

Promoting agency among people with severe psychiatric disability

Occupation-oriented interventions in home and
community settings

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“Walking is more than a task – it gets you going” (Elisabeth, Study III)

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*Occupation is a curious thing
It pervades our lives and marks our days
It defines us and is defined by us
It both shapes the world and is shaped by the world
It can be known by the tools it uses and the wake it leaves in its path
It is intangible and invisible until a person engages in it
It is a performing art
It can only be seen when a person performs it and only understood
when a person tells you its meaning*

(by Helene J. Polatajko)

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ABSTRACT

In general, people with severe psychiatric disability living in sheltered or supported housing lead passive, solitary lives. Current rehabilitative approaches often neglect considering an agentic perspective of the residents in sheltered or supported housing. Furthermore, the outreach and societal contexts are often not considered. Thus, practitioners tend to overlook the potential in providing support and rehabilitation that is adapted to their individual, collective and changing needs.

My approach was to develop a model for Everyday Life Rehabilitation (ELR), which has a potential to promote agency while targeting recovery, meaningful daily occupations, social participation, and person-driven goals. We employed two occupational therapists (OT) and offered an intervention with ELR in a medium-sized municipality in northern Sweden and evaluated this intervention from the perspectives of residents and community care workers (CCW), using a combination of quantitative and qualitative methods.

This thesis comprises four studies that focus on a home and community context, late rehabilitation efforts, daily occupations, and client-centredness. The overall aim is to understand and evaluate the impact of recovery- and occupation-oriented interventions in a home context for people with severe psychiatric disability. The study settings are sheltered and supported housing facilities.

The first study ($n=6$) explores the significance of home for occupational transformations. The analysis reveals how residential conditions facilitate rehabilitative interactions, generating occupational transformations such as increasing social competence and taking charge of daily occupations. The second study evaluates occupation- and health-related outcomes of the ELR-intervention for residents ($n=17$). Pre-, post-, and follow-up differences in tests scores on goal attainment, occupation, and health-related factors indicate that important progress is made. The third study explores residents' ($n=16$) narratives about occupational transformations in the context of everyday life and life history. Narrative analysis discloses stories of 'rediscovering agency', referring to occupational and identity transformations. The fourth study illuminates community care workers' ($n=21$) experiences of collaborating with residents and OTs, using ELR. The CCW' view on residents, rehabilitation, and the own role, along with organisational conditions in the housing facility, seem to characterise different outlooks influencing the CCWs responsiveness or resistance to the intervention.

In conclusion, rehabilitation in a supported housing context appears paradoxical due to tensions between opposing values such as authentic versus artificial, and independence versus dependence. However, if residents are engaged in challenging these tensions, they can function as

'progressive tensions' generating change. Considering the personal and social meaning of home also appears to be valuable. The intervention studies on ELR, demonstrate its value for participants and indicates that a recovery approach applying ELR would promote shared perspectives among residents, CCWs, and OTs, while facilitating 'agent-supported rehabilitation' and 'out-of-housing strategies'. The thesis provides initial support for the use of ELR interventions and proposes continued research.

Keywords:

Mental health, Psychotic disorders, Activities of daily living, Social participation, Recovery, Occupational therapy, Rehabilitation, Client centered, Residential facilities, Supported housing, Sheltered housing, Outcome assessment, Qualitative research

SVENSK SAMMANFATTNING

Personer med svåra och långvariga psykiska funktionshinder som bor i stödboende tenderar att ha en passiv, isolerad och stillasittande livsstil. Detta trots att de själva skulle vilja vara mer aktiva och utåtriktade. De står även i viss grad i beroendeställning till baspersonal, som bistår med daglig service i form av exempelvis måltider, städning och tvättning. Inom boende och rehabilitering förbises ofta de boendes möjlighet till personligt aktörskap, det vill säga kapacitet att agera troget sin person och sina värderingar. Dessutom beaktas sällan delaktighet i sociala och samhälleliga sammanhang. Personal tenderar därmed förbise potentialen i att ge stöd och rehabilitering som är anpassade till de boendes individuella, kollektiva och föränderliga behov.

Mitt angreppssätt har varit att utveckla en modell för Vardagslivets Rehabilitering, som har potential att främja personligt aktörskap hos den boende med samtidig inriktning på återhämtning, meningsfulla dagliga aktiviteter, social delaktighet och persondrivna mål. Rehabiliteringen avser stödda individens kapacitet att välja och uttrycka mål, utveckla strategier för att nå målen och successivt uppnå ökat engagemang och delaktighet i olika livssituationer.

Vi anställde två arbetsterapeuter och erbjöd personer som bodde i stödboende och hade erfarenhet av psykoser att delta i ett projekt med Vardagslivets Rehabilitering. Rehabiliteringen genomfördes i nära samarbete med befintlig baspersonal i en medelstor kommun i norra Sverige. Parallellt studerade vi interventionen från de boendes och baspersonalens perspektiv med en kombination av kvantitativa och kvalitativa metoder.

Avhandlingen består av fyra delstudier som fokuserar på sammanhang av hem- och närmiljö, dagliga aktiviteter, sena rehabiliteringsinsatser och klientcentrerat förhållningssätt. Det övergripande syftet är att undersöka och förstå återhämtnings- och aktivitetsinriktade interventioner i hemmiljö för personer med svårt psykiskt funktionshinder. Studiekontexten är stödboenden i form av så kallade 'bostad med särskild service' och 'supported housing'-komplex, det vill säga eget boende med stöd.

Den första studien (n=6) utforskar hemmets betydelse för aktivitetsförändringar när man bor i ett stödboende. Analysen visar att de speciella boendevillkoren innehåller många konflikter och olikheter mellan boende men samtidigt hur detta kan skapa rehabiliterande interaktioner som bidrar till aktivitetsförändring såsom ökad social kompetens och att successivt ta allt större ansvar över dagliga aktiviteter. Den andra studien undersöker aktivitets- och hälsorelaterade förändringar hos de boende efter att ha deltagit i Vardagslivets

Rehabilitering (n=17). Mätningar som gjordes före intervention, direkt efter och vid sexmånadersuppföljning avseende måluppfyllelse, aktivitets- och hälsorelaterade faktorer talar för att viktiga framsteg gjordes. Den tredje studien utforskar hur de boende (n=16) skapar mening av sina aktivitetsförändringar i relation till vardagsliv och livshistoria. Analysen synliggör berättelser om att 'återupptäcka aktörskap', med hänvisning till både aktivitets- och identitetsförändringar. Den fjärde studien belyser baspersonalens (n=21) erfarenheter av Vardagslivets Rehabilitering. Deras syn på de boende, rehabilitering, sin egen roll och de organisatoriska förutsättningarna karaktäriserar vissa synsätt som påverkar graden av engagemang i interventionen.

Sammanfattningsvis framstår rehabilitering i stödboenden som paradoxalt till följd av spänningsfält mellan olika värderingar, exempelvis eget autentiskt hem kontra gemensamt konstruerat boende, eller självständighet kontra beroende. Om de boende engageras i att utmana dessa spänningsfält kan de fungera som framåt drivande och medvetandegörande spänningar och därmed bidra till förändring. Att ta hänsyn till den personliga och sociala betydelsen av hem visar sig viktigt. Interventionsstudierna med Vardagslivets Rehabilitering visar dess värde för deltagarna och indikerar att ett återhämtnings- och aktivitetsinriktat tillvägagångssätt kan skapa förutsättningar som främjar de boendes möjlighet att uppnå egna mål, vilket i sig ger upphov till andra positiva förändringar. Avhandlingen ger inledande stöd för användning av Vardagslivets Rehabilitering och föreslår fortsatt forskning. Som rekommendation till praxis framträder rehabilitering som understödjer aktörskap och utåtriktade aktiviteter särskilt viktigt.

ABBREVIATIONS

ADL	Activities of Daily Living
AMPS	Assessment of Motor and Process Skills
BSI-II	Bedömning av Social Interaktion (Assessment of Social Interaction Skills) (Swedish version BSI-II)
CARF	Commission on Accreditation of Rehabilitation Facilities
CCW	Community Care Worker
CMOP-E	Canadian Model of Occupational Performance and Engagement
ELR	Everyday Life Rehabilitation
GAS	Goal Attainment Scaling
GSI	Global Severity Index
GT	Grounded Theory
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, disability and health
M	Mean value
MoHO	Model of Human Occupation
OT	Occupational Therapist
OTIPM	Occupational Therapy Intervention Process Model
PADL	Personal Activities of Daily Living
PEO	Person-Environment-Occupation model
RCT	Randomized Controlled Trial
SADL	Social Activities of Daily Living
SCL-90	Symptom Checklist - 90
SD	Standard deviation
SDO	Satisfaction with Daily Occupations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation

DEFINITION OF CENTRAL CONCEPTS

CLIENT-CENTREDNESS, originally developed by Rogers (1951), is a non-directive approach whereby the therapist creates a comfortable, non-judgmental environment by portraying genuineness, empathy, and unconditional positive regard towards the client. This aids clients in finding their own goals, solutions, and control over the content and pace of the rehabilitation. In this thesis, the words resident or participant rather than client are used in reference to the subjects, apart from when referring to the content and intentions of client-centredness.

