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From the Department of Community Medicine and Rehabilitation,  
Occupational Therapy, Umeå University, Sweden

# LIVING WITH PHYSICAL DISABILITY

Experiences of the rehabilitation process, occupations and  
participation in everyday life

Maria Larsson Lund



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Department of Community Medicine and Rehabilitation,  
Occupational Therapy  
Umeå University  
SE-901 87 Umeå, Sweden

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### **ABSTRACT**

A comprehensive understanding is lacking of the experiences persons with acquired physical disabilities have of changes in their engagement in occupations and of the conditions influencing these experiences. Furthermore, little is known about the experiences these people have of the rehabilitation process and whether the rehabilitation services satisfy their needs. Access to such knowledge would significantly add to the ability to design rehabilitation services intended to enhance participation in everyday life. The overall aim of this thesis was, therefore, to illuminate and enhance the understanding of how persons with acquired physical disabilities experienced their rehabilitation process and their possibilities to engage in occupations in everyday life.

The thesis is comprised of five studies. The planning of the clients' rehabilitation at hospital was explored through interviews with the clients ( $n=57$ ) and the professionals ( $n=50$ ). Interviews exploring how persons with physical disabilities experienced their rehabilitation process ( $n=15$ ), their occupational lives in their homes ( $n=13$ ) and the use of assistive devices ( $n=17$ ) were analysed qualitatively. Data was also collected from persons with spinal cord injury ( $n=161$ ) by the Impact on Participation and Autonomy questionnaire.

The findings showed that the professionals used different strategies to encourage the clients to participate in the planning of the rehabilitation and that the strategies were based on traditions rather than on the individual clients' desires to participate. The informants' experiences reflected three parallel chains of rehabilitation over a period of time, a medical, a psychological and a social one. The influence of the different rehabilitation chains on how the clients' lives turned out varied over time, and the professionals were predominantly involved in the medical rehabilitation chain. The informants' experiences showed that their engagement in occupations in the home differed profoundly. Access to social support, which was provided under different conditions, was of decisive importance for their occupational engagement. The findings also showed that changes in the informants' occupations in the home setting transformed the meaning of the home in general. The meaning of using assistive devices was experienced as manifold and double-edged. The incorporation of or resistance to assistive devices was understood as different approaches to adaptation with the same intention: to achieve desired occupational self-images. The majority of the informants perceived their participation in the life situation as sufficient but more than half reported one or more severe problems with participation. Access to social support in everyday occupations had a greater impact on predicting severe problems with participation than certain traditional health related factors or aspects related to the individual.

To conclude, the findings indicate that the rehabilitation services need to be better able to adapt to clients' desires to participate in the planning of their rehabilitation,

## Abstract

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and designed to satisfy the various needs the clients experience throughout the rehabilitation process. It was revealed that the societal and social environment, as manifested through social interactions, are of central importance in understanding the consequences of and possibilities to engage in occupations supporting participation in everyday life.

Keywords: disabled persons, activities of daily living, occupations, social environment, social support, disability evaluation, rehabilitation, occupational therapy, patient participation, patient-centred care.

## ORIGINAL PAPERS

This doctoral thesis is based upon the following original articles, which will be referred to by the Roman numerals I-V assigned below:

I. Larsson Lund, M., Tamm, M. & Bränholm, I-B. (2001). Patients' perceptions of their participation in rehabilitation planning and professionals' view of their strategies to encourage it. *Occupational Therapy International*, 8(3), 151-167.

II. Larsson Lund, M. & Tamm, M. (2001). How a group of disabled persons experience rehabilitation over a period of time. *Scandinavian Journal of Occupational Therapy*, 8(2), 96-104.

III. Larsson Lund, M. & Nygård, L. (In press). Occupational life in the home environment: The experiences of people with disabilities. *Canadian Journal of Occupational Therapy*.

IV. Larsson Lund, M. & Nygård, L. (2003). Incorporating or resisting assistive devices: Different approaches in achieving a desired occupational self-image. *OTJR: Occupation, Participation and Health*, 23(2), 67-75.

V. Larsson Lund, M., Nordlund, A., Nygård, L., Lexell, J & Bernspång, B. (In press). Perceptions of participation and predictors of perceived problems with participation in persons with spinal cord injury. *Journal of Rehabilitation Medicine*.

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### INTRODUCTION

It is well-known that having a disability may comprise changes of a person's possibilities to engage in occupations<sup>1</sup>, which may challenge his/her participation in society and experience of having a good life (e.g., Bränholm & Erhardsson, 1994; Fuhrer, 1996; Law, Steinwender, & Leclair, 1998; Månsson, Fredriksson, & Bränholm, 1995). Becoming a person with a disability can, therefore, be regarded as an intrusive, pervasive and profound event in a person's life. Disabilities are common in the Swedish population (Statistiska Centralbyrån [SCB], 2003; Socialstyrelsen, 1999) and the prevalence of persons with disabilities is increasing (SCB, 2003). In Sweden in 2002, about one fifth (21%) of the population in the age range 16 to 64 years had a disability, with the most common disability being restricted mobility accounting for 30% of those who have disabilities (SCB, 2003). Among the inhabitants in the age range 16 to 84 years, 6% have restricted mobility (SCB, 2002). This prevalence of people with mobility restrictions indicates that those with physical disabilities constitute a considerable part of the Swedish population with disabilities, which is the group that is the focus of attention in this thesis.

Disabilities are a complex and multifaceted field because conditions related to health, the person and the environment interact in different ways and influence a person's body functions and structures, activities and participation (World Health Organisation [WHO], 2001). Given this complexity and the individuality in the development of a disability and in how a disability is experienced, the perspective of persons with disabilities is of significant importance in the development of the knowledge base intended for use enhancing engagement<sup>2</sup> in occupations. The complexity also implies that rehabilitation professionals need different kinds of knowledge when designing rehabilitation services intended to promote participation and a good life for persons with disabilities. It is, therefore, important that different professions develop and contribute to the knowledge base, thereby sharing their unique perspective on persons with disabilities.

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<sup>1</sup> Both the terms activity and occupation are used in occupational therapy and they are often used interchangeably (Hagedorn, 1995; Pierce, 2001). However, the terms embrace different meanings (Pierce, 2001) even if no consensus has been reached in the continuing debate around the definitions (Hagedorn, 2000). Occupation is often described as a more expressive and encompassing term (Fisher, 1998; Pierce, 2001), and will therefore be used in this thesis.

<sup>2</sup> Engagement has been described as an involvement and an investment in an activity (Mattingly & Fleming, 1994) and as doing things with personal and social significance (Kielhofner, 2002). This means that the experience of engaging in occupations includes both subjective experiences of performance and the performance itself (AOTA, 2002; Kielhofner, 2002).

## Introduction

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From an occupational therapy perspective, the significance of persons being engaged in what are perceived by them to be meaningful and purposeful occupations is in focus because occupations are considered to be essential to a person's health and enjoyment in everyday life. The present thesis emerged from rehabilitation professionals' need to better understand the processes and conditions influencing the possibilities persons with acquired disabilities have to engage in occupations over time and in different contexts and life situations, and how the disabled experience their engagement. This thesis, therefore, focuses on persons with acquired physical disabilities, their experiences of the rehabilitation process and how they experience their possibilities to engage in occupations.

Apart from the personal consequences it has on the individuals concerned, disability is a major political, social and economic issue as an array of rehabilitation services are required over time and at different places, in the hospital, at home and elsewhere in society to enable people to engage in occupations, thereby supporting participation and promoting a "good life" for persons with disabilities. International guidelines stipulate that it is a basic human right to have the opportunity to live like everybody else, by, e.g., going to work, living independently and participating in all aspects of society, regardless of conditions such as disabilities (United Nations' Standard Rules on Equalisation of Opportunities for Persons with Disabilities, 1993). These guidelines form the basis for all formal support given to persons with disabilities in Sweden. General national guidelines (Regeringens proposition 1996/97:60; SOU 1995:5) stating the priorities for health care stipulate that quality of life related needs, such as being engaged in personal care, work, leisure and social relationships are equally important as medical related needs. The Social Service Act (SFS 2001:453), the Handicap Reform (Carlberg, Karlsson, & Larsson, 1992; SFS 1993:387) and the more recent so-called Investigation of Attitudes to and Treatment of Persons with disabilities (Regeringens proposition 1999/2000:79; SOU 1999:21) all strive for full participation and equality in living conditions. However, current Swedish reports show that the living conditions and the participation of persons with disabilities are, in general, poorer, no matter their age, than those of other members of the population. The reports also reveal that it is unclear whether the efforts made by society correspond with the needs of those with disabilities (Socialstyrelsen, 2003; SOU 1999:21). Thus, the government has emphasised the need for research that develops the knowledge of how the restrictions imposed by disabilities can be reduced, both on an individual level and on a society level (Regeringens proposition 1999/2000:79; SOU 1999:21).

### **BACKGROUND**

#### **Different perspectives on disability**

Disability is not a uniform concept because the perception of what circumstances are disabling and the significance of disabilities varies within different cultures and social contexts over time (Barnes, 1996; Barnes, Mercer, & Shakespeare, 1999; Ingstad & Whyte, 1995; Oliver, 1990). The way disabilities are understood, i.e. people's perception of the nature of disabilities strongly influences how persons with disabilities are treated in society, the services they request and, also, the services authorities provide for them (Oliver, 1996b). During recent decades two theoretical models of disability, the individual model and the social model, have provided the dominant, but opposite ways of understanding disabilities in the western world (Barnes et al., 1999; Oliver, 1996b), even if more complex conceptualisations also have been suggested (cf. Priestley, 1998).

The individual or medical model of disability suggests that disabilities arise from the physical or psychological pathology of the person (Oliver, 1996b). Disability is seen as a personal tragedy that makes a person passive and dependent upon others. The person is expected to manage and come to terms with his or her losses in life, in part by receiving support from medical and rehabilitative professionals. This model is derived from professional reasoning (Oliver, 1996b), but it has been criticised for the reason that it fails to acknowledge obstacles in the environment arising through the disabilities being medicalised (Barnes et al., 1999; Finkelstein, 1980; Oliver, 1996b). On the other hand, in the social model disability is considered to be caused by barriers in society, such as an excluding physical and social environment and by society's failure to provide service that take appropriate account of the needs of persons with disabilities (Barnes et al., 1999; Finkelstein, 1980; Oliver, 1989b; Oliver, 1996b). Disabilities have, therefore, been described as a form of oppression or group discrimination (Abberley, 1987; Oliver, 1996b). According to the model, the society has to change to be more inclusive if it is to reduce and eliminate disabilities. Thus, an emphasis is being put on taking political action to accomplish change (Barnes et al., 1999; Finkelstein, 1980; Oliver, 1989b; Oliver, 1996b). This model was developed through the work of activists on behalf of persons with disabilities, but it has been questioned because it neglects the significance of impairments and therefore blames society for creating disabilities (Kerr, 1980; Oliver, 1996b). Thus, these two disability models each represent a different perspective of what it means to have a disability, its origin and the actions needed to reduce its impact. These perspectives influence professionals' views and actions as well as clients'<sup>3</sup> own views of their disability and are, therefore, important when seeking to broaden the knowledge available when designing appropriate rehabilitation services.

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<sup>3</sup> Client refers to the person with a disability for whom the rehabilitation services are intended.

These two divergent ways of viewing disability have led to extensive discussion, mostly in sociological literature, concerning which of these views more closely reflects the “true” nature of disability. However, Kerr (1980) argued that there are problems with locating disability solely in the environment or in the person because a disability occurs as a result of the interaction between the two. The responsibility for reducing disabilities must therefore be shared by the person and the society. Recently the perspectives of the medical model and the social model were integrated into a biopsychosocial approach in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). According to the definition in ICF (WHO, 2001), a person’s disability (i.e. impairment, activity limitation and participation restriction) is created through an interaction between a disease or an injury and contextual factors, including both environmental and personal factors. In this thesis, the term “persons with disabilities” is based on this definition of disability. More explicitly, the term is used with reference to adult persons with acquired physical disabilities either with a rapid onset of disability, or with disability expanding over time in mid or late life. The term *physical* implies that the disability is, in part, related to a diagnosis with a physical origin, such as stroke, spinal cord injury, brain injury, multiple sclerosis and rheumatoid arthritis.

Apart from the above mentioned development in the understanding of disability, disabilities are increasingly being described as a universal characteristic of humans in the western world. From this perspective, disabilities are seen as one part of the normal variation in the population because anyone could be or could become disabled in some sense, in contrast to the classic perception that disability is associated with a minority group (Bickenbach, Chatterji, Badley, & Ustun, 1999; Shakespeare, 1996). In occupational therapy literature (e.g. Kielhofner, 2002; Yerxa, 1996), a comprehensive perspective of what it means to have a disability is the standard stance adopted rather than attempting to have a partial or selective perspective on disability. It is considered that this comprehensive perspective, based on an attempt to improve persons’ opportunities to make choices and engage in the occupations they want and need to do (despite the presence of disabilities), is influenced by complex and unique interactions between the person and his/her environment at that time. Hence, to address the possible consequences experienced by persons with disabilities, a comprehensive perspective is favoured in occupational therapy as well as in this thesis.

### **Possible consequences of disabilities with a focus on engagement in occupations**

The complex interactions between the conditions creating disabilities imply that persons with the same disease or injury will always have different experiences of their disabilities; or, in other words, the meaning of a disability for a person’s life can vary dramatically (Mattingly & Fleming, 1994). This implies that diversity and complexity characterise persons’ responses to their disabilities. However, persons with disabilities share many of the same experiences, even if their diseases or injuries

and the other conditions in their lives differ (Conrad, 1987; Parker, 1998; Shakespeare, 1996; Strauss et al., 1984). Some of the experiences that persons with disabilities might share are associated with the traumatic crisis and their adaptation to their disability (Cullberg, 1992) during the rehabilitation process. A feature at the centre of this process concerns the restrictions experienced in attempting to engage in everyday occupations and the struggle to identify new or modified goals associated with activities that are able to provide a good life (cf. Fortmeier & Thanning, 1998; Fugl- Meyer, Bränholm, & Fugl- Meyer, 1991). Hasselkus (2002) argued that people often define and describe their disabilities by the consequences they have on their everyday occupations. Thus, disabilities can be said to be an occupational experience (Hasselkus, 2002).

