comparison to occupational therapists. Barely 5% of all physiotherapists work in the care receivers' homes, compared to the figure of 28% for occupational therapists (Bellner, 1997). In the context of rehabilitation in the home, their domain claims are concentrated on examining and treating functional disorders limiting the mobility of the care receiver. Their actions are based on a judgement and analysis of the care receiver's bodily condition and problems, while taking into account psychological and social factors. Their principle duties concern functional training (Bergman, 1989).

Occupational therapists are the other professional group that has rehabilitation as its goal in a home setting. In their profession, occupational therapists utilise occupations and their task is to develop the patient's occupational ability and where relevant to compensate it, so that the care receiver can manage daily life (FSA, 1992; Kielhofner, 1995). Occupational therapists, then, apply an occupational perspective to rehabilitation. An important task in this respect is to assist an elderly or a disabled person to identify new activity preferences which can maintain or improve the person's functions. Yerxa (1994:11) contends that "occupational therapists maintain both an individualized and a social view of the activity in the eyes of that particular patient and his or her
culture". In the home-setting it is within the domain of the occupational therapist to prescribe technical aids for the purpose of facilitating for the care receiver to manage his/her daily life (Bellner, 1997). The issue of which technical aids may be proscribed by occupational therapists and other occupational groups is regulated in detail.

Home help managers (and the equivalent) investigate and make decisions about home help and rehabilitation for the elderly and disabled who cannot manage their own living unaided. In addition to help in the home, the home help assistant can make decisions about the mobility service, emergency medical alarms, the respite service, companionship service, home adaptation etc. One of the most important duties is to supervise the home helpers who provide the practical help to the elderly or disabled. These duties include responsibility for the financial aspect, recruitment, managing and developing the activities and ensuring that the home helpers have a good working environment, both in the physical and the psychosocial sense. Constant reprioritising is a routine feature of the work of home help managers, to keep a balance between the care needs of the users, the demands of the assistant home help staff for a good working environment and the expressed expectations of the organisation itself that the activities are run as economically as possible (Eliasson, 1996).

Home helpers. Home helpers is today the largest occupational group among council employees. Their organisational group is the social services. Home helpers have no professional status and so are on a lower hierarchic level than the other groups mentioned above (Eliasson, 1996). They are the category closest to the care receiver. Their duties are twofold. On the one hand they help the care receiver with practical chores, providing personal care and service. On the other hand they are involved in a process of 'substitution' and delegation of work tasks under the guidance and supervision of nurses, physiotherapists and occupational therapists. Hence, an increasing amount of basic care work and rehabilitation is transferred to home helpers and nursing assistants. Such formal procedures can be interpreted as a means of avoiding domain conflicts between organisations operating in the same organisational field where professionals work with the same clients. Home helpers main vocational aim is assistance, which means meeting the physical needs of the care receiver, such as bathing, helping with dressing and undressing etc., and psychological needs, such as listening, comforting or giving advice. Traditionally, duties such as cleaning, cooking, and shopping have dominated, but with economic cutbacks in most municipalities, most of the home helpers' work duties have become a core of personal care and assistance and (in the present context) rehabilitation supervised by other professional.
groups. The personal attachment to the clients which is integral to the work of home helpers creates a conflict when incorporated into a regular bureaucratic control system and a system of professional training (Wærness, 1984).

The chart below presents the main institutions, organisations and professional perspectives we encounter in rehabilitation in the home. An additional factor (which the chart does not present) is that concrete administrative boundaries are sometimes drawn up across institutional and professional territories: in this way both health care and medical care treatment, as well as rehabilitation, are provided both within the county council and the municipal sectors, depending on which form of accommodation the individual is in.

| Institution: | Medicine | Rehabilitation | Family | Welfare Policy |
|-------------|-----------|----------------|--------|----------------|
| Organisation: | Health- and medical care | Health- and medical care | Social services | |
| Normative basis: | Scientifically proven experience | Scientifically proven experience | Lay knowledge | Social rights |
| Rules: | Health and Med. Care Act | Health and Med. Care Act, Soc. Serv. Act | - | Social Services Act |
| Profession: | Doctor, Nurse | Physiotherapy, Occupational therapy | Care receiver, Relative | Home help man. (Nursing auxiliary) |
| Orientation: | Care, treatment, Nursing | Activity, Functional Improvement | Wellbeing, Quality of life | Social support, social service |

Figure 1: Rehabilitation in the home and its institutional settings.