DISABILITY as defined by the World Health Organisation (WHO, 2001), is an umbrella term for impairments, activity limitations, and participation restrictions, and seen as the outcome of an interaction between the individual and the environment. The social model emphasises the impact of societal limitations on the disability (Barnes & Mercer, 2004; Barnes, Mercer, & Shakespeare, 1999). The concept of disability as used in this thesis, refer to both of these perspectives. Thus, disability is not a static condition but a constantly reconstructing consequence in relation to personal and environmental factors encountering the persons' ability to act and function in private and community living.

OCCUPATION has its origin in the Latin word *occupatio*, which means taking possession or occupying space or time, and refers to units of human activity that are purposeful, self-directed and meaningful to the person who performs them (Yerxa et al., 1989). Furthermore, Yerxa et al (1989) suggest that the concept 'occupation' thus implies meaningfulness. For the purposes of this thesis, I often use the term 'meaningful occupation' to explicitly emphasise this denotation.

PARTICIPATION is defined from an individual perspective as involvement in a life situation (WHO, 2001) and from a policy perspective as describing disability rights (Gustavsson, 2004; UN, 2006).

PERSONAL AGENCY is defined as the 'capacity to act' and is grounded in the dialectic of structure and agency (Giddens, 1979). Personal agency is the interaction of acting and reacting within a context.

PSYCHOSIS is a generic psychiatric term for a mental state in which reality testing is impaired. One main feature of psychosis is the inability to distinguish between internal and external stimuli. Psychotic symptoms may include false beliefs about what is taking place or who oneself is (delusions), exaggerated unfounded fear or suspicion, hearing, seeing, or feeling things that are not there (hallucinations), and thoughts and speech that jump between unrelated topics (disordered thinking). Depending on the condition underlying the psychotic symptoms,

symptoms may be constant or they may fluctuate. Psychosis can occur as a result of a large number of medical conditions, particularly among individuals with schizophrenia and bipolar disorders.

RECOVERY, as it applies to mental health, is an approach that emphasises each individual's potential for growth. It is a way of living a fulfilling, expectant, and contributing life even with the limitations caused by illness. Recovery refers to both an internal process experienced by individuals who describe themselves as being in recovery: hope, meaningfulness, agency, opportunity, and connection; and external conditions that facilitate recovery: implementation of principles of human rights, a culture of positive risk-taking for growth and development, and recovery-oriented services.

SHELTERED HOUSING is defined as highly assisted residential facilities, with 24-hour on-site staff and mealservices in shared facilities.

SUPPORTED HOUSING is defined as an individual's own 'ordinary' housing with varying degree of support. Supported housings can involve either 1) a number of people with severe psychiatric disability living in self-contained accommodation on one site with professional support personnel available during office hours and access to communal spaces, or 2) self-contained accommodation but they do not share a site with other people with severe psychiatric disability. These people do receive regular home visits by professional outreach workers for individual social support with the minimum aim of maintenance of the tenancy (Chilvers, Macdonald, & Hayes, 2006).

SOCIAL ACTIVITIES OF DAILY LIVING (SADL) is a new concept suggested in this thesis. ADL is commonly divided into personal ADL (PADL); i.e., eating and dressing and instrumental ADL (IADL); i.e., shopping and cleaning. SADL and IADL might overlap in some respects, which would require a refinement of the concepts, but SADL is suggested to highlight the need to consider social activities of daily living as central to human occupation and the locus of social participation.

ORIGINAL PAPERS

The thesis is based on the following papers, which will be referred to in the text by their Roman numerals:

- I Lindström M, Lindberg M, Sjöström S. (2011). Home bittersweet home: the significance of home for occupational transformations. *International Journal of Social Psychiatry*, 57(3), 284-299.
- II Lindström M, Hariz G-M, Bernspång B. Dealing with real-life challenges: outcome of a home-based occupational therapy intervention for people with severe psychiatric disability. (accepted for publication in *OTJR: Occupation, Participation and Health*)
- III Lindström M, Sjöström S, Lindberg M. Stories of rediscovering agency: home-based occupational therapy for people with severe psychiatric disability. (submitted)
- IV Lindström M, Lindberg M, Sjöström S. Responsiveness or resistance: views of community care workers encountering a new rehabilitation model. (manuscript)

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PREFACE

This thesis deals with the question of how to support people with severe psychiatric disability becoming active agents in their challenges of daily occupations and life. The focus of the studies is on recovery- and occupation-based interventions in home and community settings.

At the heart of this thesis is an interest in understanding and improving the opportunities for people with severe psychiatric disabilities and to allow them to have active lives with meaningful daily occupations despite their disability. My commitment to psychiatry and persons with psychiatric disabilities is based on personal family experiences as well as from a professional perspective as an occupational therapist (OT). In the 1980s, I had summer jobs as an attendant in residential care facilities where I experienced the great benefits residents received by engaging in recreational and practical occupations. I often observed that residents responded positively to being able to attend to exercise outings, take care of one's own apartment, or have opportunities to socialise. Later when I became an OT, I was involved in developing a new kind of housing facility consistent with the concept of 'supported housing', which reinforced my theoretical knowledge with experiences of how important it can be to maintain a positive motivational spiral in daily life: to experience successful outcomes of the doing, interact with others, and further strengthening the motivation to do meaningful occupations. As occupation is considered central to human life and an important driving force in the interplay between doing, being, becoming and belonging, it is also essential in developing an occupational identity. On the contrary, I have also seen how devastating a downward spiral of inactivity can be, resulting in the opposite effect of the above-described; for example, passivity and isolation.

Over the past 13 of years as an occupational therapy educator, I have had the opportunity to deepen my knowledge and reasoning of occupational therapy theory and practice including the conceptual models of continuous interaction between person, environment, and occupation, and the process models of how to enable meaningful occupations for people where for some reason it does not work. In my professional experience, I have observed a lack of evidence-based interventions, which has resulted in my pursuit of advanced degrees in research in the field of social psychiatry. Based on my professional experience and scientific-based principles, I have developed a model of rehabilitation, Everyday Life Rehabilitation (ELR). ELR is designed for persons with severe psychiatric disabilities living in sheltered or supported housing and aims to enable meaningful daily occupations through close collaboration between OTs and community care workers (CCW). On a small scale, the ELR model tries to put formal disability policies in place by balancing medical, individualistic perspectives and societal, collectivistic

perspectives. Furthermore, it combines client-centredness with recovery oriented focus as well as inter-professional collaboration and organisational matters. Funding was received from the National Psychiatric Services Coordinators to implement this intervention model in a pilot study in a Swedish municipality, and is the basis for my doctoral studies.

By this thesis I want to take a step back to critically examine if and how the interventions are beneficial to residents with severe psychiatric disabilities.

Maria Lindström

INTRODUCTION

This thesis will focus on occupational and identity transformations in people with severe psychiatric disability, the significance of the home context for such a process, and how recovery- and occupation-based interventions can facilitate transformations. The intention has been to develop and evaluate a new intervention model, Everyday Life Rehabilitation (ELR), aimed at enabling meaningful daily occupations for people living in sheltered or supported housing. In general, this target group has a sedentary and lonely everyday life, and there is a lack of rehabilitation opportunities.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2006) has highlighted the profile of disability in the international human rights system and serves as an outline for inclusion, participation, and enabling people to be active citizens. This thesis will reflect on the potential contribution of recovery- and occupation-based interventions in a home context and the process associated with translating some of the Convention's ambitions into practical day-to-day realities. This exploration is conducted within the context of occupational therapy integrated into sheltered and supported housing in collaboration with community care workers (CCW). In order to accomplish participation, active community living, and equality for people with psychiatric disabilities, principal concepts associated with personhood, decision-making, and structure need to be highlighted. This requires a reaffirmation of the 'capacity to act' referred to as agency, and useful supports for people in daily life decision-making and acting processes.

The thesis is comprised of four studies that revolve around a home and community context, late rehabilitation efforts, daily occupations, and client-centredness. The ambition is both descriptive and analytical. The overall aim is to understand and evaluate the impact of recovery- and occupation-oriented interventions in a home context for people with severe psychiatric disability. To accomplish that aim, I have chosen to use a disability, recovery, and occupation perspective and certain associated concepts. Therefore, in the following sections, I will clarify how these concepts and theoretical frames are conceptualised in the literature. Moreover, I will present some policy, resident, organisational, and research perspectives to give a background for the studies. The introduction concludes with the rationale and aims for this thesis.