Research has shown that persons with disabilities can be constrained from engaging in occupations that they enjoy (Borell, Lilja, Carlsson-Alm, Törnqvist, & Ståhl, 1995; Sirkka & Bränholm, 2003). Consequently, they are engaged in fewer occupations than prior to their disability (Drummond, 1990; Sirkka & Bränholm, 2003; Wikström, Isacsson, & Jacobsson, 2001). The engagement of persons with disabilities in occupations is also less diverse than it is for persons without disabilities. The leisure time of persons with disabilities is more often spent on less physically demanding occupations in the home, such as watching TV and reading (e.g. Bränholm & Erhardsson, 1994; Månsson et al., 1995; Yerxa & Baum Locker, 1990). Persons with disabilities also tend to be involved in fewer occupations that provide rich contact with others (Lilja & Borell, 1997; Pound & Gompertz, 1998; Sirkka & Bränholm, 2003). In addition, many of them are hindered from doing their work. Research has also found that persons with disabilities devote more of their time to personal care and rest than persons without disabilities (Pentland, Harvey, Smith, & Walker, 1999; Yerxa & Baum Locker, 1990). The pleasure and enjoyment gained from the occupations that they engage in may also be reduced or eliminated after becoming disabled (Kielhofner, 2002). However, the research has mainly focused on what kind of occupations persons with disabilities engage in or which occupations they can perform independently. Thus, their experience of and satisfaction with their engagement in occupations has received less attention, as a result of which it has been concentrated on in the research conducted for this thesis. Such knowledge has the power to increase significantly the possibility of designing a service that enhances the meaning of occupations as experienced by the clients.

Engagement in occupations has general consequences for persons' experiences of their health. Research has found that, in persons with and without disabilities, engagement in occupations is associated with health, well-being (Dijkers, 1997; Law et al., 1998) and life satisfaction (Bränholm, 1992; Månsson et al., 1995). The engagement of persons with disabilities in occupations has also been found to influence their handicap (Fuhrer, Rintala, Hart, Clearman, & Young, 1992; Noreau & Fougereyrollas, 2000), through restrictions in the fulfilment of roles that they are expected to have and which are considered to be normal from a societal

perspective (WHO, 1980). Their handicap has in turn been found to be associated with their well-being (Dijkers, 1997; Fuhrer, 1994). However, in ICF (WHO, 2001), the concept of “handicap” has been replaced by “participation”<sup>4</sup> to call attention to the persons’ own lived experience of their involvement in life situations<sup>5</sup>. This implies that it is important not only to pay attention to persons’ participation, but also to whether it is perceived as a problem by the persons involved. As participation is a rather new concept in the WHO’s classification (2001), there is a dearth of research concerning participation in persons with disabilities and, consequently, of research concentrating on the relationship of participation to other concepts. This indicates that there is a need to initiate an investigation of the participation of persons with disabilities in everyday life and of the conditions influencing their participation from their own perspective to better prepare the rehabilitation services and to enable them to enhance participation.

Engagement in occupations is seen as a prominent means of being a particular person (Christiansen, 1999). Consequently, it has been suggested that the changes made to the engagement of those with disabilities in occupations influences their identity in terms of their occupational identity (Kielhofner, 2002), occupational self (Thorén- Jönsson & Möller, 1999) and images of occupational self (Nygård, Borell, & Gustavsson, 1995). This collapse of the former image of the self and the struggle to develop an equally valued new self-image is described by Charmaz (1983), who considered this to be a central part of the experience of being a person with a disability. This group of people is commonly given a negative identity in society and, therefore are socialised into considering themselves to be inferior. In the western world, this cultural understanding of disability and the identification of persons with disabilities is based on views that, commonly, are derived from the medical model (Shakespeare, 1996). Persons with disabilities often struggle to develop an identity in which other more important aspects of themselves are given precedence over the disability to represent the persons they are (Kelly, 1996). Most disabilities can also give rise to stigmatisation (Goffman, 1963), an undesirable deviation from the perceived norm that separates a person with a disability from the rest of society. This deviation often becomes apparent because of the visible adaptations persons with disabilities make to the performance of occupations.

The way in which people perform occupations often changes after the onset of a disability, and the performance itself may become more complicated. One common change is that many persons with disabilities use assistive devices (Gitlin, Levine, & Geiger, 1993; Gray, Quatrano, & Lieberman, 1998), i.e., they take advantage of a diverse range of equipment and appliances designed specifically for them

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<sup>4</sup> Pierce (2001) stated that, to a great extent, the use of participation in ICF corresponds with the meaning of the concept of occupation in occupational therapy.

<sup>5</sup> In this thesis, life situation is used interchangeably with everyday life.

(Blomqvist & Nicolaou, 2000), such as hand reachers, shower chairs, walking devices and power-driven wheelchairs. Another common change is that their need for support from others often increases (Johansson & Thorslund, 1992; McColl, 1995). The use of assistive devices frequently plays a decisive role in their possibilities to engage in occupations, but, at the same time, the assistive devices may also affect their interaction with others and have a negative impact on their appearance. The incorporation and use of assistive devices can therefore be seen as a complicated issue (Brooks, 1990; Gitlin, Luborsky, & Schemm, 1998; Gray et al., 1998). Research has shown that persons with disabilities quite frequently abandon the use of an assistive device and therefore sacrifice the potential benefits the device offers them in terms of the occupations of everyday living that they would be able to perform (Hastings Kraskowsky & Finlayson, 2001). Several researchers have suggested that the meanings attributed to assistive devices — meanings that emanate from the persons' use of them in everyday occupations — influence whether these devices are used or not (Bates, Spencer, Young, & Rintala, 1993; Cole Spencer, 1998; Gitlin et al., 1998). However, research has largely ignored the meanings that users ascribe to assistive devices (Brooks, 1990; Louise-Bender, Kim, & Weiner, 2002; Luborsky, 1993). In order to better understand the engagement of persons with disabilities in occupations, more knowledge is needed about the meanings these people ascribe to their assistive devices and how these meanings influence their use in everyday occupations. An understanding of these experiences should provide knowledge of importance for the rehabilitation services and, in particular, for occupational therapy programmes whose primary aim is to enable clients to engage in occupations.

This section has focused on the fact that people's occupational lives<sup>6</sup> may change profoundly after the onset of a disability. The conditions influencing these changes will be explored in the next section. The complexity of the conditions influencing persons' engagement in occupations can be understood through the use of theoretical models for the so-called person-environment interaction from the field of occupational therapy and from other disciplines. An overview of person-environment models will, therefore, be given in relation to the empirical studies of the conditions influencing engagement in occupations by persons with physical disabilities that are presented in the next section.

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<sup>6</sup> Given the complexity of the engagement people have in occupations, the concept occupational life is being used to an increasing extent in occupational therapy, but no clear definition exists. In this thesis, occupational life is taken to mean a person's all-encompassing and comprehensive experiences of his or her occupations in the context of his/her life situation.

### **Conditions influencing the engagement of persons with disabilities in occupations**

Several contemporary models of occupational therapy suggest that a person's occupational performance unfolds through dynamic and continuous interaction between the person, the task and the environment. Each one of these three conditions is multidimensional, which implies that complex interactions take place when one performs occupations (Canadian Association of Occupational Therapists [CAOT], 1997; Christiansen & Baum, 1997; Fisher, 2001; Hagedorn, 1995; Kielhofner, 2002; Law et al., 1996; Nelson, 1996). Changes in any of these conditions, such as in the demands from the environment or in the person's capability, alter the interaction between them, which may restrict or facilitate engagement in occupations. Thus, to enable or enhance a person's engagement in occupations, occupational therapy interventions focus on accomplishing changes in any or several of these three conditions to achieve a better fit between them (CAOT, 1997; Kielhofner, 2002; Law et al., 1996). However, empirical support for the complex interactions between the conditions that result in engagement in occupations, as suggested in these models, is, as yet, in short supply. Until recently, research has tended to focus on pre-defined dimensions related to a specific condition, thereby neglecting the complexity of the conditions that influence engagement in occupations from the individuals' point of view (Morgan & Jongbloed, 1990). Extensive research has investigated the impact of certain dimensions, specifically those related to the person, such as age, sex and his or her state of health, on engagement in occupations, and in preference the area of self-maintenance (e.g. Barch & VanSwearingen, 2002; Gill, 1997; Meijer et al., 2003). Nevertheless, scientific studies reflect a growing awareness that the problems of persons with disabilities should be related to the misfit between the person and the environment (Iwarsson, 1997; Rochette, Desrosiers, & Noreau, 2001; Shumway-Cook et al., 2003). Thus, the demands and opportunities in the person's environment are beginning to receive an increasing amount of attention.

The increased emphasis on the environment and its influence on disability is also evident in the recently developed ICF (WHO, 2001). Moreover, it is important to notice that theoretical models obtained from other disciplines have influenced the occupational perspective on person- environment interactions (Law et al., 1996; Law et al., 1997). One such is Lawton's ecological model of adaptation and aging (Lawton, 1986). This model suggests that humans' behaviour is a function of the balance between each person's competence and the pressure exerted by the environment. This balance can be achieved by encouraging the person to change and/or by changing the environment. According to Lawton (1986), persons with a lower level of competence (e.g., persons with disabilities) are more vulnerable to the press of the environment than those with higher level of competence. In comparison, the person-environment models emanating from occupational therapy resemble Lawton's model, but differ in that an occupational aspect is added, and also in that the focus is on occupational performance. For a more comprehensive

review of more person-environment models of particular interest from an occupational perspective, see Law et al (1997).

In some widely used models in occupational therapy, the environment is described as including physical, social, cultural and societal or institutional elements (CAOT, 1997; Christiansen & Baum, 1997). These elements of the environment provide opportunities and impose demands on a person's engagement in occupations and can, thereby, enable or constrain their doings (CAOT, 1997; Kielhofner, 2002; Law, 1991; Law et al., 1996). In clinical practice, the immediate physical<sup>7</sup> and social environment<sup>8</sup> of the person, such as inaccessible housing and amount of social support<sup>9</sup> provided have been concentrated upon, while other dimensions in the environment that influence engagement have received less attention (CAOT, 1997; Stark, 2001). Thus, it is still the case that little is known about the conditions in the environment that interact with and contribute to persons' occupational engagement. A more comprehensive understanding of the complexity of the conditions influencing engagement in occupations from the perspectives of those with disabilities is therefore needed to facilitate their engagement.

When considering the opportunities persons with disabilities have to engage in occupations that support participation, it is also important to consider the influence of the available societal resources. Factors in the societal environment, such as social structures, service and systems, including the associated laws, regulations and policies on which they are founded, and the economic possibilities can have both a positive and a negative influence on the possibilities of persons with disabilities to engage in occupations (CAOT, 1997; Fisher, 2001; Regeringens proposition 1999/2000:79; WHO, 2001). Society can hinder everyday occupations through the creation of barriers and by providing insufficient facilitators, but it can also facilitate engagement by providing adequate levels of support (WHO, 2001). In the coming section, some important characteristics of the rehabilitation service and occupational therapy will be considered briefly, as will the social service provision in Sweden for persons with disabilities. This will provide a basis for contrasting the scope and the character of the service that clients can expect to receive with their actual experiences which will be discussed later in this thesis.

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<sup>7</sup> The physical environment includes natural and built surroundings and objects (CAOT, 1997; Kielhofner, 2002).

<sup>8</sup> The social environment includes relationships with others and social groups (CAOT, 1997; Kielhofner, 2002).

<sup>9</sup> Social support refers to the support of other persons. The sources to support can be informal and formal, with formal support being those everyone has access to such as professionals, and informal support being those persons have uniquely access to such as family and friends (McCull, 1995).

### **The rehabilitation service in general and occupational therapy**

In Sweden, rehabilitation is an integral part of the health care system (SFS 1982:763) and the authorities define rehabilitation as comprehensive efforts of a medical, psychological, social, educational, technical and work-related kind (SoS-rapport 1993:10). Given such comprehensive efforts, rehabilitation services need to be provided by a multidisciplinary team. Occupational therapy is a common component of rehabilitation services with its focus on supporting health and participation through engagement in, what is considered by the client to be meaningful and purposeful occupation (American Occupational Therapy Association [AOTA], 2002; Law, 2002). One of the ultimate goals of rehabilitation is for the clients to achieve full participation in society. This implies that the health care service is to be integrated with efforts from other actors in Swedish society, such as the Social Services, the National Insurance Office, employment offices and the Employability Institute (SoS- rapport 1993:10).

In western society, rehabilitation has been formed in the medical model, focusing on clients' impairments and the restoration of these to as near normal a state as possible (Finkelstein & Frech, 1997; Oliver, 1989b; Oliver, 1996b). This implies that the medical model is associated with a biomedical perspective, and from this perspective, health is defined as the absence of disease (Boorse, 1975; Boorse, 1977). During recent decades, however, the borders of rehabilitation have been extended to include aspects related to the personal, social and physical context of the persons receiving the rehabilitation (Wade & de Jong, 2000). Barnitt and Pomeroy (1995) suggested that there is a move towards adopting holism as the ideal approach for rehabilitation. In occupational therapy, holism has a long tradition and, indeed, it forms an integral part in theory and practice (see Hemphill-Pearson & Hunter, 1997 for a review of the literature). The concept of holism embraces a holistic perspective of health, client-centredness and the enhancement of the active role of clients in the rehabilitation process (Finlay, 2001). This implies that there has been a shift from the traditional medical model's biomedical perspective on health to a holistic client-centred model of rehabilitation. This shift is important because it influences how professionals approach clients, the problems that will be focused upon and the type of service provided. It is important to be aware of the qualities that characterise the rehabilitation services when exploring whether these are reflected in clients' experiences. Therefore, the next section will explore some of the characteristics of holism and how they have been adopted in rehabilitation in general, and in occupational therapy in particular.