Potential for cooperation and conflicts - empirical illustrations

The empirical illustrations in this article are based on a number of substudies conducted during the last three years in the framework of this project. The targets of the investigation were care-receivers (most of them aged 65 and older) and their relatives, who have received rehabilitation in the home and the professional groups of care givers (physiotherapists, occupational therapists, home help managers and home helpers) as parties in the rehabilitation. The methods used in the project have been mainly qualitative, including grounded theory, in-depth interviews, and content-analyses of cooperative and ethical dilemmas. Data has been collected from several local
authorities in the counties of Västerbotten and Norrbotten, mostly of a rural character. Beside this we (the authors of the article) have also collected data through a number of semi-structured interviews, in which we have enquired as to the duties of the professional groups, which conflict and cooperation possibilities they experience in relation to other professions and in relation to care receivers and their relatives. The emphasis is on the role of the occupational therapist, as our data is mainly from occupational therapists, and as they, in comparison with other professional categories, have traditionally worked in the home of the care receivers. To a certain extent, physiotherapists and home help staff are also featured. Our point of departure is that it is not self-evident that rehabilitation in the home should function smoothly and without "collisions" when the different parties set about their different duties. Important questions that are raised in this context are: do the professional experts take into account the experiences, knowledge and wishes of care receivers? Which problems are easy to solve, and which are difficult? What critical situations arise when two basically different forms of knowledge clash, and how are these problems solved? To what extent does tension occur between the home and the requirements of the working environment, due to the home being on the one hand a workplace for the expert/employee and on the other hand the user’s natural living environment?

The experience of undergoing rehabilitation in the home: In two of our studies we have investigated what it is like to undergo rehabilitation in the home. One investigation (Lundgren & Sundqvist, 1998), a qualitative interview study performed among fourteen care receivers, has studied the care receiver’s viewpoint. The other, a qualitative interview study (Ahlström & Jonsson, 1998), has studied how occupational therapists (twelve persons) experience working in someone else’s home.

The results of the first study (Lundgren & Sundqvist, 1998) show that most of the care receivers experienced a troublesome changeover phase before they learnt to live with the technological devices and adaptations brought about occasioned by their disability. They found it hard to accept their disability, which resulted in their considering the devices and home adaptation as symbols of the disability, and they did not wish to receive either them or the help or rehabilitation that they were offered. Furthermore the care receivers found it irksome to have all the new personnel come into their homes. As one of them says:

"It was hard work starting to have different people in the home helping. There could be seven or eight people, some of whom you knew nothing about. They came and turned the place upside down and you didn’t know who was in the house, it was awful."
After a number of years the care receivers had got used to their new situation and were content on the whole with both the technical devices and the professionals’ efforts, even if their contentment with the latter was not complete. Especially when it came to home help staff they were critical. Unlike occupational therapists, physiotherapists and nurses, whom the care receiver had got to know and who often announced when they were coming, the visits of the home helpers were often thought of as infringing upon their privacy. The home helpers, work in large groups without continuity and consequently there were many different people entering the home daily, and this was experienced as “time after time you have to show your home and your belongings to unfamiliar people.” Care receivers certainly appreciate the work of home helpers, but there are organisational factors that create discontentment.

The second study (Ahlström & Jonsson, 1998) which sees rehabilitation from the professionals’ (occupational therapists’) viewpoint paints a much more positive picture. Occupational therapists have a positive opinion of working in the care receivers’ homes, because it is possible to carry out rehabilitation in a concrete and everyday context, i.e. in the care receivers’ proper environment. Interviews that we have conducted bear this out. One occupational therapist explains how she works:

“... the sense of balance, whether you find things in the larder, can you find your bearings, do you understand amounts of coffee and water, do you do things in the right order, do you remember to turn on the stove or percolator and at the same time plan things so that when the coffee is ready, the buns are on the table and the right number of coffee cups are out, how do you manage to carry things etc....”

Our occupational therapists hold that consideration must be shown not to invade the care receiver’s privacy, which can be difficult sometimes and
may complicate rehabilitation, but on the whole occupational therapists feel that it works well. Problems appear, when there is disagreement about goals and when the care receiver (or the relative) has goals that the occupational therapist finds too unrealistic.