Theoretical and conceptual framework

Ability and disability

The goals of Swedish disability politics are full participation and equality for all citizens (Regeringskansliet, 2011). However, people with disabilities encounter almost daily discrimination and marginalisation. Domestically in Sweden, as well as internationally, reports claim the need for better rehabilitation services in the home and community and evidence-based practices for people with severe psychiatric disabilities (SOU, 2006:100; UN, 2006).

Disability is the main perspective that I have used throughout this thesis. Choosing a disability concept instead of a diagnostic medical concept implies a focus on the consequences of daily life rather than treating and curing the illness. Disability is a complex and evolving concept. Previously, disability was viewed solely in individual and medical terms as a problem intrinsic to the person with the disability. Over the last half century, disability has come to be understood in dynamic social terms as a process that involves the interaction between various health conditions and the environmental and personal contextual factors in which a person lives and acts. The most broadly accepted framework for understanding disability today is the International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001). According to the ICF, environmental and personal factors interact with a health condition and determine the level and extent of one's functioning. A disability, according to this framework, is an umbrella term for impairments, activity limitations, or participation restrictions. Another framework, The Social Model (Barnes & Mercer, 2004; Barnes et al., 1999), originally developed by service users, has an even stronger focus on the impact of societal limitations on the disability. The Social Model represents efforts to theorise disability and provide conceptual frameworks that are conducive to political action (Barnes & Mercer, 2004). I will refer to both of these models throughout this thesis.

Today, western society is criticised for having an individualistic 'ableism' perspective (Campbell, 2009; Hehir, 2005). The intent of the health professional is that people should be as independent as possible, as well as to enable them to perform certain skills, have routines, tasks, and roles with a certain level of performance to meet personal needs or environmental demands. These actions imply ideas of normativity to service users, which have been criticised by service users. The perspectives of people with disabilities and the societal and communal values are often unheard or neglected at the risk of further exclusion.

The UNCRPD (UN, 2006), effective internationally since 2008, emphasises a shift in perspective regarding persons with disabilities.

Rather than viewing these individuals as objects of aid, UNCRPD emphasises respect, citizenship rights, equality, and dignity including personalisation, liberty, and social justice. The role of people with disabilities and their organisations is also accentuated in the process of implementation and monitoring policies, services, and interventions. The UNCRPD deals with particular aspects of the rights of persons with disabilities. Some rights have been addressed in previous EU/UN treaties such as the right to housing. The UNCRPD serves as an outline for inclusion and participation and focuses on enabling people to be active citizens, specifically addressing the area of personhood, decision-making, active community living, and structure; all goals in keeping with the concept of personal agency.

Personal agency

I have used agency-structure as a key analytical perspective recurrently in this thesis. The concept of personal agency, defined as the 'capacity to act', has broad and deep philosophical roots grounded in the dialectic of structure and agency (Giddens, 1979). Personal and communal agency operates within a system of socio-structural influences. These social systems are devised to regulate human dealings in diverse spheres of life by authorised sanctions and enabling resources, and influencing human development and functioning (Giddens, 1984). Throughout their lives people engage in a wide range of social systems; i.e., political, educational, professional, and municipality services. This 'reality' in which people live and perform their daily occupations is socially constructed; the social systems are created by humans in their need for social order through a process of habitualised actions (Berger & Luckman, 1966).

Contexts reflect specific constellations of features at micro, meso, and macro levels that constrain, afford and/or enable behaviour (Giddens, 1984). Different theoretical views of agency focus on different aspects of agency-structure. The psychological and socio-cognitive perspectives tend to be more normative than the sociological views. Also, different theoretical views have focused on different explanations of personal agency, which may be helpful in understanding and promoting agency. Self-determination theory (Ryan & Deci, 2000) posits three fundamental psychological needs for healthy functioning and an agentic self. *Competence* is the basic need to successfully engage in and negotiate with the environment (White, 1959). *Relatedness* reflects the necessity for close emotional bonds and feelings of connectedness to others in the social world (Baumeister & Leary, 1995; Sroufe, 1989). *Autonomy* reflects the degree to which one's actions are precipitated by the self or, when non-autonomous, by causes external to the self (deCharms, 1968). Autonomy is the quality of owning one's actions and making action choices that are integrated with the self and that serve the needs for competence, relatedness, or both. Without choice there would be no

agency (Deci & Ryan, 1995). Autonomy also plays a central role in the distinction between intrinsic or extrinsic motivation as well as the variants of internalisation along the self-determination continuum (Ryan & Deci, 2000). The attachment theory (Bowlby, 1969) holds that a secure *attachment* affords a person the room to exercise autonomy and optimise both socio-emotional and cognitive competencies. According to Bandura (Bandura, 1977, 1989), perceived *self-efficacy* is the foundation of personal agency. Self-efficacy beliefs promote desired changes through cognitive, motivational, affective, and choice processes.

According to the psychological and socio-cognitive oriented views, personal agency involves both knowing and having what it takes to achieve one's intentions in interaction with the context. Humans are assumed to be active and growth-oriented in coherence between themselves and the social world. However, development is assumed to require supports from the social environment (Deci & Ryan, 2000). According to this view, a well-adapted agentic individual is the origin of his or her actions, has high aspirations, sees more and varied options for action, learns from failures, and has a greater overall sense of well-being. In contrast, a non-agentic individual has low aspirations, is hindered with problem-solving blinders, often feels helpless, and has a greater overall sense of ill-being (Ryan & Deci, 2000). Moreover, individuals who have a sense of agency both have intentions to act and persist in their pursuits even in the face of obstacles. As a consequence, when individuals are high in agency, they can fulfil their intentions or goals more easily, and, in turn, their successes strengthen their feelings of personal agency and well-being. At the other extreme, individuals with very little personal agency have low personal standards to which they aspire and often do not even try to pursue goals. Failure can further undermine trust in their own capability which, in severe cases, can lead to harmful consequences to the self and society such as alienation, amotivation, sedentary lifestyle, helplessness, and antisocial behaviour (Bandura, 2001; Ryan & Deci, 2000).

Occupational therapy literature is grounded in the belief that individuals are inherently active and that individuals continually interact with the environment while progressing along a life path, giving form and meaning to his or her actions along the way (Kielhofner, 2008). As part of their integrated functioning, individuals continuously interpret actions and their consequences. Across the episodes of occupations in varying contexts, the individual discovers and refines who she or he is and what she or he is capable of (Unruh, 2004). Therefore agency is closely related to identity, choice, competence, productivity, sociality, and relatedness (Phelan & Kinsella, 2009). Under optimal structural and personal circumstances, this evolving interaction system gives rise to both personal and communal agency (Bandura, 2000).

People with severe psychiatric disability often perceive a disruption in their everyday life and a reorganisation of the self (Dimaggio & Lysaker, 2010), which negatively influences their agentic possibilities and abilities to engage in meaningful daily occupations. Therefore, it should be of importance to professionals to promote agency through supportive environments and by helping people maintain or establish agency despite their illness, life situation, and context.

Rehabilitation influenced by the social model perspectives on disability (Barnes et al., 1999) lead to an emphasis on opportunities of meaningfulness in daily occupations, social participation, active community living, and person-driven goals based on recognition of personhood, interrelatedness, and agency. The focus on agency within this thesis is on the rights and possibilities of people with psychiatric disabilities to experience and develop capacity to act and be heard in their everyday life, in rehabilitation practices, housing facilities, and ultimately, in participating in the society. I have mainly used a psychological and socio-cognitive perspective to understand the intrinsic vulnerability of low sense of agency among people with experiences of psychosis. To problematise the structural, institutional impact on opportunities of practicing meaningful daily occupations, active community living, and developing an agentic identity for people with severe psychiatric disability living in sheltered or supported housing facilities, I have mainly used the sociological understanding of agency-structure as explained by Giddens (1984) in the forthcoming contextualised analyses.

The dialectic perspective of agency-structure can be helpful to analytically explore and understand the context in which residents live; particularly, this thesis has focused on the housing facility structure and the participant's marginalised situation in society, and how to understand agency within such a structure.

Activity and participation

Presently, activity and participation are recognised as important factors for health and well-being (Christiansen, Baum, & Bass-Haugen, 2005; Law, 2002; Miller Polgar & Landry, 2004; Whiteneck, 2006). Participation in life is not considered a privilege but rather a basic human right (UN, 2006). According to Law (2002), when people participate in daily occupations they find meaning, purpose, and fulfillment.