### ***Rehabilitation and occupational therapy based on a holistic perspective***

The term holism derives from the Greek "holos", meaning unity or oneness (Lipowski, 1984; McColl, 1994), but the concept was first coined in the literature by Smuts in 1926 to describe the principle of wholes in the universe (Smuts, 1926/1999). Many underlying assumptions and principles have been identified for the achievement of a holistic approach to health care (Hemphill- Pearson &

Hunter, 1997), and see for example (Engel, 1980; Lipowski, 1984). One important assumption, for example, is that the understanding of a person's health should be based on a synthesis of the person in his/her individual context, rather than solely on an analysis of the person. Another important feature is that the person is viewed as a unique being with an inseparable body and mind, and with the capacity to determine what is needed for him/her to achieve good health (Finlay, 2001; Hemphill- Pearson & Hunter, 1997; McColl, 1994).

From a humanistic holistic perspective, health is defined as a person's ability to act in order to realize (vital) goals (Nordenfelt, 1987; Nordenfelt, 1996; Pörn, 1993). Similarly, occupational therapists claim that occupations are basic human needs and that it is through the process of engaging in occupations that people develop and maintain their health (CAOT, 1997; Meyer, 1922/1977; Reilly, 1962; Wilcock, 1998; Yerxa, 1998). Health has increasingly been assessed in terms of the quality and satisfaction with life with concepts such as well-being, (health related) quality of life and life satisfaction (Leplege & Hunt, 1997; Nordenfelt, 1991; Post, Van Dijk, Van Asbeck, & Schrijvers, 1998; Shumaker & Naughton, 1995; Whiteneck, 1994). This illuminates the importance of considering clients' experiences of the provision of services that enhance engagement in occupations in order to support clients' health.

In the health care services in general, *client-centred* and similar terms, such as *client driven* and *patient focused* are increasingly being used in any approach that considers the clients' needs (Gage, 1995). Thus, the definitions of these concepts often lack clarity as they are defined differently or assumed c.f. (Chewning & Sleath, 1996; Gage, 1995; Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Little et al., 2001). The concept of client-centredness and its characteristics was first described 1940/42 by the psychologist Carl Rogers (1942; 1951) who made an important contribution to the development of the quality of the interaction between clients and therapists. In occupational therapy, the client-centred approach has become more apparent within the last two decades and is now seen as an important principle right at the core of occupational therapy (CAOT, 1997; Fisher, 2001; Kielhofner, 2002; Law, 1998). Client-centred practice is considered to be the ideal in occupational therapy and has been conceptualised as a collaborative partnership with the clients to enable the clients to engage in occupations. This collaborative partnership is characterised by the clients' involvement in decision-making and a focus on the clients' needs, priorities and experiences (CAOT, 1997; Law, Baptiste, & Mills, 1995). This implies that the autonomy of the individual underlies the concept of client-centredness. Thus, a thorough understanding of the clients' view is critical for the professionals' to adopt clinical reasoning that is based on a client-centred approach. From a clinical perspective, therefore, it is important to explore whether the rehabilitation service's ideal of being client-centred is actually achieved from the perspective of the clients.

Although there has been an obvious focus on clients' priorities throughout the history of occupational therapy, the implementation of client-centred practice has been difficult. Barriers to client-centredness have been found at different levels in occupational therapy, both in the organisation and among the actors. The barriers to client-centredness have been found to take many forms, such as interventions being dominated by the medical model, professional dominance and the need for increased knowledge and awareness of client-centredness among professionals (Abberley, 1995; Rebeiro, 2000; Sumison & Smyth, 2000; Wilkins, Pollock, Rochon, & Law, 2001; Wressle & Samuelsson, 2004). This indicates that clients may not experience the services as fully client-centred, depending on the extent to which a client-centred approach has been implemented. In turn, this could have consequences for enabling occupations, but further research is needed to examine this matter.

### ***Social service support for the participation of persons with disabilities***

The Social Services Act in Sweden (SFS 2001:453) stipulates that the social service should strive to meet significant problems in humans so that the people concerned have the possibility to participate in a social life and to live like everybody else, including engaging in occupations that are meaningful for the individual. For persons with disabilities, this support can take on different forms, such as getting a home help or being provided with a service flat. The handicap reform in Sweden aimed to additionally increase the influence and autonomy of younger persons with disabilities in everyday life (> 65 years) (Carlberg et al., 1992; SFS 1993:387). One important result of the law for the support and service for certain persons with functional impairments [LSS](SFS 1993:387), which emanated from the handicap reform, is the right to have a personal assistant. Thus, the social service provision to persons with disabilities varies due to these different Swedish social services acts (SFS 1993:387; SFS 2001:453). In 2003, about 143 000 persons received home help services (Socialstyrelsen, 2004b; Socialstyrelsen, 2004c) and approximately 53 000 received support and service according to LSS (Socialstyrelsen, 2004a).

Access to rehabilitation and the social service is described by The National Board of Health and Welfare (Socialstyrelsen, 2003) as being essential to enable persons with disabilities to participate in society like everybody else. However, it is unclear whether the kind of services provided meets with the needs of the recipients in Sweden (Socialstyrelsen, 2003). In a study specifically addressing the interplay between parties belonging to different organisations Lindqvist and Tamm (1999) have highlighted the fact that there can be difficulties in the interplay between the parties which may affect the opportunities of obtaining success in the rehabilitation of persons with disabilities who are living in their own homes. This indicates a need for further research on these matters.

With this description of some of the services that are provided for persons with disabilities as a base, it is possible to concentrate on the clients' experiences of the rehabilitation process.

### **The rehabilitation process**

The rehabilitation process can be described as the course that rehabilitation takes over time viewed from the point of view of the persons with disabilities. This process includes the person's experiences of his or her illness as well as changes in and the development of a person's ability and changes to their the personality (Fortmeier & Thanning, 1998). Elsewhere, the rehabilitation process has been characterized somewhat differently, as a problem solving process (Frieden & Cole, 1984; McGrath & Davis, 1992), an adaptation process (Forsberg-Wärleby & Möller, 1996) and a process of learning to live with a disability within one's own environment (Whalley Hammell, 1995). The rehabilitation process has also been characterised as a coping process (Fugl- Meyer et al., 1991) comprising the efforts of the person afflicted to manage external and internal demands arising from the existential threat and stress that may press upon or overwhelm the resources of the person (Lazarus & Folkman, 1984). The overall aim of the rehabilitation process is described somewhat differently within different frameworks, but most scholars agree that the primary importance is for the client to restore his/her ability to perform activities of daily living (Fugl- Meyer et al., 1991; Post, de Witte, & Schrijvers, 1999; SoS- rapport 1993:10), identify new and meaningful realizable goals (Fugl- Meyer et al., 1991), participate in society (SoS- rapport 1993:10; Wade & de Jong, 2000; WHO, 2001) and achieve "a good life" in terms of optimising well-being, (health related) quality of life, or life satisfaction (Fugl- Meyer et al., 1991; Fuhrer, 1994; Post et al., 1999; SoS- rapport 1993:10). The rehabilitation process, including its aims, can be assessed from an objective and a subjective perspective. In assessing the impact of a disability, the former perspective has received much attention, but the importance of examining the latter has been pointed out nevertheless (Carr & Thompson, 1994; Whiteneck, 1994). This thesis concentrates on the subjective reality as experienced by persons with disabilities.

### ***Clients' participation in planning their rehabilitation services***

The very nature of the overall aims of the rehabilitation service, i.e., engagement in occupations, participation in society and ensuring that the clients are able to live "a good life", requires that clients identify what they consider to be meaningful occupations related to these concepts. This implies that the clients' should participate actively in the planning, including the goal-setting, and in the implementation of rehabilitation services; something that has been emphasised by the Swedish authorities (SFS 1982:763; SOU, 1997:154), in the rehabilitation literature in general (Davis et al., 1992; McGrath & Davis, 1992) and in occupational therapy in particular (CAOT, 1997; Fisher, 2001; Kielhofner, 2002). Shared decision making between the client and the professional is advocated as the

ideal for supporting the autonomy of the client (Ottosson, 1999; SFS 1982:763; SOU 1997:154). Moreover, the sharing of information between clients and professionals and the clients' feelings of having some control have also been emphasised as important ingredients of participation in the planning. A review of the literature confirms that the clients' participation in the planning of rehabilitation services tends to improve the outcome in terms of behavioural change in the management of the disability in everyday life occupations (Wade, 1998). Clients' participation in the planning is also important as their perceptions of their needs from the rehabilitation differ from the professionals' perceptions of the clients' needs (Caradoc- Davies, Dixon, & Campbell, 1989; Kersten, George, McLellan, Smith, & Mullee, 2000). Despite these norms for and the benefits of clients' participation in the planning, evidence obtained from research indicates that the complexity of the relationship between the client and the professional can affect the implementation of a successful joint planning process (cf. Benbassat, Pilpel, & Tidhar, 1998; Gerteis et al., 1993; Ottosson, 1999). This makes the complexity of this relationship worthy of research.

Theories and empirical research have examined the roles of the client and professionals, their perceptions of participation and the relationship between the client and professional in planning the rehabilitation services because of the emphasis that has been placed on the clients' right to participate actively. The theoretical conceptualisations of the nature of the relationship between clients and professionals have changed over time. In the beginning of the 1950s, Parson (1952) described the patient-doctor relationship as a relationship that is characterised by paternalism. Nowadays, above all else, the relationship is described as being diverse, but with the common denominator that it is client-centred (Emanuel & Emanuel, 1992; Peters, 1994). Empirical research suggests that clients' participation in planning means different things to clients and professionals, and also different things to different individuals in both groups. The clients' desire and ability to participate in the planning can also deviate from the professionals' ambitions and strategies to include the client (Benbassat et al., 1998; Gerteis et al., 1993; Guadagnoli & Ward, 1998). Moreover, different kinds of needs may influence the clients' participation in the planning of their rehabilitation service (Benbassat et al., 1998; Biley, 1992), but studies exploring clients' participation with other professional rehabilitators than physicians, such as occupational therapists, are relatively rare. The research has focused on either the clients' or the professionals' perceptions at any one time rather than considering the perceptions of both at the same time (e.g. Guadagnoli & Ward, 1998; Northen, Rust, Nelson, & Watts, 1995). This implies that knowledge relevant to the perceptions of both clients and professionals involved in the same planning process are rare, particularly for other professional groups than physicians. Contrasting the clients' and professionals' perceptions of the joint planning of the rehabilitation would give insights into how to enhance client-centredness in the planning.

Both theoretical descriptions and empirical findings show that the approach chosen by professionals to planning the clients' rehabilitation influences the focus of the goals and the clients' possibilities of participating in the planning of the their rehabilitation (Davis et al., 1992; Gage, 1994; Larsson & Bränholm, 1996; McGrath & Davis, 1992). This highlights the importance of not only considering the relationship between the client and the professional, but also of considering how the professional's work is organised in order to more fully understand client's participation in the planning.

As the participation of clients in the planning of rehabilitation services, including the goal- setting, is only one aspect of the rehabilitation process, it is also important to focus on the clients' experiences and needs during the course of rehabilitation over a period of time.

### ***The clients' needs in relation to the rehabilitation services provided over time***

In Sweden, over time, the rehabilitation services, including individual parts of the services, such as occupational therapy, can be considered to be vertically organised, with the different levels providing different levels of care, for example, hospital care and primary care. In these levels, the care can be provided in various forms, such as specialised rehabilitation, home rehabilitation or rehabilitation at day centres and given by different organisations. This can be contrasted to the clients' experiences and needs, which may be perceived to be evolving along a horizontal continuum over a long period of time, spanning the period from hospital to home and, therefrom, to reintegration in society. This may cause problems for clients if different organisations lack co-ordination because this may lead to a break in the so-called "*chain of rehabilitation services*" (Åhgren, 1997). The need to adopt a comprehensive long- term perspective that focuses on the clients' experiences, needs and expectations has, therefore, been emphasised as a basis for improving the continuum of rehabilitation services in Sweden, and internationally (Gerteis et al., 1993; Svenska Kommunförbundet, 1996; Åhgren, 1997). The use of the concept "chain of care" to refer to the collaboration between different providers with the aim of co-ordinating rehabilitation over time (Spri, 1997; Svenska Kommunförbundet, 1996) has underscored this focus in Sweden during the past decade. A well-functioning chain of care is considered to be particularly important as the length of stay in hospitals has been decreasing in Sweden, thereby meaning that there is an increased need for rehabilitation after discharge (Spri, 1997). Moreover, the clients' experiences of the rehabilitation process can give an indication of the quality of their rehabilitation i.e. whether their needs are met throughout the process or not (Krevers, Närvänen, & Öberg, 2002; Åhgren, 1997).

Although the insider's perspective, i.e., the clients' subjective experience of the rehabilitation process and of the outcome, is acknowledged to be important to understand for rehabilitation providers, it has been eclipsed — both in rehabilitation practice and research — by the outsider's perspectives, which present

views other than the clients' experiences (Kramer, 1997; Peters, 1996). In addition, the rehabilitation services are commonly examined in specific settings, such as in hospital or in the home, rather than by assessing the whole chain of services (e.g. Eastwood, Hagglund, Ragnarsson, & Gordon, 1999; Mayo et al., 2000; von Koch, Widen Holmqvist, Kostulas, Almazan, & de Pedro-Cuesta, 2000). Research related to the chain of care often concentrates on the transfer of information between different providers, such as between occupational therapists in different organisations (e.g., Lilja, Nygård, & Borell, 2002). Moreover, the subjective experiences have hardly been integrated into models of disablement in a theoretical and systematic way (Peters, 1996). This implies that rehabilitation providers may not be fully aware of the subjective experiences of their clients and of how these compare with the clients' needs. Thus, this indicates a need for increased knowledge of the experiences of the "chain of care" in persons with disabilities throughout their rehabilitation process to ensure that the services are fully adapted to meet the clients' needs.