Disparate goals: In two studies (Bryggman et al., 1998) occupational therapists (five persons), care receivers (eight persons) and relatives (nine persons) have been asked during a qualitative interview what goals they have for rehabilitation. The results obtained show that in the majority of cases of elderly people it is the professionals who set the goals. The care receivers and their relatives have certainly been informed of the goals or have been involved in discussions, but have left it to the professionals as "they are experts and know best". Upon closer analysis it appears that the care receivers' goals were formulated in everyday language "wanting to walk again", "being able to fish, hunt, visit the summer cabin" etc., while the occupational therapists' goals were more about care receivers learning to manage daily activities, such as personal hygiene and living, being active in different ways etc.

The care receiver and the expert can also have widely disparate goals concerning technical aids. It can be due to the person in question being too disabled to manage alone a power wheelchair or to travel unaided outside alone with a power wheelchair, but insisting on having one. And "then you cannot prescribe one for the person", says one occupational therapist. The goal of the disabled person to get out among people here collides with the occupational therapists fears that the care receiver will not manage the technical aid and might even injure him/herself in the event of mishaps or accidents. The occupational therapist, namely, has the formal responsibility for any technical aids prescribed being used in a secure way.

Another example is when the goals of the disabled person to continue living at home require very expensive and technically advanced home adaptation. If the care receiver's prognosis is such that a transfer to institutional care seems imminent, there is a difficult dilemma for the occupational therapist (Bäckström & Tamm, 1999).

From the results it is apparent that the different parties speak different languages - the layman's versus the professional's.

View of relatives: Many studies have shown that relatives are seen as a hindrance in rehabilitation (Chiou & Burnett, 1985; Gitlin, 1993; Hasselkus, 1991, Watson, 1987). In one grounded theory study seen from the perspective from the occupational therapist (Tamm, 1999a) and in studies we are currently carrying out, it emerges that relatives are seen both as a help and a hindrance. Relatives acted as a help for the occupational therapist when they were learning to rehabilitate the care receiver, when helping the occupational therapist to adapt the home or when
acting as information suppliers to the occupational therapist. Relatives were seen as a hindrance when helping too much (i.e. when they adopted a helping approach rather than a rehabilitating approach), when they slowed down rehabilitation by setting other goals and when they did not want the home to be adapted to the wishes of the occupational therapist (re-arranging furniture, removing mats). So relatives are seen as a help when they agree with the occupational therapist and have taken a rehabilitating view and as a hindrance when they have ideas of their own that do not coincide with those of the occupational therapist. The system of values that rehabilitation in the home was based on, then, was that of the professionals.

In a qualitative content-analysed study within this project, carried out among physiotherapists (Eriksson & Flinkfeldt, 1998) similar views could be noted. Physiotherapists saw relatives as a hindrance when they wanted to help too much, had other goals or opposed changes in the home that from the physiotherapeutic point of view were necessary in order not to compromise the health of the care receiver. Some relatives saw the professionals as lacking in both knowledge and understanding of how they as a family function and what the illness of the care receiver means to them (cp. also Bowers, 1987).

The rehabilitation team: Occupational therapists/physiotherapists - home helpers: Several of our studies among occupational therapists (Ahlström & Jonsson, 1998; Tamm, 1996) and physiotherapists (Eriksson & Flinkfeldt, 1998) and the interviews we (the authors) have carried out have indicated that both occupational therapists and physiotherapists find that it is difficult for home helpers to use a rehabilitating approach and that they tend to help too much. Home helpers in the home setting are supervised both by occupational therapists and physiotherapists and are delegated rehabilitation tasks. According to the Health and Medical Care Act it is then a requirement that whoever delegates a task ensures that the person taking on the task has the skills to perform it. Not only can this create a conflict with the wish of home helpers first and foremost to help the patient, but can also create a conflict also with the users' legitimate right as far as possible to influence how help is designed, and in the long run with the recruitment of the care personnel working in the care receiver's own home. When the care receiver demands help from home helpers, and time does not allow rehabilitation, then according to the other professions, they help too much. Both physiotherapists and occupational therapists find this help an obstacle to rehabilitation.

The two professional viewpoints then, are in conflict with one another. Physiotherapists and occupational therapists have a rehabilitating ideology, which means that it is the care receiver who must train to do as much as
possible to manage daily life. The home helpers for their part have vocational education in the care providing ideology, i.e. being as helpful and supportive as possible. In that situation, the care receivers who are not primarily interested in rehabilitation (and they are numerous) are often on the side of the home helpers and demand help, as the care receiver de facto is paying for this help. The conflict between the different professional groups and care receivers is consequently inevitable.