ICF introduces basic definitions of activity as “an execution of a task or action by a person” and participation as “a person's involvement in a life situation” (WHO, 2001). Thus, activity and participation are closely related and not separated in the classification of capacity and performance within ICF. ICF classifies capacity and performance, but fails to capture subjective experiences of participation (Borell, Asaba,

Rosenberg, Schult, & Townsend, 2006; Larsson Lund & Lexell, 2009). In previous research, participation has been explored in more depth with a focus on different orientations such as social engagement (Mendes de Leon, Glass, & Berkman, 2003), social interaction (Yilmaz, 2009), social networks (Holtzman et al., 2004; Isaksson, 2007), environmental aspects (Eriksson, 2006; Haak, 2006; Vik, 2008), social contacts (Drageset, 2004), engagement of a person's body, mind, and soul (Miller Polgar & Landry, 2004), and being active, social, and having agency (Borell et al., 2006). Within this thesis I refer to participation mainly from these social perspectives and a societal perspective describing disability rights (Gustavsson, 2004; UN, 2006).

Occupational perspectives: Person-environment-occupation

Within occupational therapy, 'activity and participation' can also be denoted as 'occupation'. Occupation is used to describe both the means and the ends, and thus both the process and product, of occupational therapy (Hasselkus, 2000). This concept of occupation is derived from the Latin word *occupatio*, to seize or take possession (Yerxa et al., 1989). Occupation is referred to as units of human activity that are purposeful, self-directed and meaningful to the person who performs them.

In OT vocabulary, terms such as activities, everyday activities, and activities of daily living (ADL) are often used synonymously with occupation (Duncan, 2006). The concept of ADL can be divided into personal ADL (PADL) (Katz et al., 1963) including personal care, and instrumental ADL (IADL) (Fricke & Unsworth, 2001; Sonn & Hulter Åsberg, 1991) including more complex activities that involve tools such as housekeeping or food preparation.

'Occupational performance' is the actual doing in a dynamic interplay between person (P), environment (E) and occupation (O) in present time and over a person's lifespan, as depicted in the PEO-model (Law et al., 1996). Several conceptual models of occupation; i.e., the Model of Human Occupation (MoHO) (Kielhofner, 2008) and the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007), are based on similar constructs. The personal component entails physical, cognitive, and affective aspects. The environmental component entails cultural, economic, institutional, physical and social aspects. The occupational component involves what we do, organised in a certain way, and given value and meaning by the person and environment.

The concept of humans as 'socially-occupied beings' (Lawlor, 2003) adds to the perspective of how human experiences exist through the interrelatedness with others and how the meaning of doing is unified with whom one is doing it with. By engaging in occupations, people construct

themselves as occupational beings which shape their occupational identity (Christiansen, 1999; Christiansen, 2004). Identity is the way we label ourselves in relation to others, and is based on how we view ourselves (Christiansen, 1999). Kielhofner (2002) established the concept of 'occupational identity' including a synthesis of how we view ourselves in terms of our capacity and effectiveness for doing, preferences, roles, relations, and opportunities arising from or restraints imposed by the context. This theoretical view is similar to the view of agency-structure (Giddens, 1984).

The occupational perspective applied in this thesis emphasises the importance of understanding the subjective experiences of the *meaning* of doing and the *performance* of occupations in each individual's unique life context (Kielhofner, 2008; Townsend & Polatajko, 2007; Yerxa, 1998). These perspectives reflect a two-fold practice of occupational therapy; connecting the subjective narrative view with the bio-psycho-social view (Mattingly & Fleming, 1994).

Occupational justice

When people are prevented from performing what they believe to be meaningful daily occupations, they risk stagnation and inhibited experiences of everyday life. From a societal perspective, occupational deprivation, marginalisation, alienation, and imbalance are matters of serious public health concern (Townsend & Wilcock, 2004). *Occupational justice* considers these as contributors to the increased rate of poor health and occupational imbalance among people with severe and long-term psychiatric disabilities. Therefore, societal, organizational, and personal factors influencing the way psychiatric disability is dealt with are important. Meaningful daily occupations are a critical feature for all humans especially when living in a housing facility and being subordinated under certain limitations (Nilsson & Townsend, 2010).

The value of controlling one's own home also relates to an *occupational justice* perspective (Nilsson & Townsend, 2010), which promotes the importance of participation in daily life including having and managing a home. Additionally, occupational justice implies the rights of occupational well-being such as meaningfulness, enrichment, variation, choices, and equal privileges for diverse participation in occupations, which should be taken into consideration as important occupational therapy outcomes (Doble & Santha, 2008).

Recovery

Recovery has come to the forefront of the mental health policy agenda and the broader goal of occupational justice and social inclusion (Bonney & Stickley, 2008). The recovery approach has now been explicitly adopted as the guiding principle of mental health systems in a number of

countries and states. The key points (Chandler & Repper, 2011) characterising a recovery approach can be summarised as building a meaningful and satisfying life as defined by the person themselves, moving away from an illness focus towards one of health and wellness, enhancing hope by each person experiencing how they can have more active control over their lives, partnering person-centeredness, and being able to take on occupational roles within local communities rather than in segregated services. Some of these aspects; for example, 'defined by the person', 'active control over one's life', and 'being able to take on occupational roles in community' are closely related to personal agency.

Without denying that the individual has an illness, the recovery paradigm focuses on the path towards participation in community life by including the social context in which the person experiences disability. Thus, occupational engagement and agency can contribute to recovery and the enablement of managing meaningful daily occupations and participation (Bonney & Stickley, 2008). Social networks are also vital to the recovery process among people with severe psychiatric disability (Topor, Borg, Di Girolamo, & Davidson, 2011); however, generally the social networks are small for people in this group. Some research points to recovery as a self-healing process, whilst others emphasise the need for professionals to lead the way towards recovery for people with severe psychiatric disability (Onken, Craig, Ridgway, Ralph, & Cook, 2007). Accordingly, the recovery paradigm contrasts with the medical, and often more normative paradigm.

The use of the concept 'recovery' in mental health emerged as deinstitutionalisation resulted in more individuals living in the community. It gained force due to a perceived failure by services or society to adequately support social inclusion and by studies demonstrating that many can recover, also including complete recovery from the illness and symptoms, off of medication (Bleuler, 1974; Harding, Brooks, Ashikaga, Strauss, & al, 1987; Huber, Gross, & Schüttler, 1975). A later study (DeSisto, Harding, McCormick, Ashikaga, & Brooks, 1995) compared the rates from two long-term studies covering three decades in two different states: Vermont and Maine. They found that the two states had very different mental health policies resulting in significantly higher recovery rate in Vermont. Vermont emphasised rehabilitation, community integration, and active individuals. Maine focused on symptom reduction and continuation. The conclusion was that the major reason for the superior recovery rate in Vermont was due to the social policy emphasising hope, rehabilitation, and a belief that each person is capable of living a full life in the community regardless of the severity of their condition.

Living with psychiatric disability

Psychotic disorders, treatment, and consequences in daily life

Psychiatric problems can be diverse and complex, ranging from practical to psychological or medical. People with schizophrenia or other psychotic-related disorders living in the community often need care and support in the form of effective psychosocial interventions. A 2006 national survey (SOU, 2006:100) indicates that approximately 50 000 people in Sweden are presently diagnosed with schizophrenia and about 60-80 percent of those are in need of society's efforts.

The single most important intervention to prevent the recurrence of acute psychosis is regular treatment with antipsychotic medication (Clinical Guidelines, 2009). While in many cases medication is necessary, it is often insufficient for the majority of these cases when it comes to social, practical, and psychological recovery. Additionally, medication is less effective in treating the so called negative symptoms such as inactivity and inability to initiate and perform activities (Chugg & Craik, 2002). People with schizophrenia who have residual positive or negative symptoms are described as a 'difficult-to-treat' group. The diagnosis, with its unique symptoms, can vary in the individual experience as well as in the consequences in daily life.

People with psychosis-related disorders typically perceive the world in a different way. The consequence is often a disruption in their everyday life and occupations, and a reorganisation of the self (Dimaggio & Lysaker, 2010; Nagle, Cook, & Polatajko, 2002). Many suffer from problems in metacognition, the act of thinking about one's own thought processes, which can limit their insight and ability to recognise, express, and manage naturally-occurring emotions and routine social problems, and grasp the intentions of others (Dimaggio & Lysaker, 2010). Moreover, people with severe and long-term psychiatric disability risk experiencing feelings of worthlessness, loss of friends, communication and interaction problems, social isolation, cognitive difficulties, altered personality, disruptive behaviours and dependency on their caregivers (Meaden & Hacker, 2011). In general, they also need both healthcare services and resources in municipal assisted living facilities (Thorncroft & Tansella, 2004). Psychiatric problems are often disabling with severe consequences for the person and their family. Individuals with a psychiatric disability often have a complex life situation due to their illness, which has an effect on their perceived participation in life (Yilmaz, 2009).

Extensive scientific research has been compiled about how to understand and learn more about psychotic experiences (Geekie, Randal, Lampshire, & Read, 2011). However, in existing research the voice of subjective

experience from transformative processes in daily life is rarely taken into consideration. In this thesis, first-person accounts are illuminated to contribute to deeper understanding and the development of rehabilitation.