Persons with disabilities have provided many insightful narratives of their experiences of the reality of the everyday life they experience (e.g. Cant, 1997; Murphy, 1990), but these are limited to single case presentations and therefore lack the benefit of scientific analysis. Research on the experiences of the rehabilitation process in persons with disabilities mostly covers the early episodes and describes changes, losses and other consequences of disability on persons' everyday life, as well as their needs (e.g. Doolittle, 1991; Pound & Gompertz, 1998; Sisson, 1998). Consequently, far less is known about their experiences and their needs over a longer period of time (Hafsteinsdottir & Grypdonck, 1997; Morse & O'Brien, 1995). Research has suggested that the needs of clients differ during different phases at the beginning of rehabilitation (Krevers et al., 2002), indicating a need to examine these matters more extensively throughout the rehabilitation process. Other studies have focused on isolated aspects of the rehabilitation process, such as the inner psychosocial adjustment (Carpenter, 1994; Morse & O'Brien, 1995) and changes in the body and identity (Charmaz, 1987; Corbin & Strauss, 1987). Most research of the rehabilitation process has also paid limited attention to the interactions between persons with disabilities and others (e.g., professionals, people close to them and society as a whole) over time. As the whole social environment of the persons concerned, and particularly of their family (Mattingly & Lawlor, 2003; McColl, 1995) is central in the persons' adaptation during the rehabilitation process, it is important to consider the interactions of those in rehabilitation with others over time. Thus, the literature shows that the rehabilitation process can be seen as an important condition for persons' possibilities to engage in occupations that will enhance their participation and the experience of living a "good life". At the same time, engagement in occupations is an important part of the rehabilitation process — both as a goal and as a means — for the client because the occupations are embedded in and characterise their everyday life and adaptation.

## Background

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To sum up, engagement in occupations is of significant importance to the lives of persons with disabilities. However, a more comprehensive understanding of the experiences that persons with disabilities have of the changes in their occupations and the conditions that influence these experiences is lacking, as is a comprehensive study of their experiences of the rehabilitation process. In addition, it is unclear whether the services provided to enhance engagement in occupations, in terms of rehabilitation services and social services, actually satisfy the needs of clients. The focus on occupations in everyday life to support participation and to bring about a “good life”, as reflected in international and national recommendations, laws and policies (Regeringens proposition 1996/97:60; SFS 1982:763; SFS 2001:453; United Nations' Standard Rules on Equalisation of Opportunities for Persons with Disabilities, 1993), emphasises that the client's subjective experiences, preferences and needs should be the base for designing the services that are provided. Nevertheless, the insider perspective has received little attention in research. Thus, research concentrating on the everyday realities as experienced by persons with disabilities can provide professionals with a new understanding of the nature of engaging in occupations that support participation and promote a “good life”. Such an understanding promises to be an important resource for enabling professionals to develop and adapt their service more appropriately to meet the needs people with disabilities have identified as being important to themselves.

### AIMS OF THE THESIS

The overall aim of this thesis was to illuminate and enhance the understanding of how persons with acquired physical disabilities experience their rehabilitation process and their possibilities to engage in occupations in everyday life.

From the overall aim, specific aims were formulated as follows:

- firstly, to describe how clients perceived their participation in the planning of their rehabilitation in hospital; secondly, to describe the view that registered nurses and registered occupational therapists had of the strategies they used to encourage clients' participation in the planning; and thirdly, to compare the perceptions of the two groups (Study I).
- to describe how persons with disabilities with a sudden onset experienced their rehabilitation process, focusing on their interactions with rehabilitation professionals, relatives and the community (Study II).
- to describe and enhance the understanding of how persons with disabilities receiving social and rehabilitation services experienced their occupational lives in their homes (Study III).
- to enhance the understanding of how persons with disabilities experienced the meaning of their assistive devices in their occupations and how they acted on this experience (Study IV).
- to map out and describe how persons with spinal cord injury (SCI) perceived their participation in life situations and to determine the relationship between their participation and the perceived problems with participation. The purpose was also to evaluate the influence of age, sex, level of injury, time since injury, marital status and the access to social support on perceived problems with participation (Study V).

**METHODS**

The design of the thesis was emergent (cf. Lincoln & Guba, 1985) rather than constructed a priori because the specific research questions addressed derived from the analysis and results of a preceding study in the thesis. As a starting point, Study I focused on one aspect of the rehabilitation process in the hospital, i.e., the planning. This led to further exploration of how persons with disabilities experienced their rehabilitation over a longer period of time in Study II. The persons' experiences showed that their engagement in occupations at home seemed to become of significant importance for how their lives turned out but that their engagement varied and the ground for this circumstance remained unknown. In addition, during the data collection, it was noted that persons with disabilities experienced their assistive devices in different ways and that their use of them in engaging in their occupations varied. In Studies III and IV these circumstances were explored in greater depth. Finally, Study V emanated from the result of Study III in which it was found that the social support provided was decisive for the engagement in occupations and for participation in life situations for a minor group of persons with disabilities. Study V, therefore, was conducted to investigate these circumstances in a larger sample. An overview of the empirical studies is given in Table 1.

Table 1. *Informants, data collection methods and data analysis methods in Studies I-V.*

	<b>Informants</b>	<b>Data collection methods</b>	<b>Data analysis methods</b>
Study I	<i>n</i> =107 (57 Persons with physical disabilities receiving rehabilitation at hospital and after discharge, 39 Reg. nurses and 11 Reg. occupational therapists)	Semi-structured interviews	Content analysis
Study II	<i>n</i> =15 Persons with physical disabilities with a sudden onset of disease or injury who had received rehabilitation at hospital and after discharge	Unstructured open-ended interviews	Constant comparative analysis
Study III	<i>n</i> =13 Persons with physical disabilities receiving rehabilitation and social service in the home	Unstructured open-ended interviews	Constant comparative analysis
Study IV	<i>n</i> =17 Persons with physical disabilities using assistive devices	Unstructured open-ended interviews	Constant comparative analysis and a hermeneutic approach to analysis
Study V	<i>n</i> =161 Persons with a spinal cord injury	Questionnaire IPA*	Descriptive statistical analysis, Spearman's rank-order correlation and logistic regression

\* Impact on Participation and Autonomy (Cardol & de Jong, 2001).

### **Selection of informants**

The sample in all studies comprised adult persons with acquired physical disabilities. In accordance with the literature from the field of occupational therapy (cf. Kielhofner, 2002; Mattingly & Fleming, 1994; Polatajko, 1992; Rogers, 1982; Yerxa, 1992), this thesis aimed to focus on the persons' experiences of the consequences in their everyday life rather than on the disease or injury per se. A sample of persons with heterogenous physical disabilities was, therefore, favoured. However, medical research has traditionally focused on particular diagnostic subgroups of people with diseases or injuries rather than on the experiences persons with disabilities may share. Researchers, mostly in the field of disability research, have therefore emphasised the need to acknowledge and investigate the complexity of persons' common experiences of having a disability, rather than focus on assumed differences related to medical dimensions (Conrad, 1987; Shakespeare, 1996; Strauss et al., 1984). Similarly, Parker (1998) stated that there are differences between age groups in the process of disability and in the needs of the individuals concerned, but that there are also many similarities that need to be understood.

The selection of informants was guided by different sampling procedures and different inclusion criteria in accordance with the aim of each study and the chosen approach for the research. An overview of the informants in all studies is given in Table 2. In accordance with the criteria for each study, staff at hospitals (Studies I and V), in primary health care and at associations for the disabled (II-IV) identified potential informants with physical disabilities who fulfilled the criteria for each study. In study I the number of informants depended on clients fulfilling the inclusion criteria throughout the two month data collection period. In studies II-IV, the sampling terminated when no new understanding emerged from new data, i.e., when saturation was achieved (cf. Glaser & Strauss, 1967; Strauss & Corbin, 1990). Table 2 presents an overview of the demographic characteristics of the informants.

## Methods

Table 2. *Demographic characteristic of informants in Studies I-V.*

	Study I	Study II	Study III	Study IV	Study V
<i>Persons with disabilities</i>	<i>n</i> =57	<i>n</i> =15	<i>n</i> =13*	<i>n</i> =17**	<i>n</i> =161
Age, years					
mean	79	58	53	50	52
median	75	61	57	47	55
range	28-95	30-84	25-73	25-73	17-84
Sex, <i>n</i>					
women	35	6	9	10	59
men	22	9	4	7	102
Marital status, <i>n</i>					
single	23	9	10	8	59
married/ cohabiting	24	6	3	9	102
Employment, <i>n</i>					
work full or part time/ education	-	2	2	5	59
sickness-benefit	6	2	1	-	19
disability pension	4	4	4	6	34
retirement pension	47	7	6	6	43
unemployed	-	-	-	-	2
no information	-	-	-	-	4
<i>Professionals</i>					
Reg. nurses	<i>n</i> =39				
Reg. occupational therapists	<i>n</i> =11				

\* Three of these informants also participated in Study II.

\*\* Six of these informants also participated in Study III and two participated in Study II.

Note: no informant participated in more than two studies.

### ***Informants in Study I***

In Study I consecutive sampling was accomplished with clients who (a) received rehabilitation in one of the departments located in one of the two hospitals included in the study, (b) lived in the hospitals' catchment area, (c) were in need of some kind of post-hospital assistance, such as primary health care or home help, (d) did not suffer from conditions that made them unable to respond in the interview, such as dementia, confusion or aphasia and (e) did not receive palliative care. Registered nurses and registered occupational therapists also constituted a part of the sample included in Study I. The only inclusion criteria applied for the nurses and the occupational therapists was that they should be responsible for a client who was participating in the study.

Study I comprised a total of 107 informants of whom 57 were clients, 39 registered nurses and 11 registered occupational therapists. Of the 57 clients, 37 had stayed in acute wards and 20 in rehabilitation wards. The number of professionals involved was less than the number of clients in the sample as some nurses and occupational therapists were engaged in the provision of rehabilitation services to several of the clients included in this study.

### *Informants in Study II*

Study II included a purposive sample (cf. Patton, 1990c) of informants who (a) had suffered from a sudden-onset disease or injury, (b) had received rehabilitation both at the hospital and after discharge, (c) had been in the rehabilitation process for some time and (d) did not suffer from conditions that would hamper participation in an interview. In the selection of the informants, the time that they had been in the rehabilitation process became especially important as a sample comprised of persons who had been in the rehabilitation process for different lengths of time was favoured to ensure that a description was obtained that reflected the process over a period of time.

Fifteen informants were included in this study. The time that had passed from the onset of the disease or injury ranged from three months to nine years (mean 3,5 years). Fourteen of the informants were in need of formal and/or informal support to engage in their daily occupations and twelve used some kind of mobility aid. All of the informants had suffered from a sudden-onset disease or injury, the most common of which were strokes and spinal cord injury.

### *Informants in study III*

The criteria for the purposeful selection (cf. Patton, 1990c) of informants in Study III were that they should (a) live in their own home, (b) receive home help or personal assistance, (c) have received rehabilitation in their home, such as training in the performance of activities of everyday living, assistive devices and adaptations to their physical environment and (d) not suffer from memory deficits, aphasia or other conditions hampering the interview dialogue.

The informants in this study were 13 persons who had received formal support from home-helps and/or personal assistants in their daily occupations for many years. Most of the informants also received informal support from their relatives. Eleven of the informants used a wheelchair for mobility. The informants' medical diagnoses were spinal cord injury, stroke, traumatic brain injury, multiple sclerosis and rheumatoid arthritis.

### *Informants in Study IV*

In study IV, the inclusion criteria in the purposeful sampling procedure (cf. Patton, 1990c) were that informants should (a) live in their own home, (b) have several

assistive devices and (c) not suffer from conditions that would hamper their responses in the interviews.

This study included 17 persons. The number of assistive devices the informants used ranged from four to about 20. All of the informants used some kind of mobility aid and devices for self-maintenance. Fifteen informants had had experience of using assistive devices for more than five years. All informants had received formal and/or informal support in their everyday doings. The informants use of assistive devices was related to spinal cord injury, rheumatoid arthritis, traumatic brain injury, multiple sclerosis, muscular dystrophy, osteoarthritis and fractures.

### *Informants in Study V*

In this study the total selection of all persons with a spinal cord injury (SCI) who had been rehabilitated at a centre in southern Sweden from 1993 to 2001 constituted the sample. The sample of people with SCI was chosen since it was reasonable to believe that this group would provide a crude informative reflection of the consequences for participation as perceived by persons with acquired physical disabilities. The reason for this expectation was that their disabilities vary on a continuum, from persons able to engage in everyday occupations on their own to persons in need of continuous social support in their occupations. Other reasons for the selection was that the persons' ages were expected to vary considerably, from younger adults to older people, and these people did not suffer from conditions hampering their possibilities to give comprehensive information about their situation.

A questionnaire was mailed to 278 potential informants of whom 161 persons agreed to participate in the study. Thus, the response rate was 58%. Sixty two percent of the informants had paraplegia while the remaining 38% had tetraplegia. The cause of injury was accident (52%) and disease (48%) almost to the same extent. Most of the informants used some kind of mobility aid (70%) and a majority of all informants (56%) reported that they received social support for their activities of daily living. Among all informants, 13% reported that the support they received was insufficient.

### **Data collection methods**

The data collection method in Studies I-IV was interviews while questionnaires were used in Study V.