Home-workplace: In one of our studies, in which we qualitatively analysed about forty ethical dilemmas (Tamm, 1996) and in another qualitative study on ethical dilemmas in connection with the introduction of technical aids in the home (Bäckström & Tamm, 1999) as well as in many of the interviews we (the authors) have conducted with the different professional groups, it is apparent that one of the basic conflicts in rehabilitation in the home is over the discord between the home as a home and the home as a workplace for professionals (cf. also Tamm, 1999). Care receivers have a right to keep the home intact as a home. Although they can agree to make certain necessary changes in the home, it is the care receiver and his/her family who decide over the home. When rehabilitation takes place in the home, the home automatically becomes a workplace for care providers and according to the Occupational Health and Safety Act the home environment must be such that it can be classified as a good working environment for care providers. Herein lies the conflict. When the home helper is to give help to the care receiver he/she can, and does, then request occupational devices (hoists and other equipment) to facilitate the work. Care receivers for their part have little interest in filling their homes with labour technical equipment or in being lifted in hoists instead of manually, in order to safeguard the health of the home helper. The basic conflict, then, lies in the friction between private and public.

Adaptation of the working environment also places both home help managers and occupational therapists in a role conflict. In the role as assistance assessor the home help manager is to safeguard the care receiver’s rights in accordance with the Social Services Act. In the role as middle manager she is the employer’s representative and responsible for the working environment. For the occupational therapist it is the issue of technical aids that causes a role conflict. She is the extension of the care receiver as regards the care receiver’s personal aids. It is she who decides which technical aids a care receiver needs, and the person who tests them. At the same time she is responsible for vocational aids, i.e. aids to be acquired and installed in order to achieve a satisfactory working environment for home helpers. The twin roles that the above mentioned occupational groups have lead to conflicting
expectations. The interviews indicate that the conflict is difficult to resolve, and the different parties must continually compromise and find solutions that are acceptable to all (Berg, 1994; Johansson & Lindell, 1990). But if none of the parties should give way, but make a stand for their legal rights, it could end in the dwelling being ruled out as a workplace.

Discussion
Rehabilitation in the home is characterised by its forming a force field of different institutions, organisations and professional perspectives. It is at the intersection of these different forces that both personnel and care receivers feel that care, treatment and rehabilitation do not function well. The theoretical perspective used here, namely New Institutionalism in organisation analysis, makes a tool for localising collisions, coordinative problems and ethical dilemmas that occur in the encounter between interests based in different institutional environments. In a situation where central control is diminishing and the different local interests' room for manoeuvre is expanding, the issue of how these conflicts and problems are constituted is more open than ever. Unlike Strauss et al. (1985) who sees care, treatment and rehabilitation as a hive of different personnel groups, and sees their different duties as a series of negotiations and offers of actions, i.e. as a pluralistic process in which most structural powers can be negotiated away, we are of the opinion that the institutional frameworks that provide cognitive, normative and regulative structures and activities constitute palpable limitations to what is negotiable and what is not negotiable.

But there are also possibilities for increased consensus on the issues of goals, approach and work methods. The strengthened legal position of the care receiver in nursing and rehabilitation contexts can be seen as an impulse toward a shift of power in the interplay between the user and the different professional groups. This can be an opportunity for increased autonomy and self-determination for the care receiver and other users. It can also function as a normative pressure on the professionals to be prepared to adapt to a greater degree both to each other and to the wishes of the care receivers for the activity that they perform to be considered legitimate.

As suggested by our empirical data, there are two types of conflict in rehabilitation in the home: firstly there is a conflict between professionals, and care receivers and their relatives – and secondly there are inter-professional conflicts between occupational therapists, physiotherapists and home helpers. These conflicts take place against a background of different institutional settings, different organisational affiliation, different systems of regulations and differing professional perspectives. The former conflict is rooted in diverging cognitive perspectives. The home as an institutional setting is a private setting and as such is poorly suited to care and
rehabilitation. When the professionals want to re-form the home through different types of adaptation, they sometimes encounter unwilling care receivers and/or care receiver’s relatives who wish to protect the home from the intrusion of unfamiliar things and persons, i.e. protect the privacy of the home. The conflict is then a conflict of values: what is a home and when does it cease to be a home? Who decides over my home, me or the professionals? It is feasible that the conflict will become increasingly common, as official policy is for more and more people to be rehabilitated in their own homes (leading to experts to a certain extent deciding over activities in the home) at the same time as the care receiver’s right to increased autonomy is stressed.