Daily occupations

Psychosis-related disorders have a major impact on the ability of an individual to engage in meaningful daily occupations and on community functioning (Aubin, Stip, Gélinas, Rainville, & Chapparo, 2009; Bejerholm & Eklund, 2004; Ivarsson, 2002). People with severe psychiatric disabilities have difficulties in organising and performing their daily occupations in a satisfactory way. In general, they have a sedentary lifestyle, sleep a lot, spend most of their time alone at home, and mainly perform passive activities (Aubin, Hachey, & Mercier, 1999; Bejerholm & Eklund, 2004; Chugg & Craik, 2002; Leufstadius, 2008; Shimitras, Fossey, & Harvey, 2003). When performing leisure occupations they tend to be of more passive character than leisure in general, which is negative for the health (Krupa, McLean, Eastabrook, Bonham, & Baksh, 2003). Furthermore, persistent mental illness hamper social interaction and participation (Yilmaz, 2009) and the majority have a sparse social network (Brunt & Hansson, 2002; Eklund & Hansson, 2007).

Satisfying and meaningful everyday occupations are found to be important as they can contribute to a better life quality for those who have a severe psychiatric disability (Aubin et al., 1999; Eklund, 2009; Eklund, Hermansson, & Håkansson, 2011; Goldberg, Brintell, & Goldberg, 2002). Engagement in meaningful occupation is also central for personal and social identity (Laliberte Rudman, 2002; Lin, Kirsh, Polatajko, & Seto, 2009), and for belonging, participating and contributing in a social context (Argentzell, Håkansson, & Eklund, 2011; Hvalsoe & Josephsson, 2003; Leufstadius, Erlandsson, Björkman, & Eklund, 2008; Nagle et al., 2002; Yilmaz, Josephsson, Danermark, & Ivarsson, 2008). Argentzell et al (2011) also found that taking care of body and mind, being diverted or relaxing, also were of meaning for unemployed people with severe psychiatric disability. Gender may also influence the everyday life and daily occupations. A study by Bejerholm & Eklund (2006) show that women with psychiatric disability in general prefer occupations in their home environment while men prefer occupations outside their home environment.

Home and housing perspectives

In general, home is a location where the most basic needs of a person are met. The views and values of home can have different meanings to different people. Després (1991) conducted a review on the meaning of

home, focusing on the ideas of security, control, permanence, and continuity. Furthermore, home is a reflection of one's ideas and a symbol of values and personal status. Home is also a central place for activities, relationships with family and friends, and a refuge from the outside world (Després, 1991; Padgett, 2007).

When people are in need of sheltered or supported housing, they are also subordinated under certain structures within the housing facility and municipality services organisation. People with psychiatric disabilities share a diversified view of living in a housing facility (Piat et al., 2008; Tsai, Bond, Salyers, Godfrey, & Davis, 2010). While the majority prefers independent housing, many also describe benefits of supported housing.

Regardless of the severity of disability, the home is a key activity arena where people spend a lot of time. For people with severe psychiatric disabilities, the home can have an even greater significance because they tend to spend most of their time at home (Bejerholm & Eklund, 2004; Leufstadius, 2008). The ability to maintain a home is traditionally also an important prerequisite for other occupational domains in life such as leisure and work. Considering that the home and community are principal settings for daily occupations and people with severe psychiatric disabilities spend most of their everyday lives at home, it may also be an important setting for rehabilitation. Therefore it is important to more completely understand these contexts.

Support, care, and rehabilitation services in home and community

The deinstitutionalisation process and community living

In the 1990s, decentralisation, deinstitutionalisation, and normalisation, became central to Nordic disability policy and research (Lindqvist et al., 2011). For example, Sweden closed all large mental institutions and made local governments responsible for all municipality services such as housing and day centres (Markström, 2003). This created tremendous challenges for service users, families, organisations, and professionals in new rehabilitation contexts (Gahnström-Strandqvist, 2003).

Between 1995 and 2011 county councils and municipalities have made some progress in improving support and services for people with psychiatric disabilities, but the reform process has been slow (Lindqvist et al., 2011; Markström, 2003; SOU, 2006:100). At the same time, expectations for improved and evidence-based interventions have been

raised due to increasing community awareness and state governmental reports (SOU, 2006:100). Unmet need, personalisation, lack of home- and community-based rehabilitation, and a lack of inter-professional collaboration are still critical issues and most responses to mental health problems occur across a diverse range of services (Rosenberg, 2009). The same challenges occur internationally (Disability, 2010). This raises challenges for clinicians, researchers, and service planners.

Article 19 of the UNCRPD (UN, 2006) states that institutionalisation of disabled people is no longer an acceptable strategy and highlights state level responsibility to ensure “equal rights of all persons with disabilities to live in the community with choices equal to others” and requires states to ensure that “persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, and are not obligated to live in a particular living arrangement”.

Residential care

The types of residential care and housing facilities for people with psychiatric disabilities vary internationally and nationally and have changed over time. In this thesis, sheltered housing includes own room with pantry and bathroom, access to communal dining rooms with mealservice three times a day, services in daily activities such as cleaning, washing etcetera, and personnel available 24 hours a day. Supported housing is defined according to international standards (Chilvers et al., 2006) and includes the individual's own 'ordinary' housing with extensive outreach support of personnel. Supported housing has increasingly become the preferred housing solution for people with severe psychiatric disability (Rog, 2004).

In Sweden, around 15,500 of the people with psychiatric disabilities receive support from community care workers (CCWs) in own 'ordinary' housing, while 8,000 people live in some kind of residential care facility; i.e., nursing home, service flat, or sheltered housing (Socialstyrelsen, 2010). Most of these people require supervision, social support, functional support, daily care, and/or nursing care.

One of the groups with the greatest difficulty in having their needs met by municipal social services (Socialstyrelsen, 2007) are people with psychiatric disabilities. For example, it is difficult to find the right forms of occupation and housing for people in this category. More special forms of supported housing are needed (Rog, 2004), and personnel shortages and a need for personnel development are pointed out as increasingly common in existing housing (Lindqvist et al., 2011). Also, living a sedentary lifestyle has become the norm for many residents (Bejerholm & Eklund, 2004).

Services available in the community have a significant impact on a person's occupational performance opportunities (Drake, Green, Mueser, & Goldman, 2003; May, 1999) and agentic possibilities. However, little attention has been paid to home as a place for development and transformations.

Traditional contra recovery paradigm

Both research and the community have clearly recognised the central role of recovery-oriented services (Abdallah, Cohen, Sanchez-Almira, Reyes, & Ramirez, 2009; Chandler & Repper, 2011). By contrast, mainstream home services and housing facilities in the municipalities around Sweden have failed to acknowledge a recovery-oriented rehabilitative perspective. In general, CCWs still tend to follow a traditional stable ambition with calm and caring ambitions versus the recovery ambition with positive risk-taking and hope of change as central features (Lindqvist, Markström, & Rosenberg, 2010). The protection defined as safety and calmness often leads to sub-institutionalisation instead of recovery (Thornicroft, Rose, & Mehta, 2010). Consequently, there are weaknesses and discontinuity in the municipality psychiatry system depending on where one lives and how aware one is of one's rights (SOU, 2006:100).

In health and social care settings, positive risk-taking is generally understood as enabling individuals to make choices about all aspects of their lives, which may involve an element of risk, but if managed properly should not result in harm (Alaszewski & Alaszewski, 2002). The success of positive risk-taking approaches with people with psychiatric disabilities relies on 'shared risk-taking' where professionals and people with psychiatric disabilities work together to agree plans and actions (Drake et al., 2003). However, little attention has been paid to how to best support practitioners to develop these practices. There is some research into the role of risk-taking in promoting learning new skills (Waters & Begley, 2007) but this is not specifically related to people with psychiatric disabilities.

Home- and community-based rehabilitation

While primary care and municipality services encounter many people with severe and long-term psychiatric disability, the identification of rehabilitative needs is extremely low and poorly supported by rehabilitative services (SOU, 2006:100). Rehabilitation access is especially limited among people that have lived with psychiatric disability for an extended period of time, who are not able to attend vocational rehabilitation services, and spend most of their time at home. The results are high levels of inactivity, sustained disability, and entrenched chronicity.

According to the World Health Organisation (WHO, 2011), “Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination”. In general, people with severe psychiatric disability desire more meaningful daily occupations including increased social interactions, and to come in and out of the housing, but municipality services have not succeeded in providing the support, rehabilitation, or options needed to fulfil these needs (SOU, 2006:100). Therefore, these services need to be improved.

Normally, the access to rehabilitation opportunities is beyond a resident’s control (Rosenberg, 2009). The power is under the control of CCWs and institutional rules, information is insufficient, and discussions regarding resident priorities and goals are generally limited to daily needs such as food, sleep, and order, rather than meaningful daily occupations of the resident’s choosing, or social participation in community life. This is one reason for arguing that rehabilitation ought to be offered in a home and community context rather than in an institutional housing facility environment, even though these overlap in many ways.