### ***Interviews***

Data were collected in studies I-IV through individual interviews, with a varied amount of structure, to capture the informants' qualitative descriptions of their perceptions and experiences of particular aspects of their life. In Study I a *semi-structured* interview was conducted in order to collect comparable data for all the informants (cf. Holloway & Wheeler, 1996). The interviews in Studies II-IV were *unstructured* because the aim was to understand the experiences and the meanings these experiences have from an insider perspective. These unstructured interviews can be characterised as informal conversations (cf. Kvale, 1997; Patton, 1990a). However, despite the varied amount of structure in the interviews, the response formats in all interviews were open-ended. Moreover, interview guides (cf. Holloway & Wheeler, 1996) were used in all studies containing a list of questions (Study I) or a few topics designed as broad questions (Studies II-IV) to be covered in the interviews. The topics in the interview guides were maintained through each study, but in parallel with the analysis, the later interviews were consequently influenced by the ideas and questions that arose during the analysis. The informants whose experiences needed to be clarified and probed further were interviewed more than once. The topics that were explored in greater detail in the subsequent interviews depended on which experiences needed to be explored further. Thus, the topics in the subsequent interviews differed from one informant to another.

All interviews were conducted and transcribed by the author. The interviews in Study I lasted approximately 15 minutes with the professionals and 30 minutes with the clients, while the first interviews with the informants in Studies II-IV lasted between 45 minutes and 2 ½ hours. A second interview was conducted with some of the informants in Studies III-IV. These second interviews lasted between 25 minutes and 1 hour. In Study I, the interviews were either tape-recorded, or handwritten notes were taken during the interviews, while all interviews in Studies II-IV were tape-recorded. The interviews took place in hospitals for Study I and in the informants' home for Studies II-IV. In Study III, the informants often showed the interviewer the places where they carried out their occupations in their home and in Study IV they frequently demonstrated the assistive devices that used to accomplish occupations. Notes were taken on these. During each interview notes were also taken to facilitate the conversation with the interviewees.

### *Questionnaire*

The choice of questionnaire in Study V was guided by the aim of assessing the persons' own perceptions of participation rather than performing an assessment of each person's disadvantages in comparison to the expected norm in society (cf. Carr & Thompson, 1994). The generic self-assessment questionnaire selected was the Impact on Participation and Autonomy (IPA) (Cardol et al., 2002a; Cardol, de Haan, de Jong, van den Bos, & de Groot, 2001; Cardol, de Haan, van den Bos, de Jong, & de Groot, 1999; Cardol & de Jong, 2001).

*The Impact on Participation and Autonomy* is a recently developed questionnaire that makes it possible to examine participation in accordance with the intentions of the ICF. The IPA questionnaire is intended to assess the perceived participation, including autonomy (see discussion in Cardol, de Jong, & Ward, 2002b) in the domains of autonomy indoors, autonomy outdoors, family role, social relationships and work and education. Through the use of eight items, the questionnaire also addresses whether participation in any of the following is perceived to be a problem: mobility, self-care, family role, finances, leisure, social relations, work, education and learning. Perceived participation is estimated on a 5-point scale (from very good through good, fair and poor to very poor) and problems with participation on a 3-point scale (with the alternatives being no problem, a minor problem and a severe problem) (Cardol & de Jong, 2001). Since the questionnaire was not available in Swedish, a forward-backward translation procedure was implemented by professional translators to develop a Swedish version equivalent to the original version of the IPA (cf. Hilton & Skrutkowski, 2002; Su & Parham, 2002). The original version of the IPA has been found to have a good construct validity, convergent validity and divergent validity. However, the domains of work and education and the items relating to problem experience were not included in the test of different aspects of validity for the original version of the IPA. The IPA show good homogeneity and test-retest reliability (Cardol et al., 2002a; Cardol et al., 2001; Cardol et al., 1999). Tests of the responsiveness show that the IPA detects changes over time (Cardol et al., 2002a).

A questionnaire containing the IPA and sociodemographic characteristics was mailed to the potential sample of informants. Two repeat mailings were sent to those informants who did not answer the questionnaire.

### **Data analysis methods**

The data analysis in Studies I-IV was characterised by an iterative non-linear process. These analyses were carried out in parallel with the data collection in Studies II-IV. This is in contrast to the statistical analysis in Study V which proceeded in a more linear fashion after the data collection had been completed.

### ***Content analysis***

The clients' and the professionals' perceptions in Study I were analysed using content analysis. According to Polit and Hungler (1999), content analysis can be seen as a broad approach to the analysis of qualitative data with the aim of identifying patterns or categories. The choice of method was guided by the intention of describing and summarizing characteristics in the informants' conversations (cf. Polit & Hungler, 1995; Polit & Hungler, 1999). Content analysis entails counting the numbers of informants in each category and examining their responses to discover and confirm patterns in the data (Morgan, 1993; Sandelowski, 2000) with the intention of obtaining a comprehensive analysis of a qualitative data set (Sandelowski, 2001). When performing content analysis it is common that a framework or perspective is used to analyze the data (Downe -Wamboldt, 1992). In Study I, Cahill's (1996) definition of client participation was chosen to form a basis for the analyses of the informational content of the data. The first step of the analysis, which was carried out independently by two of the authors with the deliberate intention of revealing as much as possible from the data, started with readings and coding of the interview transcripts. The codes that reflected a pattern relating to the participation or to a pattern of strategies that encouraged participation were grouped in a category. Thereafter, the authors discussed their codes and categories to develop a common scheme for categorising data (see Polit & Hungler, 1995; Polit & Hungler, 1999). Through moving back and forth between data and emerging categories the categorising scheme was validated (Downe -Wamboldt, 1992). In the second step of the analysis, the categorisation scheme developed was used independently by the authors, whereupon their categorizations were compared to check the agreement — meaning the reliability — of the analysis. In the next stage of the analysis, the clients and professionals assigned to the different categories were counted along with the occurrence of different characteristics relating to participation in each of the categories (cf. Morgan, 1993; Sandelowski, 2000). Finally, the category each client was assigned to and the category that the professionals working with him or her had been assigned to were compared.

### ***The constant comparative method***

In Studies II-IV, a constant comparative method described by Strauss and Corbin (1990) was used to inductively uncover patterns of actions and processes present in the interactions experienced by the informants in their rehabilitation process (Study II) or in their occupations (Studies III-IV) and the meaning experienced in these interactions. The constant comparative method was developed by Glaser and

Strauss (1967) to develop theory grounded in empirical data. However, the procedure in the constant comparative analysis can also be used for alternative purposes, such as in concept development, in conceptual ordering and for description (Strauss & Corbin, 1990; Strauss & Corbin, 1998), which corresponded with our intentions in Studies II-IV. The theoretical framework of the constant comparative method is rooted in symbolic interactionism and focuses on people's social reality (Mead, 1967). Symbolic interactionism assumes that people create their experiences by acting on the basis of the meaning of the things and the people in their environment. These meanings derive from social interactions and interactions within the individual. Consequently, to understand people, the actions of the people need to be understood in their context and from the point of view of the individuals concerned if they are to retain their meaning (i.e., the meaning of their interaction).

The procedure of constant comparative analysis (Strauss & Corbin, 1990) began with repeated readings of the interview transcripts to get a comprehensive understanding of each informant's experiences related to the purpose of the respective study. Thereafter, a line-by-line analysis was conducted to identify the data containing actions, events and meanings in the rehabilitation process (Study II) or in the occupations (Studies III and IV). These pieces of data were given codes, the names of which corresponded to the wording of the informants as closely as was possible. The codes were then compared, and the codes that seemed to reflect similar meanings were clustered into categories formulated by the authors, whilst remaining close to the informants' experiences. During the next step, the categories were compared for similarities and differences, to identify relationships between them and to identify higher order categories. Simultaneously, a continuous back and forth process was carried out, moving between the data, the emerging higher order categories and the literature. The analysis continued until no new discoveries were made from the data (Strauss & Corbin, 1990). Quotations from the informants were selected to illuminate their experiences and to validate the research findings (Sandelowski, 1994). The continuous back and forth process performed in the analysis, going between the data and the emerging findings, ensured that the findings were grounded in the data (Strauss & Corbin, 1990). The emerging codes and categories were discussed by the authors throughout the research process to ensure that they were as sensitive to the information in the data as possible and to strengthen the validity of the analysis (Kvale, 1997; Strauss & Corbin, 1990). Finally, it should be noted that the findings were peer reviewed (cf. Lincoln & Guba, 1985) by researchers familiar with the field of research and the methodology. In study II member checks (cf. Lincoln & Guba, 1985) of the findings were made with some of the informants.

### ***A hermeneutic approach to analysis***

Since the comparative analysis in Study IV did not provide a means with which to understand the difference between the informants' experiences of acting with their

assistive devices, the analysis continued using a hermeneutic approach (cf. Gustavsson, 2000a; Gustavsson, 2000b; Ödman, 1979). A hermeneutic approach is used to understand the meaning of informants' actions through interpretations. The possible meanings in the data were found by conducting a spiralling movement from the whole to its parts and back again in the process of searching for new understanding. In this spiralling analysis, it is necessary to consider both experience near and experience distant interpretations (Gustavsson, 2000a; Gustavsson, 2000b). An experience near interpretation reflects what the informant meant in performing the action, while the experience distant interpretation goes beyond what the informant meant. The possible interpretations that were formulated were controlled against the data until the most fruitful interpretation was determined by applying two criteria for validation, as suggested by Gustavsson (2000a; 2000b) and Ödman (1979). The first criterion to be fulfilled was that the interpretation should correspond to all essential data. Secondly, the interpretation should be the only one that explains the essential data in a reasonable manner. The final interpretation in Study IV was the only one found that fulfilled these two criteria.

### *Statistical analysis*

In Study V, a non-random sample responded to the questionnaire with variables that were, by preference, on an ordinal level. Therefore, descriptive statistics, Spearman's rank-order correlation analysis and logistic regression (Kerlinger & Lee, 2000) were to be applied. The correlation analysis examined the relationships between the five IPA domains, on the basis of scores defined by each respondent's number of poor or very poor reports for the items included in the domain, and for the eight items for perceived problems with participation. In the logistic regression applied, the influence of age, time since injury, level of injury, sex, marital status and access to social support on perceived problems with participation were all examined. The items relating to perceived problems with participation, i.e., the dependent variables in the analysis, were dichotomised into two categories, one including no or minor problems and another including severe problems.

### **ETHICAL CONSIDERATIONS**

The ethical committee of Umeå University approved Studies I-IV (Um 97-180; Um 98- 287) and the ethical committee of Lund University gave permission to carry out Study V (LU 294-02).

The research process in all studies in this thesis was guided by the Medical Research Council's principles of research ethics (Medicinska Forskningsrådet, 2000). As participation in the studies involved taking part in interviews (Studies I-IV) or answering questionnaires (Study V) concerning personal matters, the possibility that strong emotional feelings could arise was considered and, to minimise the consequences, all presumptive informants in Studies I-IV received written and verbal information about what participation in the studies would entail, whereupon they gave their verbal informed consent. In addition, in Study I, all clients also gave their approval to the gathering of information regarding their rehabilitation from their nurses and occupational therapists before the professionals were asked to participate. In Study V, the informants received written information in a cover letter mailed with the package of questionnaires. The information given in all studies included the aim and design of the study and emphasised that participation was voluntary. The informants were informed that they could withdraw from the studies at any time without having to give an explanation. In Studies II-IV the informants were asked if the interviews could take place in their home. As this is the territory in which one conducts one's private life, the informants were given the opportunity to choose another place for the interview to avoid possible feelings of discomfort arising.

The importance of anonymity and confidentiality were also considered throughout the research process. Staff at the different wards in the hospitals (Study I) and in the primary care and also staff working for the associations for persons with disabilities (Studies II-IV) were asked to tell potential informants about the research study and ask them if they would consent to be contacted by the researcher who wished to send them more information. In this way, the anonymity of those who did not want to take part was protected. In addition, when the informants' statements in the interviews or their demographic characteristics seemed too specific to retain confidentially, such as information relating to a particular occupation or a specific diagnosis, this information was omitted when the findings were presented.

In accordance with the ethical guidelines for research, the foreseeable benefits of each study were considered to outweigh any foreseeable discomfort for the informants.

## **MAIN FINDINGS**

### **Clients' perceptions of their participation in the planning of their rehabilitation and professionals' view of the strategies they adopt to encourage it (Study I)**

The findings showed that some of the clients perceived that they had surrendered the planning to the professionals, while others said that they shared the planning throughout the rehabilitation, including the making of decisions relating to the planning. Yet other clients perceived that they only participated occasionally in the planning and that they had limited opportunities to influence the planning and the decisions. The professionals' views of their strategies to encourage the clients' participation showed that some of the registered nurses and occupational therapists first planned the rehabilitation and then informed their clients of the intended course of the rehabilitation. Other professionals perceived that they encouraged and shared the planning with their clients throughout the rehabilitation. The nurses said that their strategies to encourage client participation were influenced by routines for the planning on the ward, while the occupational therapists said that they could encourage client participation by implementing the traditional professional approach to planning. The comparison of the clients' and the professionals' perception indicates that the professionals did not adapt their strategies to encourage the clients' participation to the clients' desire. This suggests that professionals need to become more aware of their clients' individual desires for participation in the rehabilitation planning if they are to promote a client-centred rehabilitation that enhances each client's autonomy.

### **The experiences that persons with disabilities have of their rehabilitation process (Study II)**

The findings revealed that the persons' experiences reflected parallel chains evolving over a period of time and in different phases. These chains were conceptualised as the medical rehabilitation chain, the psychological rehabilitation chain and the social rehabilitation chain. The chains started and ended at different points of time in the rehabilitation process and the time needed to pass through the different phases varied from person to person. The experiences the persons had of their frequent interactions with professionals that formed the medical rehabilitation chain were intensive at the onset of their disability, but were of relatively short duration. The psychological rehabilitation chain was formed by each person's own struggle with the reorientation of his or her personal life, something that was of central importance for each individual throughout the rehabilitation process. The persons' experiences of social aspects of their life reflected their interactions with close persons and with society as a whole in the social rehabilitation chain. This chain was visible later in the rehabilitation process, but the importance of these experiences for the persons' life increased over time. Thus, the persons' experiences were that professionals were involved to a very limited extent in the psychological and social rehabilitation chains. This indicates that these persons did not experience

the rehabilitation provided by professionals as holistic. Furthermore, the persons' experiences also reflected the fact that the influence of the different rehabilitation chains on how their life turned out varied over time, indicating a need to concentrate on different aspect of the rehabilitation at different phases.