Normatively speaking, it can be said that the opportunities of success with such a value conflict in rehabilitation in the home lie in rehabilitation staff respecting and starting out from the care receiver’s preferences, goals and needs. This has also been emphasised lately by the Swedish government report on health and medical care (SOU, 1997:154). In order to do this then, professionals should abandon the medical models and the methods for rehabilitation that have guided them in institutional care, be open to new work models and apply a different ethic that helps achieve working cooperation between them and the care receivers, i.e. a sort of partnership, in which the goals are set and decisions made jointly.

Is this a realistic proposition? We believe that one must see this from the perspective that there is an inner differentiation within the different occupational groups. There is tension between on the one side biomedically-oriented, increasingly subspecialised physiotherapists (and perhaps to a certain extent occupational therapists) active within a hierarchically organised institutional care, and on the other side members of less specialised all-round occupations in non-institutional care and care for the elderly. As regards the former category, one should not, at least for the present, contemplate a partnership with care receivers featuring joint decision-making toward goals jointly agreed upon: the influence of experts and the links to the medical model are too powerful to permit that. But when the environment for rehabilitation is the home rather than the care institution, the medical model for rehabilitation will be less crucial to what is done, especially if this development is also supported by laws that strengthen the care receiver’s position. The problem is that the help receivers and relatives must make their voices heard. This is not easy with regard to the fact that medical intervention and rehabilitatory intervention increasingly seem to presuppose the involvement of experts, who represent their respective fields and therefore also have the duty of defining and categorising the needs of the individual and stating how the needs are to be met.
The other type of conflict reflected in our empirical data is, like the previous conflict, one of a cognitive nature, but now between two occupational groups. Physiotherapists and occupational therapists represent a rehabilitation perspective based on functional training and activity, and home helpers stand for the perspective of care based on social studies. In home setting rehabilitation the home helpers are drawn into a conflict of competing values. Professionally, they have an aim to provide assistance, i.e. to help the care receiver by providing personal care and so on; supervised by physiotherapists and occupational therapists, the home helpers are expected to rehabilitate the care receiver, which among other things means that they should not give the help they normally give, but should allow the care receiver to take care of the tasks him/herself, under the surveillance of the home helper. In working with the care receiver, then, the home helper should keep a balance between a care-orientated and a rehabilitation approach, which is not always easy. If increased cooperation between different occupational groups is to come about, in the sense that goals and activities are set up jointly with the user, then this means, as Hvinden (1994:10) says, the horizontal integration of different organisations. Facilitating this requires "mutual awareness, compatibility of perceptions and goals and interdependence between actors."

There is a further type of conflict in our empirical data, which concerns the fact that nursing, care and rehabilitation are provided in the form of generalised salaried labour. The fact that a body of regulations, the Occupational Health and Safety Act, is intended to ensure that all employees have a good working environment, while other laws, the Health and Medical Care Act and the Social Services Act, in more detail regulate the activities of rehabilitation and home help personnel in relation to care receivers, can lead to conflicts. The last two laws assert the right of the individual care-receiver to autonomy and that the care-receiver should be treated in such a way that his/her personal dignity and freedom of choice are respected. All three laws are framework laws in the sense that terms such as 'good working environment', 'good care and rehabilitation', 'social security and active participation in community life' are not defined in detail. From a legal perspective there is no conflict between the three bodies of regulations; they simply regulate separate situations. But if one considers the relationship between the care-receiver's right to self-determination and the home helpers right to a good working environment, it is evident that there is a conflict. When conflicts arise they must be solved under the existing circumstances, often in the individual home.

The whole set of problems leads to the question: Can a combination of home and public workplace work at all? Can the home function as a
workplace in the traditional sense without ceasing to be a home? The issue has not been resolved and what we see is the fact that with rehabilitation in a home setting the public sector is moved into the home. Thereby the values that govern public life also come to apply in the home setting. Therefore this type of conflict also, even though it concerns different bodies of regulations, is basically a conflict of values to do with different ideological standpoints.