Providing recovery oriented rehabilitation in home and community settings offers unique, individual conditions and challenges for enabling occupation. In the home it is possible to see the person with psychiatric disability in the context where most everyday occupations take place (Borg & Davidson, 2008; Davidson et al., 2005). Though, when the OT and CCW work in another person’s home, it is also central to ethically reflect on and consider aspects such as autonomy and identities (Magnusson, 2003) and how the meaning of home may change when it also becomes a place for professionals to act within (Sjöström, 2008).

Effective rehabilitation interventions which target people with severe psychiatric disability are a societal and municipality priority and are required to reduce the burden of disabilities created by psychotic disorders and/or environmental hindrances. Occupational therapy is one recommended part of rehabilitation for people with psychoses-related disorders and disabilities (Socialstyrelsen, 2011). As a result, collaboration between OTs and CCWs is increasingly common. Therefore, one part of this thesis focuses on what happens in collaborations in rehabilitation using a shared framework.

Evidence supporting OT interventions

Previous research relevant for the development of OT interventions

Direct evidence for the effectiveness of OT interventions is very limited (Johnston & Case-Smith, 2009). A systematic review evaluating the effectiveness of OT interventions focusing on recovery for people with severe psychiatric disabilities (Gibson, D'Amico, Jaffe, & Arbesman, 2011) indicates moderate to strong evidence for social skills training and for supported employment using individual placement and support to result in competitive employment. Moderate evidence is found for life skills and IADLs training to improve performance, as well as for integrating cognitive-behavioural intervention and neuro-cognitive training with skills training within the areas of work, social participation and IADLs. Furthermore, the evidence for client-centred intervention and increased intensity and duration of treatment is limited but positive according to the criteria in this review. In the same review, Gibson et al also conclude that the evidence for providing intervention in natural contexts rather than clinical settings is limited and inconclusive. In addition, a few older studies show better effects of rehabilitation provided outside mental institutions rather than within them (Falloon & Fadden, 1993; Falloon & Talbot, 1982).

Complex interventions are generally considered difficult to study (Richards & Borglin, 2011). For instance, there are different opinions about the relative importance of specific and general factors for the effect of interventions (Lambert & Ogles, 2004). The dynamic interaction between them is difficult to separate in terms of interventions in real life contexts (Hohmann & Shear, 2002). An overview based on a large number of studies within psychotherapy and psychiatry (Wampold, 2001) suggests that the specific factors account for about eight percent of the total effect, while general factors including placebo account for about 70 percent of an intervention.

Thus, there are several general factors to consider. Research points to the therapeutic relationship as the single most important one for the outcome (Lambert & Ogles, 2004). The therapeutic relationship contains two critical factors: an affective aspect influencing the attachment between participant and therapist, and a collaborative aspect influencing how well the participant and therapist understand each other and agree on goals and means of the arrangement. Specifically, a good initial therapeutic alliance between the client and OT is shown to be important to the outcome (Cole & McLean, 2003; Gunnarsson & Eklund, 2009). Client-centredness (Rogers, 1951; Townsend & Polatajko, 2007) is based on a good therapeutic relationship and a partnering approach to agree on goals and means in line with the client wishes and conditions along the

whole intervention process. Another general factor of importance for the outcome of psychiatric services has proved to be the psycho-social environment and atmosphere within the setting (Eklund & Hansson, 1996).

In this way, some evidence for OT interventions can be found indirectly by examining the components or mechanisms of client-centred praxis, general factors in treatment, relationship factors, environmental factors, recovery factors, and enabling factors for meaningful daily occupations. Furthermore, several studies with process or outcome designs show scientific support for a number of components important in the design of new recovery- and occupation-based interventions, as described in the following. *Engagement in meaningful occupations* can contribute to recovery and managing daily living (Bonney & Stickley, 2008); engagement can be hindered by, but also preventive of psychiatric symptoms (Bejerholm & Eklund, 2007) and correlated with quality of life (Bejerholm & Eklund, 2007; Goldberg et al., 2002). In order to find meaningful occupations, an *individually based rehabilitation* is crucial (Eklund, 1999). *Participation in social networks* is related to valued and satisfying occupations (Eklund, 2006) and to health-related factors (Eklund & Hansson, 2007). Furthermore, returning to active and *valued roles* in community living is emphasised as an important recovery outcome (Waghorn, Chant, & King, 2007). *Real life* challenges are found to be vital, as recovery unfolds within the context of natural environments and occupations (Borg & Davidson, 2008; Davidson et al., 2005; Webster & Schwartzberg, 1992). *Optimal match* between the individual's skills, the environment, and the targeted occupation is essential for enabling performance (Christiansen, 2005; Velde & Fidler, 2002). Being *challenged* and *learning* something is crucial according to participants (Eklund, 1997; Webster & Schwartzberg, 1992). A *maintenance phase* after withdrawal of the intervention has been emphasised (Kaplan & Smith, 1977; Kielhofner & Brinson, 1989) to help the participant maintain the new level of competence over time. *Collaboration* between professionals has also been highlighted as an essential ingredient in municipality psychiatric services (Drake, Bond, & Essock, 2009; Drake et al., 2003; Green et al., 2008; Rosen & Callaly, 2005; Rosenberg, 2009). It is generally accepted within rehabilitation research that the *goal setting process* is significant for the outcome of an intervention (Playford, Siegert, Levack, & Freeman, 2009). Goal setting in rehabilitation is described as an important, interactive process between the participant and the therapist, supporting adherence (Levack et al., 2006). When facilitating person-driven goals, the role of the occupational therapist is to enable the participant to view his/her life context and subsequently value everyday tasks in order to be able to prioritise which daily occupations he/she would like to perform better or participate in. Outlining goals can be a valid tool in rehabilitation by directing the participant's attention to the therapy process and increasing

their motivation to actively participate (Hurn, Kneebone, & Cropley, 2006).

Lastly, there is some evidence implying that *early* interventions focusing on employment and family therapy are important in psychotic conditions, suggesting that they improve social and vocational functioning, quality of life, and medication adherence; however, there is still some question about whether gains are maintained. Studies are diverse and mostly small in scale, suggesting a need for replication with larger and longer term trials (Marshall & Rathbone, 2011). In contrast to existing research on early intervention, this thesis aims to explore whether *late* rehabilitation focusing recovery and meaningful daily occupations can bring about change in people with severe psychiatric disabilities.

The results of the above-described systematic reviews, together with general factors and more specific factors of importance, indicate that more research in the area is needed. In particular, there is a lack of intervention models for people with long-term sedentary conditions in sheltered and supported housing. Thus, there is a need to develop a model based on such evidence. Therefore, some of the above-described mechanisms and enabling factors in rehabilitation have inspired the construction of the ELR model, as described in the subsequent methods section of this thesis.

Intervention study design

Because OTs individualise interventions based on evaluating the unique needs of a person in unique contexts, considering intervention options, and matching the intervention to help the participant gradually reach the individual goal, two primary challenges are heterogeneity and complexity (Johnston & Smith, 2010). The great variability of populations served, disabilities perceived, mechanisms involved, outcome relevancies, and contextual effects contribute to the complexity of OT intervention research. Therefore, considerable exploratory, single-case and small group designed research is needed to design a successful, definitive randomized controlled trial (RCT) (Johnston & Case-Smith, 2009). Smaller, more practical, and more in depth research designs are also needed to advance knowledge in most areas of OT practice.

It is not unusual that performance immediately returns to baseline rehabilitation levels when support services are removed (Portney & Watkins, 2009). Therefore, a withdrawal phase and follow-up assessment are important in the research design. In single-case and small group designs, a minimum of three to four baseline and outcome assessment series are recommended (Portney & Watkins, 2009). In regards to the intervention and assessments used, feasibility together with reliable, valid, and responsive assessments are fundamental to the study of interventions aimed at increasing the level of engagement in meaningful

daily occupations for people with psychiatric disabilities (Johnston & Case-Smith, 2009; Law, Baum, & Dunn, 2005). Consequently, in order to individualise rehabilitation in a recovery-oriented and client-centred way and work in an evidence-based manner, it is necessary to use well-defined guidelines from a structured, but flexible intervention model based on specified principles and process-steps with individualised content.