### **The experiences persons with disabilities have of their occupational lives in their homes (Study III)**

From the analysis it was found that the experiences persons had of engaging in occupations at home differed profoundly. Some persons experienced that their engagement in occupations was characterised by continuous interaction with others. Others experienced that they were occasionally disrupted in their everyday doings by the professionals who gave them support. Yet another group was characterised by those who experienced that they were deprived of the possibility to engage in what they considered to be necessary occupations. All the persons' experiences of their occupations were influenced by multifaceted conditions related to the interaction between the person and the environment. Their experiences reflected the fact that access to social support — which also was provided under different conditions — proved to be a condition of decisive importance for the opportunity to engage in occupations. The persons' experiences revealed that the interaction between the multifaceted conditions influenced aspects related to their occupations in different ways. Thus, aspects such as their use of time, the temporal structure of their day, the occupational space in which they engaged in occupations and their experience of the meaning of their occupations and of dependency were all influenced. When the persons' occupations in the home setting changed, their experiences also reflected that the meaning of the home in general was transformed, as well as the home as a physical place, as a relational place and as a place for personal identification. The findings indicate that interventions in the home setting need to be better designed to satisfy the occupational needs of the individuals concerned and to preserve the meaning of the home for persons with disabilities.

### **The experiences persons with disabilities have of the meaning of their assistive devices (Study IV)**

The findings of the study showed that the meaning of using assistive devices were experienced as manifold and double-edged. The findings also showed that the persons responded differently to these meanings. Some persons took a pragmatic view of their use of assistive devices and incorporated them in their lives to ensure that they would be able to continue their engagement in their desired occupations. Others, however, were ambivalent about using assistive devices and were, therefore, hesitant to incorporate them in their everyday occupations. Thus, their engagement in occupations was characterised by mixed feelings because the usage of aids was associated with the relinquishment of the hope of further recovery. Yet others were reluctant to use assistive devices and, as a consequence, chose to avoid or to cease engaging in occupations they actually considered as meaningful. The differences between these responses to assistive devices were understood as representing

different adaptive approaches all of which had the same intention: to achieve and present desired occupational self-images. Thus, the findings suggest that the incorporation of or resistance to the use of assistive devices can serve as a means by which to achieve a desired occupational self-image. The findings also suggest that the social environment was important for the kind of occupational self-images the persons strove for.

### **The perceptions of persons with spinal cord injury on their participation in life situations (Study V)**

The results demonstrated that the majority of the informants with SCI reported that their participation was sufficient in most of the occupations addressed. Insufficient participation was mostly reported in the items relating to different kinds of occupations outside the home and in intimate relationships. An appreciable proportion of the informants (40-56%) perceived themselves to have minor problems with their participation in life situations in all eight aspects studied. The majority of the informants (57%) reported one or more severe problems with the eight studied aspects of perceived problems with participation. The correlation analysis showed that the domains for participation and the items for perceived problems with participation were positively correlated (0.16- 0.71). The majority of the coefficients of correlation were above 0.47. This implies that, even if the persons perceived themselves to suffer from insufficient participation, this was not the same as perceiving this to be a problem. The logistic regression showed that the access to social support was the variable with the strongest influence in predicting perceived severe problems with participation in all eight items, as compared to certain personal (sex, age and marital status) and health-related (level of injury, time since injury) variables. The informants who perceived that they had insufficient social support to enable them to engage in their occupations had a greater risk of perceiving themselves to have severe problems with participation compared to those who received no or sufficient social support. The findings suggest that it is important to concentrate on the aspects of participation that were considered to be a severe problem by the person involved, rather than focusing on restrictions to participation in general in rehabilitation. A better insight of the problems that clients perceive themselves to have with participation can be obtained by considering the clients' possibilities to engage in occupations when, where and in the way they want. The findings indicate that it is important that rehabilitation professionals consider whether the access to social support is sufficient to satisfy their clients' needs to fulfill their occupations in order to decrease their problems with participation in health-promoting life situations.

### GENERAL DISCUSSION

The main empirical findings of the studies included in this thesis can be divided into two themes. The first theme illuminates the central importance of the societal and social environments in attempting to understand the experiences of persons with disabilities of the client-centredness of the rehabilitation services throughout their rehabilitation process, and of understanding their experiences of the consequences of engaging in occupations and of participating in everyday life. The second theme illuminates the crucial importance of different aspects of the experiences persons with disabilities have of their engagement in occupations in understanding the meaning that living with a disability has. The discussion elaborates upon these two major themes and includes implications for how the rehabilitation service can support engagement in occupations.

#### **The vital role of societal and social environments for enabling occupations**

One main theme in the findings that was reflected in all the studies was how, in different ways, the societal and social environment was of central importance in influencing the possibilities for persons with disabilities to engage in occupations (Studies II-V) and in their experience of the rehabilitation process (Studies I-II). The influence of the societal environment was reflected in the organization of the rehabilitation service in the hospital (Study I), the rehabilitation services provided over time (Study II), and the access to formal support in the engagement of occupations (Study III). The influence of the social environment was demonstrated through the clients' interactions with the personnel engaged to work with them (Studies I-III), with their significant others and with people in public life (Studies II-V). The persons' experiences reflect how the societal and the social environment may both facilitate and constrain their possibilities to carry out occupations (study II- V) or their participation in the planning (Study I) or in their life situation (Study V). In addition, the influence of the social and societal environment on how the persons experienced the rehabilitation process (Study II) increased over a period of time and seemed to be decisive for their experiences of living with their disabilities later on in the process. These findings all stress the importance of taking the societal and social environment into account, both in research and in clinical practice, in order to more fully understand the experience of having a disability.

#### ***Overall consequences of environmental influences for the future design of services***

The findings indicate that the access to social support, which was in part influenced by the societal environment in the form of formal support provision regulated by legislation, appeared to be more influential on the engagement of persons with disabilities in occupations than other conditions (Study III and V) that have been described in theoretical models of the person-environment interactions (CAOT, 1997; Christiansen & Baum, 1997; Kielhofner, 2002; Law et al., 1996). Thus, other commonly empirically assessed conditions for engagement in occupations, such as factors related to the persons' background and health, were not found to be

as influential as expected on the basis of previous research, which has concentrated on these conditions (see for example Meijer et al., 2003; Noreau & Fougereyrollas, 2000). Consequently, the findings of Studies III and V suggest that the environment influences engagement in occupations and participation in life situations to a greater extent than the impairments experienced by persons with disabilities. However, more comprehensive research of the conditions influencing engagement in occupations is needed to substantiate these findings.

The recently developed ICF (WHO, 2001) emphasises the influence of the environment on clients' functioning and disability, in contrast to its precursor, the ICIDH (WHO, 1980) which concentrated on the individual. The ICF (WHO, 2001) can encourage professionals to focus on the complexity of conditions influencing disability, including the environment, if the ICF model as a whole and its part is taken into consideration. However, the findings of these studies suggest that if professionals only consider some of the conditions influencing disability, the ICF model's potential to develop the quality of rehabilitation service that clients needs might be limited. In adopting a client-centred approach in clinical practice, it is important that professionals take the complexity of conditions influencing the disabilities experienced by clients into account, focusing on the clients' priorities, rather than acting on the basis of customary patterns that concentrate on a limited number of pre-defined conditions.

When interventions are undertaken with the intention of enhancing the engagement of persons with disabilities in occupations, the findings of Studies II-V indicate the need to address not only the immediate environment of persons with disabilities, but also the community services and social attitudes, structures and policies that characterise society as a whole. Researchers in the field of occupational therapy have highlighted the importance of adopting an occupational perspective of justice to be able to recognise and provide for occupational needs as a part of a fair and empowering society (Wilcock & Townsend, 2000; Wilcock, 1998). These authors described occupational justice as a complement to social justice. The findings of the research presented here, and particularly of Study III, evidently show that some of the persons with disabilities engage in a variety of occupations that they find meaningful, while others feel that their occupational needs are unmet and that they are unable to develop their occupational potential. Their experiences also revealed that they were often relegated to a life in which they were unable to meet the occupational challenges of their communities and that they felt that they were being a burden to society. These circumstances, which can be said to illustrate occupational injustice, reflect the need to create policies that take into consideration the occupational needs of those with disabilities' more fully to ensure that they are able to have equal opportunities for a diverse and a rich occupational life, for justice and health, as every other member of society (cf. Wilcock & Townsend, 2000; Wilcock, 1998).

The fact of, what can be considered to be the more distant environment, composed of the community and persons and places within it, is an important determinant for the occupational opportunities of those with disabilities (Studies II-IV) has implications for the knowledge base used by rehabilitation professionals when designing the services to be provided. The client-centred approach that is an ideal for the rehabilitation services of today (Cardol et al., 2002b; Law, 1998) concentrates on the client in his or her immediate environment (McColl, 1998). This implies that the environment is commonly discussed from the perspective of the individual and restrictions in the more distant environment are often not considered. Thus, in order to change the more distant environment to more fully enable occupations for citizens with disabilities, it is suggested that rehabilitation professionals also need to apply a community-based approach, focusing on changing the community. The community-based approach implies that a social perspective needs to be adopted to disability (Lysack & Kaufert, 1994) and it implies that the professional role will differ from the traditional role in rehabilitation, based on an individual medical perspective (Lysack & Kaufert, 1994; McColl, 1998). This reveals that the client-centred approach, that seemingly takes clients' all encompassing needs into consideration, still needs to be supplemented by a community based approach if those with disabilities are to be able to be more fully occupationally engaged. Moreover, many of the models of practice used by rehabilitation professionals are based on an individual perspective and take impairments as their starting point (e.g. Kielhofner, 1997). The influences of the more distant environment on the occupational engagement can, therefore, be said to challenge the professionals by forcing them to examine whether their knowledge base and the professionals' role is appropriate for the individual client's occupational needs and also in relation to different kinds of practice and arenas in which services are provided. It is particularly important that professionals are aware of how their knowledge base influences the services they provide when one considers that it influences the opportunity people with disabilities have to engage in occupations.

### ***The influence of social interactions on the experience of engaging in occupations***

An undesired change in the number of occupation related social interactions was manifested through some of the persons with disabilities only being able to engage in occupations in the presence of others who could provide them with support, while others were more or less obliged to engage in occupations in solitude (Study III). For many persons with disabilities, the number of occupations that were naturally embedded with interactions with others decreased (Studies II-IV). The importance of having access to sufficient social support to enable people to engage in the occupations they desired was demonstrated in the findings (Studies II, III and V). In Study V, those who perceived that they had insufficient access to social support to enable them to engage in occupations had a higher risk of perceiving themselves to have severe problems with participation in comparison to those with sufficient access or who had no need of support. Previous research in the

area has confirmed the general importance of the availability of social support for general health, adjustment, coping and life satisfaction (e.g., Fuhrer et al., 1992; McColl, Lei, & Skinner, 1995; McColl, 1995; Pentland, Harvey, & Walker, 1998). From the findings of Studies II, III and V, it has become obvious that it is important to consider not only what kind of social support clients will have access to, but also to consider if this support will provide sufficient opportunities for the clients to engage in the occupations they desire. It is also important to consider whether the number of social interactions is ideally adapted to satisfy clients' needs to do occupations in solitude and in company.

Moreover, the findings demonstrate that interpersonal interactions influence how people experience engagement in occupations. When professionals or significant others provided support in such a way that the persons with disabilities had the experience that the occupation was of reciprocal interest, those with disabilities had a meaningful experience of engaging in the occupations. However, when they experienced that the others who were engaged in the occupations were only doing so for the sake of the other, the meaning was diminished for them (Study III). In line with these findings, other researchers (Barron, 1997; Skär, 2002) have highlighted that the formal support can be provided in quite different ways depending on how professionals adopt their superior position of power and control in the interaction with the client. In the provision of an adequate social support, the importance of professionals facilitating reciprocal relationships with the clients has been emphasised (McColl, 1995). On the basis of the findings of Study III, it is suggested that one important part of the nature of a reciprocal relationship that needs to be made more explicit, is gaining an understanding of the meaning of engaging in an occupation for the client and how this meaning is influenced by the social interactions that arise as a result of the provision of support. By giving the subjective construction of meaning in occupations increased attention, it is argued that the possibilities of facilitating meaningful occupational experiences and hence increasing the wellbeing of persons with disabilities can be enhanced. As the empirical research in this area is unclear (cf. McColl, 1995), more in-depth knowledge is needed on the characteristics and consequences of different kinds of interpersonal interactions when persons with disabilities engage in occupations and whether interventions can alter these to better support occupational engagement. From a research perspective, it is also important to investigate how different aspects in the immediate and the more distant environment interact and influence occupational engagement and participation in the life situation.