References:

Ahlström C, Jonsson T (1998). Att arbeta i någon annans hem - ur arbetsterapeutens synpunkt [Working in somebody else’s home - from the viewpoint of the occupational therapist]. Boden University College of Health Sciences (Examensarbete 10 p).

Arras J D, Dubler NN (1994). Bringing the hospital home. Ethical and social implications of high-tech home care. Hastings Centre Report 24: 19-28.

Bellner A-L (1997). Professionalization and rehabilitation. The case of Swedish occupational and physical therapists. (Diss.) Linköping University, Linköping Studies in Arts and Science, No 166.

Berg E (1994). Public work in the home of the private individual. Luleå University of Technology, Research report, Department of Human Work Sciences.

Bergman B (1989). Being a physiotherapist. Professional role, utilization of time and vocational strategies. Umeå University, Dept of Physical Medicine and Rehabilitation (diss.).

Bowers B J (1987). Intergenerational caregiving: Adult caregivers and their aging parents. Advanced Nursing Science 9: 20-31.

Bryggman A, Pettersson T, Töyrö C (1998). Vårdtagarens, anhörigas och arbetsterapeuters upplevelser av autonomi vid rehabilitering i hemmet [The experiences of autonomy of care receivers, relatives and occupational therapists in rehabilitation in a home-setting]. Boden University College of Health Sciences, (Examensarbete 10 p).

Bäckström G, Tamm M (1999). Att införa medicintekniska hjälpmedel i hemmet - en kvalitativ studie om etiska konflikter för [Introducing medical-technical aids in the home - a qualitative study on ethical conflicts facing the occupational therapist]. Umeå University, Dept of Physical Medicine and Rehabilitation. (Magister-uppsats).

Carpenter M (1993). The subordination of nurses in health care: towards a social divisions approach. In: Riska E, Wegar K, eds. Gender, work and medicine. Women and the medical division of labour. London, Sage.

Chiou IL, Burnett CN (1985). A survey of stroke patients and their home therapists. Physical Therapy 65: 901-906.

Clark PG (1996). Communication between providers and patient: Values, biography and empowerment in clinical practice. Ageing and Society 16: 747-774.

Collopy B, Dubler N, Zuckerman C (1990). The ethics of home care: Autonomy and Accomodation. Hastings Centre Report, March/April, 1-16.

Davies C (1996). Gender and the predicament of nursing. Buckingham, Open University Press.

Delbanco T (1992). Enriching the doctor-patient relationship by inviting the patient’s perspective. Annals of Internal Medicine 116: 414-418.

DiMaggio PJ, Powell WW (1991). The iron cage revisited: institutional isomorphism and collective rationality. In: Powell WW, DiMaggio P, eds. The New Institutionalism in Organisational Analysis. Chicago, The University of Chicago Press.

Eliasson R-M (1996). Omsorgens skiftningar. Begreppet, vardagen, politiken, forskningen [Varieties of care. Concept, everyday life and politics]. Lund, Studentlitteratur.
Eriksson R, Flinkfeldt M (1998). *Etiska problem hos sjukgymnaster vid rehabilitering i hemmet* [Ethical problems experienced by physiotherapists in rehabilitation in home-settings]. Boden University College of Health Sciences (Examensarbete 10 p.)

Etzioni A (1969) *The Semi-Professions and Their Organizations: Teachers, Nurses, Social Workers*, New York, Free Press.

Freidson E (1988). *Profession of Medicine. A Sociology of Applied Knowledge*, Chicago, Chicago University Press.

Friedland R, Alford R (1991). Bringing society back in: Symbols, practices and institutional contradictions. In: Powell WW, DiMaggio P, eds. *The New Institutionalism in Organisational Analysis*. Chicago, The University of Chicago Press.

FSA (1992). *Etisk kod för arbetsterapeuter* [Ethical code för occupational therapists]. Nacka, Förbundet Sveriges Arbetsterapeuter.

Gage M (1995). *Re-engineering of health care: Opportunity or threat for occupational therapists?* *Canadian Journal of Occupational Therapy* 62: 197-207.

Gitlin LN, Burgh D (1995). Issuing assistive devices to older patients in rehabilitation: An exploratory study. *American Journal of Occupational Therapy* 49: 994-1000.

Hasenfeld Y (1992). The nature of human service organizations. In: Hasenfeld Y, ed. *Human services as complex organizations*. London, Sage.