Traditionally, research and evaluation of intervention programs focus on measuring effects by deductive analysis. Using a *deductive* perspective means choosing certain predetermined categories or variables to describe or analyse the phenomenon being studied and eventual changes in these variables in regards to the intervention (Pritchard, 2010). However, when a new type of intervention is being studied, different phases of intervention research including inductive perspectives are recommended (Johnston & Case-Smith, 2009) because there might be unknown categories or variables important to the comprehensive understanding and evaluation of the impact of an intervention. These are important to identify and understand before conducting larger RCT-studies. Using an *inductive* perspective means discovering categories or dimensions from open-ended observations in the data (Pritchard, 2010). Hence, the development and refinement of occupational therapy intervention programs require a combination of deductive and inductive perspectives. Besides focusing on the outcome of an intervention, it may also be relevant to focus on other 'impact evaluations' and add other approaches and analytical techniques to understand more about the dynamic processes of an intervention and its implementation (Potvin, Gendron, Bilodeau, & Chabot, 2005). Such dynamics could include participant meaning-making of the transformations, mechanisms of the intervention, experiences, awareness, and reasoning in residents and personnel as well as the impacts of service organising. Despite changes in research emphasis from demonstrating effect of interventions to understanding the dynamics, complexities, therapeutic processes, and implementation processes, this type of research is uncommon in OT research. Therefore, a mixed methods approach is preferred to enrich the knowledge base of complex interventions (Maxwell & Loomis, 2003; Mortenson & Oliffe, 2009).

Implementation of intervention

Implementing a new kind of intervention requires strengthening capacity at several levels, developing assets, and appropriate readiness within the organisation for endorsing the intervention (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). Implementation structure describes how actors at different levels take part in the initiation, anchoring, preparations, and decisions for delivering and managing the local interventions (Damschroder et al., 2009). Local interventions are dependent on local support and goodwill in order to facilitate and

legitimate actions. A supportive environment characterised by inter-professional collaboration can build a crucial intervening structure or vice versa (Fixsen et al., 2005). Improving rehabilitation may also involve reorienting the structure and services provided, advocating for occupational justice policies or creating supportive environments that enhance opportunities for meaningful daily occupations of the residents own choosing. Educational strategies may include specific education programs, training, skill building, and model counselling to individuals or groups such as professionals or user organisations (Nilsen, 2010).

Rationale for the thesis

The late reforms and changing perspectives in society (Lindqvist et al., 2011) have brought both new opportunities and risks for people with psychiatric disability, and also new challenges for professionals. Living with severe psychiatric disabilities in a housing facility often means a sedentary lifestyle with lack of meaningful daily occupations (Bejerholm & Eklund, 2004; Leufstadius & Eklund, 2008). This is of great societal, health, and human value loss.

Research supports early interventions for people suffering from psychotic-related disorders (Marshall & Rathbone, 2011), but there is a lack of research showing the impact of late rehabilitation efforts on people with severe and long-term consequences of psychotic-related disorders in community living; that is psychiatric disabilities, and also how to go about providing rehabilitative services. Few studies have addressed the mechanisms by which meaningful daily occupations can be facilitated for people with psychiatric disabilities. There is also little understanding of the significance of home for occupational transformations or why and how the home and community context supports rehabilitation.

Understanding transformative processes and enabling meaningful daily occupations among people with severe psychiatric disability living in sheltered or supported housing are important, but also complex processes in a multi-faceted arena why there is a need for more knowledge in the field. Also, in order to work in an evidence-based manner, it is necessary to establish strategies that are feasible for practice, well-structured in their components and process-steps, but at the same time flexible enough to enable individual choices of meaningful daily occupations. Previous research reveals a knowledge gap and the need to develop a model that brings together existing evidence for the application of recovery- and occupation-oriented interventions for people with severe and long-term psychiatric disability. Therefore, a model for Everyday Life Rehabilitation (ELR) was developed and studied from different perspectives in the studies within this thesis to reveal if and how

this intervention may be helpful. The idea was to offer occupational therapy interventions integrated into sheltered and supported housing in close collaboration with CCWs to enable meaningful daily occupations for residents. Thereby, we wanted to gain an understanding of the resident and CCWs perspectives and contribute to the contextualised knowledge of integrated rehabilitation in the home and community environment.

AIMS OF THE THESIS

The global research question was how to support people with severe psychiatric disabilities to become active agents in their everyday occupations. To address this research question, we used three samples from sheltered and supported housing facilities and designed the studies from two main points of departure: a home context and an intervention focus.

The overall aim of this thesis was to understand and evaluate the impact of recovery- and occupation-oriented interventions in a home context for people with severe psychiatric disability.

The specific aims were to further understand and evaluate:

- the significance of home for occupational transformations (Study I);
- the outcome of the ELR intervention (Study II);
- the residents' experiences of the ELR intervention and meaning-making of their transformations (Study III);
- the personnel views of the ELR intervention (Study IV); and
- the feasibility of intervention, assessments, and collaboration (Studies I-IV)

METHODS

In this thesis we apply a mixed methods approach (Maxwell & Loomis, 2003; Mortenson & Oliffe, 2009), using both quantitative and qualitative methods to develop contextually relevant knowledge towards improving home- and community based interventions. The first study focuses on the home context, when living in a supported housing facility, and its significance for occupational transformations (I). This study formed the basis in developing a specified model for integrated occupational therapy in sheltered and supported housing; the Everyday Life Rehabilitation (ELR) (Lindström, 2007) (Figure 2, p 42). We offered an intervention project using the ELR to a municipality in northern Sweden who embraced the project running 2006-2008, and in parallel we evaluated the intervention project from the perspectives of residents and CCWs (II-IV).

Overall research design

The thesis includes four studies based on three samples. The overall research design takes one point of departure in understanding the home as the context for occupation-based interventions and transformations (I) and one point of departure in an intervention project (II-IV) (Figure 1). The interventions used in these contexts are similar. An overview of the four studies and methodologies is given in Table 1.

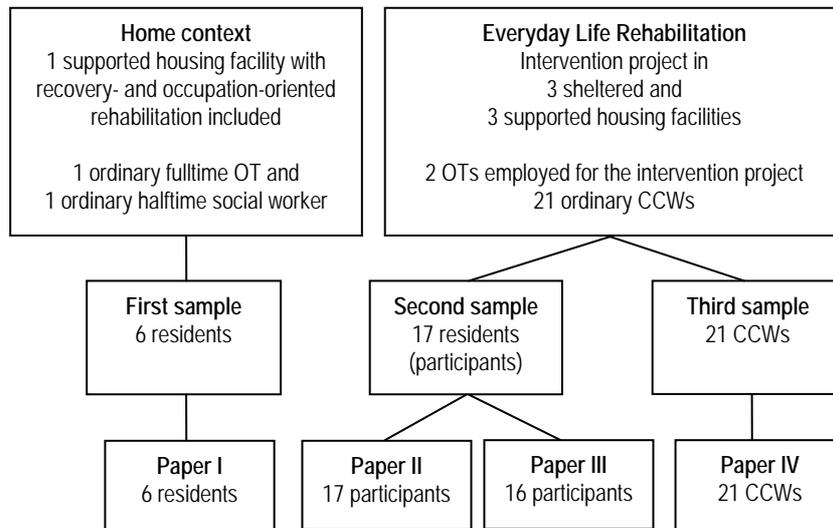


Figure 1. The two main points of departure and three study sample in papers I-IV.

Table 1. Overview of the samples, settings, interventions, data collection, and analyses in Study I-IV

Study	I	II	III	IV
Sample	6 residents	17 residents (participants)	16 residents (participants)	21 community care workers
Duration disability (yrs)	8-19 (<i>M</i> 13)	9-48 (<i>M</i> 22)	9-48 (<i>M</i> 23)	-
Age (yrs)	24-37 (<i>M</i> 31)	27-66 (<i>M</i> 48)	27-66 (<i>M</i> 48)	24-63
Gender women/men	2/4	7/10	7/9	16/5
Housing	supported	supported (3) sheltered (14)	supported (3) sheltered (13)	(referring to II and III)
Intervention	Recovery- and occupation-oriented rehabilitation	Everyday Life Rehabilitation (ELR)	Everyday Life Rehabilitation (ELR)	Everyday Life Rehabilitation (ELR)
Intervention phase	Recurrent during 4 years	Range 2-17 month (<i>M</i> 6,4)	Range 2-17 month (<i>M</i> 6,4)	Range 2-17 month + maintenance phase
Data collection	Qualitative interviews	Pre-, post-, and follow-up test	Qualitative interviews, and field observations	Focus group interviews
Analysis	Constant comparative analysis (GT)	Non parametric statistics	Narrative analysis	Qualitative content analysis

The home context study (I)

Setting, recruitment, and participants (I)

This study took place in a supported housing residence in northern Sweden where seven persons each lived in a self-contained apartment. There were also shared facilities in connection to the seven apartments, such as an 'open' apartment that was available to all residents for socializing. All seven residents were asked to participate in the study and informed about the aim, procedure, and confidentiality. Six residents (two women) consented to participate in the study. All the residents suffered occasionally from psychosis due to severe mental illness. Five had been diagnosed with schizophrenia, and one with borderline personality disorder. They had experiences of severe psychiatric disability for 6-18 years (*M* 13). Their ages varied from 24 to 37 years (*M* 31). All but one had a limited social network. At the time of the interviews, their occupational performance and their self-knowledge had improved from

year one to year four, evaluated by standardized assessments of motor, process, and social interaction skills, together with a standardized semi-structured interview on occupational self-efficacy.