The interpersonal interactions also influence persons with disabilities' possibilities and their willingness to engage in occupations (study II, IV). Negative attitudes experienced by the persons with disabilities and the treatment that they received by others when they engaged in occupations caused them, at least in part, to strive for images of their occupational self that would present them as being capable occupational performers (study IV). Previous research (Nygård et al., 1995) has also

found that persons with disabilities both seek and compromise occupational encounters that will enable them to avoid portraying a poor self-image. The stigma that was felt to be attributed to persons with disabilities also influenced their choice of whether to engage in occupations or not (Studies II and IV). Researchers have discussed the importance of not ignoring the influences of social structures, embedded in attitudes, that influence the outcome of interpersonal interactions (Barnes et al., 1999; Oliver, 1990; Oliver, 1996a). This implies that changes are needed both on the individual and the social level in order to influence the quality of occupational encounters between persons with disabilities and the public. However, it is known that bringing about changes in the attitudes and treatment of persons with disabilities is complex but research evidence exists which shows that population-based programmes focusing on changing attitudes can reduce disability (Buchbinder & Jolley, 2004; Buchbinder, Jolley, & Wyatt, 2001). In Sweden, the work against discrimination of people with disabilities is an area that has been prioritised and different promising actions are being taken at present to improve the treatment of this group of people (Regeringens proposition 1999/2000:79; SOU 1999:21). However, the effectiveness of public programmes aimed to bring about changes in the societal and social environment to reduce clients' experiences of disabilities needs to be investigated. Further research is also needed to determine how changes in societal and social environments can best be achieved and whether these can improve the engagement of persons with disabilities in occupations and improve their participation in life situations. More knowledge is also needed about clients' experiences of managing their occupational self-images and how this management influence their occupational adaptation.

### ***Adapting rehabilitation services to meet clients' needs over time***

In Study II, the experiences of the clients, who were persons with disabilities, of rehabilitation over time reflected a process of change facilitated by their interactions with different parties. The findings revealed that clients mainly interacted with professionals in the medical rehabilitation chain, which was concentrated to the clients' time in hospital and a short period after their discharge, and focus was on reducing or overcoming physical limitations. This is in contrast to the description of the rehabilitation services prescribed by the Swedish authorities, who specify that the service should be co-ordinated between different care providers, taking place over a long period of time and focusing on clients' all-encompassing medical, social and psychological needs (SoS-rapport 1993:10). In addition, the findings also indicate that the provision of rehabilitation services was not adapted to meet the clients' diverse needs throughout the process. Accordingly, the provision of client-centred rehabilitation services over time needs to be enhanced. On the basis of these findings, the importance of discussing and continuing to examine whether the intentions of the rehabilitation service are being met seems obvious if rehabilitation services are to be developed that satisfy clients' needs over time.

The findings showed that the experiences of persons with disabilities' of the struggle to regain the ability to engage in everyday occupations was essential for the rehabilitation process. The experiences of these people reflected how, even if the problems they encountered with everyday doings was obvious at the onset of their disability, the extent of their problems became more evident when they had been discharged from hospital for a period of time, and had tried to engage in various occupations in their familiar environment. This insight appeared almost at the same time as the regular rehabilitation services ceased. Thus, there was no continued support when the occupations perceived by those afflicted to be most necessary to live a life at home were attempted because the rehabilitation had stopped. However, the struggle went on to adapt to the prioritised occupations and to achieve goals, but the former clients were obliged to continue the battle on their own over the years. In addition, their experience reflected how the provision of continued support specifically intended to enable occupations had been helpful (Study II). These findings have several significant implications that can strengthen client-centredness in practice. Firstly, interventions conducted with the aim of enhancing occupations should be provided in clients' current habitual environment. Secondly, occupational therapy should support individuals in finding and realising new or modified occupational goals throughout the rehabilitation process, i.e., not only at the beginning of the process. Finally, the findings imply that there is a need not only to focus on the occupations that are necessary to be able to live at home. Researchers have shown that occupational therapy interventions of low intensity can enable and increase clients' engagement in occupations and enhance their sense of well-being (e.g. Clark et al., 1993). This implies that even small resources for enhancing occupational engagement can be valuable in achieving a positive outcome from the rehabilitation process.

The discovery that the medical, psychological and social rehabilitation chains prevailed to various extents at different phases of the rehabilitation indicates that the rehabilitation service needs to change its focus over time (Study II). This implies that different professions might be needed to a greater extent in some of the phases of the rehabilitation, and that the specific requirements will depend on clients' needs in each particular phase. The fact that the clients' experiences of the nature of their disability changed over time (Study II), from being experienced as an individual problem to being felt to be a major social problem, also has implications for the focus of the rehabilitation services over time. On the basis of these findings, it is suggested that professionals need to be aware of each client's perspective of the nature of his or her disability if they are to be able to adapt their interventions accordingly.

### ***Adapting the planning of rehabilitation to clients' desire to participate***

The findings of Studies I and II showed that clients differ in the extent to which they want to participate in the planning — including the decision-making — of their rehabilitation. In fact, some of the clients preferred to relinquish all control of the planning to the professionals (Study I), which is in sharp contrast with the aim of adopting a client-centred approach that emphasises the clients' active role in all parts of the treatment process (see CAOT, 1997; Law et al., 1995). Thus, there is a possible risk that clients who do not assume responsibility for the planning of their rehabilitation can be considered as obstacles to the implementation of a client-centred approach (cf. Law et al., 1995). On the basis of the findings it is suggested, in line with the claim made by Wilkins and co-workers (2001) that one aspect of being client centred is to acknowledge that clients differ in their desire to participate in the decision-making process and for the professionals to act accordingly. Studies I and II also showed that some clients perceived that the professionals did not invite them to participate in the planning to the extent that they would have liked. This implies that the professionals' actions can be considered to be a barrier to client-centredness from the perspective of these clients. The professionals' view of the strategies they adopted to encourage client participation in the planning of rehabilitation reflected how they were influenced by firmly routed traditions and routines within their profession and working organisation rather than by clients' individual desires (Study I). Hence, many of the clients were obliged to adapt to the professionals' way of planning the rehabilitation, rather than the other way around. This reveals that professionals need to reflect on and understand each particular client's desire to participate to be able to encourage participation accordingly. It also reveals that the obstacles to the organisation of the rehabilitation services need to be removed to enhance client-centredness in the planning of rehabilitation.

### **The influence of engaging in occupations on the meaning experienced of disability**

Another main theme shown in the findings concerned the persons' possibilities to engage in occupations when, where and in the way they wanted to and the relationship between these possibilities and their experience of participation in life situations (Study V), the meaning of autonomy (Studies III and IV), meaning in occupations (Studies III and IV), occupational self-image (Study IV) and the meaning of the home (Study III). These reflect the importance of understanding the experiences persons with disabilities have of their engagement in occupations as a base for understanding the experience of living with disability. In addition, several therapeutic effects from engaging in occupations that meet the preferences and needs of the person with the disability were indicated and reflected in these findings. Overall, the findings support the assumption that health can be achieved and maintained through the process of engaging in occupations despite the presence of a disease or an injury (cf. CAOT, 1997; Wilcock, 1998; Yerxa, 1998).

***The influence of autonomy in everyday occupations on participation in life situations***

The findings indicate that the persons with disabilities' subjective perceptions of the problems they had with participation were related to their autonomy in terms of their ability and opportunities to engage in occupations when, where and in the way they wanted (Study V). This is in agreement with the ICF, which states that participation is closely related to activities in daily life as, together, the concepts describe people's functioning from both a personal and a societal perspective (WHO, 2001). The complex relationship between autonomy and participation has recently received extensive attention. Most researchers agree that autonomy is an important part of or goal in rehabilitation and that it aims to enhance participation (Catz & Itzkovich, 2002; Chan, 2002; Grimby, 2002). Cardol and co-workers (Cardol et al., 2002b) take it even further and suggest, in accordance with our findings, that both decisional and executive autonomy form a base for participation in life situations. In addition, Cardol and co-workers suggest that autonomy adds a personal perspective that is important to participation. However, in the ICF classification framework participation is coded through performance and assessed against population standards. This can be seen to be contradictory as, in the ICF, the concept of participation emphasises the lived experience of those who are involved (cf. Cardol et al., 2002b; Grimby, 2002). Because of this one could argue that the way participation is assessed in the ICF classification framework needs to be developed further to fully take into consideration the intention behind the use of the concept of participation. Otherwise, objective perspectives may overshadow the lived experience of those with the disability. This is particularly important as the professionals' understanding and assessment of participation inevitably influences their priorities and the design of the services provided to persons with disabilities and, above all, their opportunities to participate in life situations. Moreover, as reflected in the findings of Studies III and V, the comprehensive relationships between autonomy, occupation and participation in life situations, provide an understanding of a possible pattern influencing the experienced meaning of living with a disability that is of importance in designing rehabilitation services.

***The influence of occupational engagement on autonomy***

Study III showed that persons with disabilities who had access to formal support in their occupations to the extent and at the quality they needed still felt themselves to be independent or interdependent. In addition, the opportunities that these people had to use their time in accordance with their desires influenced the temporal structure of their days, the sphere they occupy and, above all, how they experienced their occupations. Accordingly, being able to make one's own decisions and having control over one's engagement in occupations was found to be more important for this group of people than being able to perform the occupations without assistance. This finding has implications for the practice of rehabilitation professionals who commonly concentrate on supporting clients to independence in terms of physical

independence in everyday occupations (Cardol et al., 2002b; Cederfeldt, Lundgren Pierre, & Sadlo, 2003; Crabtree, 2000; Oliver, 1989a). Hence, it is argued that professionals need to reflect on the fact that the concepts they use, such as independence, may not mean the same to their clients. By avoiding putting too great an emphasis on independence from the professional perspective, the client-centred perspective of rehabilitation can be enhanced. Some researchers (Hinojosa & Youngstrom, 2002) have suggested that the professionals' narrow definition of independence should be broadened to include issues like self-determination which are obviously of great importance to the clients. However, others have argued that the concept of autonomy provides a more solid ground for enabling occupations that are meaningful to persons with disabilities (Barron, 1997; Crabtree, 2000). In this argumentation, Barron (1997) and Crabtree (2000) refer to autonomy as a person's possibilities to exert influence, be in control of and be able to make decisions about his or her life. From their point of view this incorporates the essence of autonomy, even if the concept of autonomy is multifaceted and complex and also includes what is known as executional autonomy, which refers to the implementation of one's decisions (cf. Collopy, 1988).

The findings also reveal that the conditions of autonomy can be understood in different ways. The fact that the possibilities of persons with disabilities to exert their autonomy were highly influenced by their access to social support (Studies III and V) highlights the fact that autonomy cannot be understood solely by an individual's capability, as is suggested by the perspective adopted in the medical model (cf. Oliver, 1989a; Oliver, 1996b). Rather, a person's autonomy is contingent on whether the social situation enables the person to exert his or her autonomy, which has been discussed in previous research (Barron, 1997). Oliver (1989a; 1990) and Magnus Reindal (1999) argue, from the perspective of the social model, that all people in modern society live in a state of mutual interdependence. That is, we are all dependent upon one another and the dependency of persons with disabilities just constitutes a different pattern of interdependence. To close this discussion, it should be noted that, independent of which concept professionals choose to use in professional discussions, it is important that the concept used by clients and the meaning they have of it is what is concentrated on in clinical practice.

### ***The influence of engaging in occupations on the meaning of the home and on the personal identification***

Study III illustrates how changes to the engagement of persons with disabilities in occupations in the home, brought about because of the presence of adaptations to the home, assistive devices and/or the provision of social support, can transform the personal meaning of their home, both as a whole and different aspects within it. The discovery that the meaning of the home as a place for personal identification changed (Study III) confirms Rowles' suggestion that relationships with the settings

in which we live our lives may be of special significance to the identity and wellbeing of persons with restricted mobility (Rowles, 1991). In addition, the findings of Study IV suggest that assistive devices were used as a means by which to achieve a desired occupational self-image in occupations. In agreement with previous research, the findings reflect that objects make skills obvious, embody goals (Csikszentmihalyi & Rochberg-Halton, 1981) and form self and identity (Csikszentmihalyi & Rochberg-Halton, 1981; Rubinstein, 1987). Therefore it seems important that professionals consider the relationship between objects, places, occupations and personal identification when deciding on the best course of treatment for a client. In agreement with this, Rowles argued that the habitual use of the environment, as manifested in everyday occupations, is important for peoples' experience of the places in which their lives take place (Rowles, 2000). Other researchers have also indicated that everyday occupations and routines contribute to peoples' experience of the home (Allan & Crow, 1989; Després, 1991). Given this body of evidence, professionals need to be aware of the difficulties of only enabling their clients to engage in occupations because they also need to consider how the clients' possibilities to retain and enhance the personal meaning of the home can be supported. For further knowledge development it seems important to study how persons with disabilities experience the meaning of their engagement in occupations in relation to the personal meaning of settings, environments and contexts other than the home. As Studies III and IV concentrated on the use of a certain kind of object, i.e., assistive devices, it will be important in future research to study how different kinds of objects used in occupations influence people's engagement in occupations, and their feeling of self.

## **METHODOLOGICAL CONSIDERATIONS**

The findings of the studies must be considered in the light of the methodological limitations because these may have an impact on the conclusions drawn.

### **Studies I-IV**

The understanding the researcher had prior to the study can both facilitate and bias the quality of the research findings and it is, therefore, important to consider this (see Kvale, 1997; Patton, 1990b; Strauss & Corbin, 1990). The ambition was to be as open-minded as possible to the informants' experiences by constantly reflecting on and questioning the researcher's performance during the data collection and the analysis. Co-operation with experienced researchers (in Studies I-IV), peer reviews (Studies II-IV) and the member check (Study II) has also assisted the researcher to be conscious of the impact of professional and personal experiences. Hence, the risk that any understanding that existed prior to the study influenced the findings was reduced (cf. Lincoln & Guba, 1985). However, it is worth mentioning that the author's prior knowledge of the field has facilitated the establishment of rapport with the informants and improved communication during interviews, in addition to which, it enhanced the sensitivity in understanding and giving meaning to the data during the analysis. These advantages will have strengthened the quality of the findings to some extent.