Hasselkus BR (1989). The meaning of daily activity in family caregiving for the elderly. *American Journal of Occupational Therapy* 43: 649-656.

Helman CG (1994). *Culture, health and illness*. (3:d ed.). London, Butterworth-Heinemann Ltd.

Heyman I (1995). *Gårde hatt till... Omvårdnadsforskningens framväxt i Sverige - sjukkösterskors avhandlingar 1974-1997* [The emergence of nursing research in Sweden]. Göteborg, Daidalos.

HSL, Hälso- och sjukvårdslagen 1982:763. (Health and Medical Care Act). Författningshandbok 1998. Stockholm, Liber AB.

Hvinden B (1994). *Divided against itself. A study of integration in welfare bureaucracy*. Oslo, Scandinavian University Press.

Johansson R (1992). *Vid byråkratin gränser* [At the boundaries of bureaucracy]. Lund, Arkiv.

Johansson S, Lindell M (1990). Erik ställs mot lag vid vård i hemmet. Personalen offrar sina intressen [Ethics against law in care in the home-setting. Employees sacrificing their interests]. *Läkartidningen* 87: 2125-2129.

Kielholnner G (1995). *A Model of Human Occupations* (2:d ed.). Baltimore, William & Wilkins.

Lipsky M (1980). *Street-Level Bureaucracy*. New York, Russel Sage Foundation.

Lundgren K, Sundqvist L (1998). Vårddagar upplevelser och erfarenheter av arbetsterapi och annan rehabilitering i hemmet [Care receivers’ experiences of occupational therapy and other rehabilitation in the home-setting]. Boden University College of Health Sciences (Examensarbete arbete 10 p).

Meyer JW (1994). Rationalized Environments. In: Scott R, Meyer JW, eds. *Institutional Environments and Organisations*. Thousand Oaks, Sage.

Murphy R (1987). *The body silent*. New York, W.W. Norton.

Reiser S (1993). The era of the patient. *Journal of the Medical Association* 269: 1012-1017.

Sahlin-Andersson K (1997). Kvinnomyrken i omvandling. Om ändrade gränser och relationer i sjukvården [Female occupations in transition. On transformed boundaries and relations in health care]. In: Sundin E, ed SOU 1997:83 Om makt och kön [ On power and gender. Swedish public investigations]. Stockholm, Fritzes.

Scott R (1991). Unpacking institutional arguments, In: Powell WW, DiMaggio P, eds. *The New Institutionalism in Organisational Analysis*. Chicago, Chicago University Press.

Scott R (1992). *Organizations: Rational, natural and open systems* (3:d ed.). Thousands Oaks, Sage.
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Scott R (1995). *Institutions and Organisations*. Thousand Oakes, Sage.

Sim J (1985). Physiotherapy: a professional profile. *Physiotherapy Practice* 1: 14-22.

SoL. Socialtjänstlagen [Social Services Act] 1980:620. Författningshandbok 1998. Stockholm, Liber AB.

SoS (1993:10). Rehabilitering inom hälso- och sjukvården [Rehabilitation in health care]. Stockholm, Socialstyrelsen [National Swedish board of Health and Welfare].

SOU 1997:154. *Patienten har rätt*. [The patient is right. Swedish public investigations]. Stockholm, Fritzes.

Strauss A, Fargerhaugh S, Suczek B, Wiener C (1985) *The social organisation of medical work*. Chicago, Chicago University Press.

Tamm M (1996). Ethical Dilemmas encountered by community-based occupational therapists in home care settings. *Scandinavian Journal of Occupational Therapy* 3: 180-187.

Tamm, M (1999). What does a home mean and when does it cease to be a home? Home as a setting for rehabilitation and care. *Disability and Rehabilitation*. 21:49-55.

Tamm M (1999a). Relatives as a help or a hindrance - a grounded theory study seen from the perspective of the occupational therapist. *Scandinavian Journal of Occupational Therapy* 6:36-45.

Watson PG (1987). Family participation in the rehabilitation process: The rehabilitators’ perspective. *Rehabilitation Nursing* 12: 2.

Wænness K (1984). The rationality of caring. *Economic and Industrial Democracy* 5: 185-211.

Yerxa EJ (1994). In search of good ideas for occupational therapy. *Scandinavian Journal of Occupational Therapy* 1:7-15.

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