It is important to consider the selection of informants since this influences the findings obtained. In the selection of informants in Studies I-IV, the author had no influence on who the staff identified as potential informants of those who fulfilled the criteria for each study. This implies that there is a possibility that the staff might have biased the selection by, for example, identifying persons who they thought had benefited from the rehabilitation provided. The consecutive and purposive sampling strategies guided the selection of homogenous samples as far as the informants' physical disabilities were concerned, but these samples were heterogeneous with reference to, for example, the diseases or injuries, the time that had elapsed since the injury took place, for those with injuries, and age. The intention of adopting these strategies was to maximise the scope and range of variation of the experiences the clients had had with the intention of forming an as rich and accurate base for describing the informants' experiences as possible. This is in accordance with the principles for conducting qualitative inquiries (see, for example, Patton, 1990b). Thus, from this perspective, the selection of a heterogeneous sample is not biased. The fact that new informants continued to be selected as the preliminary findings emerged from the analysis, meant that there was an increased opportunity to gain relevant data with greater variation and density (see Strauss & Corbin, 1990). The purposive sampling also influenced the sample sizes in the studies (Studies II-IV), which should not be too small because the size would support claims of saturation, and which should not be too large to permit an in-depth analysis; a sample of inadequate size can weaken the credibility of the qualitative findings (cf. Sandelowski, 1995). The intention of the selection

procedures laid down was not to form a base from which to generalise the findings to a large population, but to enhance the understanding of how different matters can be experienced by individuals (cf. Kvale, 1997).

The decision to use interviews as the source of information was based on the fact that interviews are necessary if one is to obtain the meaning of interactions as they are experienced by the informant (cf. Kvale, 1997). Despite this advantage of the interview as a data collection method, one needs to reflect on the possibility that several data sources may have enriched the data. The informants were interviewed on one or more occasions, depending on when saturation (Strauss & Corbin, 1990) seemed to occur in the individual interview and the subsequent analysis. Nevertheless, one needs to consider the possibility that repeated interviews, above all with those only interviewed once, had added new information to their descriptions.

In Study I, note-based interviews were selected to strengthen the quality of data as it was thought that this would enhance the establishment of open and trustful contact with professionals and clients who declined to use a tape recorder. The hand-written notes were reviewed and transcribed immediately after the interviews to maximise the quality of the data collected (cf. Patton, 1990b). In comparing the quality of the note-based and the tape-recorded interviews, it was found that the information content was of similar quality. Still, the note-based interviews constitute a possible limitation because the informants' words may not have been reproduced in appropriate terms. In Studies II-IV, which were based on long, detailed, in-depth interviews with the informants, the quality of the data would probably have been reduced if a tape-recorder had not been used. On this issue, Lincoln and Guba (1985) have recommended that the use of recorders should be carefully considered as they can influence the credibility of data in both a positive and a negative sense.

The trustworthiness of the informants' descriptions needs to be considered as these are all subjective reconstructions of experiences (cf. Kvale, 1997). Consequently, their experiences can be influenced by their memory and by retrospective interpretation. However, the fact that the onset of the disability was a significant event in their lives and one the informants were used to talking about probably strengthened the quality of their descriptions. This was manifested in the interviews, for example, by the fact that they seldom hesitated in giving descriptions. It is also important to contemplate on the trustworthiness of the content of their statements because it is possible that the statements might have been given a slant to enable the people to represent themselves and their experiences in a certain light (cf. Kvale, 1997). As the informants' descriptions reflected a plenitude of mixed experiences, and as their descriptions were often of an emotional nature, it is reasonable to believe that they genuinely shared their

experiences as these appeared to them at the time at which the interviews were conducted. This implies that data collected under other circumstances might have provided additional dimensions.

Similarly, it is possible that other patterns, themes and categories than those presented in the findings of this thesis can be found from similar inquiry in similar populations because no single objective or correct meaning exists. Thus, different researchers are not expected to obtain exactly the same findings from a set of data. Rather, a legitimate multiplicity of interpretations is possible with qualitative data since the interpretation of the data will be influenced by the research perspective, the research question and the method of analysis (see Kvale, 1997). In analysing the data, interpretations close to the informants' experiences were searched for rather than interpretations that were distant from them because of the character of the research questions. In addition, the intent was to reach a new understanding that was not incorporated in our pre-understanding (cf. Alvesson & Sköldberg, 1994; Gustavsson, 2000a; Gustavsson, 2000b; Kvale, 1997; Ödman, 1979). For instance, in Study IV, the constant comparative method (Strauss & Corbin, 1990) did not provide a new and coherent understanding, so the hermeneutic approach to analysis (Gustavsson, 2000a; Gustavsson, 2000b; Ödman, 1979) was therefore chosen. It is also important that readers evaluate whether the findings can be transferred to other contexts to further understand the experiences of other persons (cf. Lincoln & Guba, 1985). The fact that the findings of Study III point in the same direction as those of Study V can be considered as a validation of the findings. The connections of the findings of all of the studies to previous research and existing models can also be considered as a validation.

### **Study V**

The possibility of generalising the results of this study are also limited because the informants were a total selection of a population with SCI at a rehabilitation centre in southern Sweden, i.e., this was not a random sample. In addition, it is important to consider that participation is influenced by complex interactions between the health, the person and the environment (cf.

WHO, 2001). This implies that under other conditions, for instance in other habitats, such as in northern Sweden, participation could differ. Replication of the study in other populations is therefore needed. However, as the informants were heterogeneous with reference to age, the provision of social support to accomplish everyday occupations, and mobility, it can be concluded that the results of this study show some tendencies in terms of the perceptions Swedish people with SCI and other physical disabilities have of participation. The fact that the sample was reasonably representative in terms of the basic socio-demographic characteristics of the base population suggest that it is reasonable to believe that equivalent results would have been obtained even if the response rate had been higher in this population.

Following guidelines for forward-backward translation of questionnaires, professional translators translated the IPA items and adapted them culturally to ensure that the equivalence of meaning was maintained (see Hilton & Skrutkowski, 2002; Su & Parham, 2002). The back-translated version and the original version were then compared repeatedly to identify any eventual discrepancies until consensus was reached between the translators. The Swedish version of the IPA that was used can, therefore, be said to be equivalent to the original version (cf. Hilton & Skrutkowski, 2002; Su & Parham, 2002). However, one needs to consider that even if the translation process was rigorous, differences may still exist between the back-translated version and original one and that the translators may have influenced the quality of the translation (cf. Hilton & Skrutkowski, 2002). Thus tests of the Swedish version of the IPA psychometric properties still need to be conducted. The internal response rate on the IPA was high, and the comments given by the informants on the items and the reports that they answered the questionnaires by themselves all strengthen the accuracy of the responses given.

In the logistic regression, only a few variables influencing participation in the person-environment interaction were examined. This admits a possibility that other independent variables might have influenced the variables tested. The substantial influence of social support on participation can be related to the fact that perceived access to social support and perceived participation have certain similarities because both concepts capture the persons' expectations and the fulfilment of these. Thus, further research is needed on mechanisms that influence participation.

### CONCLUSIONS

The research discussed in this thesis showed that the planning of the rehabilitation service in hospitals was not adapted to the variations clients had in their desire to participate, and also that the rehabilitation service provided over a period of time was not sufficiently adapted to clients' manifold needs during this process. Thus, the findings indicate that the rehabilitation services should be better adapted if they are to satisfy clients' needs and desires. The findings also showed that the influences of the societal and social environment, as manifested in social interactions, was of central importance for the possibilities that persons with disabilities had to engage in occupations and for the consequences they experienced in their occupational life. Thus, this shows that, in enabling occupations, there is a need to not only take into account the clients and their immediate environment, but also the more distant environment, encompassing the community and the persons and places within it, as well as social attitudes and policies. This implies that both individual and social perspectives on disabilities need to be considered in understanding the occupational engagement of persons with disabilities. The opportunities of persons with disabilities' to exert their autonomy and engage in occupations when, where and in the way they wanted to influenced the meaning their disability had to them. On the basis of the findings, it is argued that an occupational perspective is important not only on the level of the individual, but also on the level of society if engagement in occupations and participation in everyday life are to be enhanced for persons with disabilities. This research can support rehabilitation professionals in the struggle to widen their vision of the conditions that influence the occupational engagement of persons with disabilities and also to deepen professionals' understanding of inter-relationships between aspects of occupational engagement and participation in the life situation. This knowledge can enable professionals to better understand relations and conditions that might contribute to the outcomes desired by their clients.

## **SAMMANFATTNING (SUMMARY IN SWEDISH)**

### **Att leva med fysiskt funktionshinder- erfarenheter av rehabiliteringsprocessen, aktiviteter och delaktighet i dagligt liv**

Människors engagemang i dagliga aktiviteter är av central betydelse för deras upplevelse av sitt liv och sin hälsa. En mer omfattande förståelse för de förändringar personer med förvärvade fysiska funktionshinder själva upplever i sina dagliga aktiviteter och för de villkor som influerar dessa erfarenheter saknas likväl som för deras erfarenheter av sin rehabiliteringsprocess och huruvida rehabiliteringen tillgodoser deras behov. Att utveckla sådan kunskap är viktigt för att utforma rehabiliteringsinsatser som syftar till att stärka klienters delaktighet i dagligt liv. Det övergripande syftet med studierna i denna avhandling var därför att beskriva och få en fördjupad förståelse för hur personer med förvärvade fysiska funktionshinder upplevde sin rehabiliteringsprocess och sina möjligheter till aktiviteter i dagligt liv.

I studie I studerades hur patienter med fysiska funktionshinder uppfattade sin delaktighet i planeringen av rehabiliteringen på sjukhus och hur patienternas sjuksköterskor och arbetsterapeuter uppfattade sina strategier för att understödja deras delaktighet. Vidare så jämfördes patienternas och de professionellas uppfattningar. En innehållsanalys av semistrukturerade intervjuer med 57 patienter och 50 professionella genomfördes. Resultatet visade att patienternas faktiska delaktighet varierade liksom deras önskemål om delaktighet. De professionella använde olika strategier för att understödja patientens delaktighet, vilka hade sin grund i professionernas och verksamheternas traditioner snarare än i patienternas individuella önskemål om delaktighet, något som är eftersträvansvärt.

I Studie II undersöktes hur personer med funktionshinder upplevde rehabiliteringen över tid. Femton personer intervjuades och data analyserades med en komparativ metod. Deras erfarenheter reflekterade tre olika slag av parallella rehabiliteringskedjor: en medicinsk, en psykologisk och en social, vilka började vid olika tidpunkter och fortskred olika länge över tid. Respektive kedjas betydelse för personernas liv förändrades över tid vilket visar på att rehabiliteringen bör ha olika fokus i olika skeenden. Personerna upplevde att de professionella medverkade nästan enbart i den medicinska rehabiliteringskedjan, vilket tyder på att de inte upplevde rehabiliteringen som holistisk.

Syftet med studie III var att beskriva och fördjupa förståelsen för hur personer med funktionshinder upplevde sin aktivitetstillvaro i hemmet. Intervjuer med 13 personer analyserades med en komparativ metod. Deras erfarenheter av aktiviteterna var olika till sin karaktär, somliga upplevde att de ständigt utförde aktiviteter med andra, några att aktiviteterna tillfälligtvis stördes medan andra upplevde aktivitetsdeprivation. Detta influerades av ett samspel mellan personen och olika aspekter i miljön, där tillgången till stöd från andra i utförandet var av avgörande betydelse för deras aktivitetstillvaro. Dessutom framkom det att när aktiviteterna som var förknippade med hemmet förändrats så förändrades även

hemmets betydelse för personerna. Resultaten visar att insatserna i hemmet behöver utvecklas för att tillgodose individuella behov och för att bevara hemmets betydelse för personer med funktionshinder.

I studie IV var avsikten att få en fördjupad förståelse för hjälpmedels betydelse för personer med funktionshinder och hur denna betydelse influerade deras användning av hjälpmedel i aktivitet. Sjutton personer intervjuades och data analyserades med en tolkande ansats. Hjälpmedlen hade dubbeltydliga meningar som personerna vägde samman på olika sätt. Detta medförde att personernas hjälpmedelsanvändande skilde sig och karaktäriserades som antingen pragmatiskt, ambivalent eller motvilligt. Resultatet visade att hjälpmedlen i sig själva inte var viktiga för betydelsen, utan snarare var de betydelsefulla som redskap som användes på olika sätt för att uppnå en önskad självbild.

Studie V syftade till att beskriva hur personer med ryggmärgsskada uppfattar delaktigheten i sin livssituation och att undersöka relationen mellan deras delaktighet och deras uppfattning om problem med delaktigheten. Studien syftade även till att utröna inflytandet av ålder, kön, skadenivå, tid efter skada, civilstånd och tillgång till socialt stöd i aktivitet på uppfattningen om problem med delaktighet. En postenkät som inkluderade instrumentet "Inverkan på delaktighet och autonomi" besvarades av 161 personer. Data analyserades deskriptivt och med Spearmans rangkorrelation samt logistisk regression. Resultatet visade att en majoritet av de tillfrågade uppgav att deras delaktighet var tillfredsställande i de flesta av aktiviteterna men en majoritet uppgav att de hade ett eller flera allvarliga problem med sin delaktighet. Resultatet indikerar att även om de tillfrågade uppgav att deras delaktighet var otillräcklig var det inte detsamma som att de uppfattade det som ett problem. Det framkom även att tillgången till socialt stöd i aktivitet var den mest framträdande faktorn för att förutsäga allvarliga problem med delaktigheten, i jämförelse med vissa personliga och hälsorelaterade faktorer. Resultatet visar på betydelsen av att i rehabiliteringen uppmärksamma tillgången till socialt stöd för att optimera klienters delaktighet i livssituationen.

Sammanfattningsvis indikerar resultaten av studierna att rehabiliteringen behöver anpassas till klienters individuella önskemål om delaktighet i planeringen och även att rehabiliteringsinsatserna behöver anpassas för att bättre tillgodose klienters behov över tid. Resultaten indikerar även att inflytandet av den samhälleliga och sociala miljön, som manifesteras i sociala interaktioner, är av central betydelse för att förstå konsekvenser och möjligheter till aktiviteter som främjar upplevelsen av delaktighet i dagligt liv hos personer med förvärvade fysiska funktionshinder.

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