Intervention: Recovery- and occupation-oriented rehabilitation (I)

The supported housing facility adopted, when it was new from start, a rehabilitative approach inspired by a recovery paradigm, and the MoHO (Kielhofner, 1995; 2008). The individual processes were pursued in respect to client-centredness (Rogers, 1951) and using the basic standards of rehabilitative efforts: evaluation, goal, intervention, and follow-up (CARF, 1998; 2011). The rehabilitation was voluntary and offered continuously, in recurrent phases, during a period of four years, prior to the data-collection for study I. Additionally, the supported housing had ambitions of providing the daily support needed for individual wishes of for instance home management, and community integration tasks related to socializing, education, work experiences, study circles, managing money etcetera.

One fulltime OT and one halftime social worker, entitled 'coaches', were employed to provide both the rehabilitative services and the supportive services. Coaching and support were offered to both individuals and groups.

Data-collection and methods of analysis (I)

Grounded Theory – constant comparative analysis (I)

In this study a Grounded Theory (GT) approach (Strauss & Corbin, 1990) was chosen. GT is rooted in symbolic interactionism (Mead, 1967) and is used to explore basic social processes in certain contexts by analysing and mapping the logic and words of the participants to create an explanatory pattern or theory of the experience, grounded in the empirical data. A constructivist orientation of the grounded theory approach (Strauss & Corbin, 1990) allows previous knowledge to influence the analysis. The method stresses a constant comparative analysis of data to discover properties within and relations between categories.

Over three months, two to four qualitative interviews were carried out with each informant, by me as a researcher with a former relationship to the housing facility. All interviews began by talking about overall experiences of the process of change. The interviews continued with dialogues about experiences of the rehabilitation process, and the meaning of 'home' as a place for personal processes of change. Along the process of collecting and analysing data, emerging categories were tested in the interviews that followed. In addition, some residents participated

in follow-up interviews, to clarify or fill out some aspects, and to try deriving categories.

Transcription of each interview, and an open, line-by-line, selective coding procedure, was conducted before every next interview. Thereafter, the open codes were collated into related categories. Moving back and forth in constant comparisons, each category was carefully examined and labelled in order to identify the properties of the categories, as well as sub-categories. As the process of analysis proceeded, we found that the material contained several elements of conflict. These conflicts were labelled 'progressive tensions'. Within each category we found a progressive tension, and above these there were also two overarching progressive tensions. In the final step, a core category was identified, capturing the essence of the interactive processes.

The ELR-intervention project (II-IV)

Implementation and recruitment (II-IV)

The intervention project was conducted within the social psychiatry organization of a medium-sized municipality in northern Sweden. The intervention project was prepared during the fall of 2005 through collaboration with local user associations, and by anchoring and planning with relevant managers. Contracts were established with housing managers, regulating the responsibilities between project leader and housing managers. The contracts regulated for instance the housing managers' support to CCWs and regulations regarding working conditions and workplace for OTs in the forthcoming project. The two OTs were employed by the municipality via money from the project, and the project leader held the main responsibility for their employment and rights. As OT services are regulated by Swedish law - for instance The Health and Medical Services Act and The Patient Data Act - data-log requirements were deployed. Furthermore, documents regulating privacy for residents, and documents for rehabilitation plans, were prepared.

During a period of two months before the intervention project started, information meetings were held for relatives, residents (potential participants), CCWs, managers, and other health care workers involved in the municipality. Brochures were distributed via channels such as CCWs, user associations, and at repeated open information meetings. Information meetings were held both in a general conference room down town and at the common housing facilities in the municipality. Letters describing the project including invitation to participate were distributed by the local user association. CCWs and OTs received model-education, as described under the heading 'Intervention' below.

The intervention ELR, including occupational therapy services in collaboration with CCWs, were offered free of charge to all citizens with psychosis-related disabilities living in sheltered or supported housing in the municipality. Residents included in the intervention were recruited by open announcements, brochures, meetings and letters, distributed to all supported and sheltered housings in the municipality. Each resident had one to two contact persons among the CCWs, who automatically became involved in the rehabilitation when their resident decided to take part in the intervention.

Intervention: Everyday Life Rehabilitation (ELR) (II-IV)

Based on experiences from study I and incipient evidence for some intervention principles, I developed the ELR model (Lindström, 2007) as a platform for rehabilitation in sheltered and supported housing. ELR is built on core principles and manualized process-steps, allowing for individualized content. The aim is to enable meaningful daily occupations for people with severe psychiatric disabilities in their natural everyday contexts. ELR was developed in order to clarify the recovery- and occupation-oriented perspectives and enhance collaboration between OTs and CCWs (Figure 2).

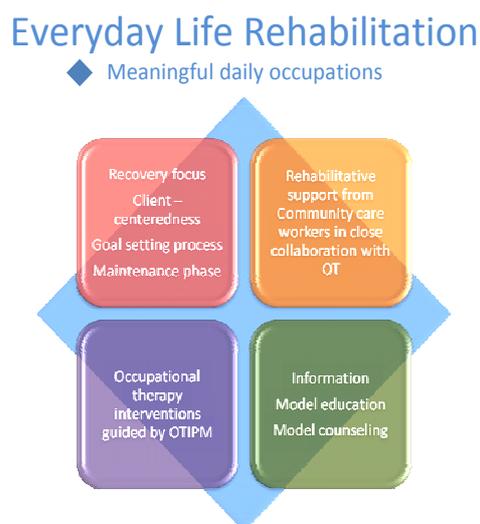


Figure 2. The model Everyday Life Rehabilitation (ELR)

ELR is based on the following principles: eligibility of occupational therapy for people living in sheltered or supported housing; a recovery focus; close collaboration between CCWs, OT, and resident; partnering client centeredness; goal setting based on resident choices; occupation based training in real-life settings; individually set time-frames; and support during a maintenance phase after goal attainment. The role of the OT is to guide the rehabilitation process, in partnering approach with the residents/participants, and in close collaboration with the CCWs. The role of the CCW is to, in close collaboration with the OT, support the participant to integrate the gradually increasing abilities into their everyday routines and when the goal has been attained, sustaining the conditions for maintenance of new competencies and continued development.

The process-steps follow the Occupational Therapy Intervention Process Model (OTIPM) (Fisher, 2009). The process steps include to: develop therapeutic relationships; identify resources and limitations within client-centred performance context; identify and prioritize client-reported strengths and problems of occupational performance; observe and analyze task performance; interpret cause; select model for intervention; plan and implement interventions; and re-evaluate.

OTIPM (Fisher, 2009) details methods for posing clinical questions; what the OT should ask to obtain relevant information; and how to select the best strategy to meet any occupational situation. Throughout the process, the OT interweaves the best available evidence with insights on how to build rapport and enhance client motivation and participation. In a partnering approach, the OT suggests well-matched strategies to help participants overcome their problems based on their specific needs, values and wishes. The intervention strategies can be restorative or acquisitional such as occupation-based training in prioritized daily life tasks, but also compensatory such as stress-reducing techniques and technical aids, or educational such as the group program of social skills training. Overall, both the evaluations and interventions focus on the person, environment, and/or the occupation for each individual circumstance.

Client-driven goals are central within the ELR and identifying goals is an ongoing parallel process along the evaluations and different process-steps of OTIPM. Using meaningful daily occupations as goals and means, the OT gradually increases the difficulty of the activities until the participant reaches the targeted goal. When a goal has been attained, the CCW are responsible of supporting the resident in maintaining the new competence.

As described previously, ELR also contains implemental facets, such as model education for OTs as well as CCWs and their managers; model counseling for the OTs; and information strategies, i.e. brochures, and

information meetings with residents, relatives, CCWs, other collaborative persons and user organizations.

Procedure. I was, in the role of project leader, responsible for the information, model education and model counseling. Two part-time OTs, trained in OTIPM, were employed to provide project services, and ordinary CCWs were involved in the collaboration, as described below.

Within this intervention project, each participant had the opportunity to work with one prioritized goal. The goals were formulated according to the Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968). Some examples of goal areas were going for regular walks, social interaction with friends, initiating small talk with women, taking control of pocket money, eating in lunch restaurant without compulsive behavior, weekly sauna bathing, and healthy cooking. Another device that was used during the intervention was a 'goal-sheet' of the individual goal, to put up somewhere in the home of each resident as a reminder or motivation emblem. The participant and the OT met once or twice a week and each session lasted for about one to two hours. In between, the OT and CCWs met to reconcile the planned activities. The length of the intervention phase was individually set, corresponding to the goal ambition of each individual, and ranged from 2 to 17 months (mean 6.4).

Interveners. As this intervention was not part of ordinary services, the OTs who provided the intervention according to ELR were recruited especially for this project. One OT had 30 years of experience as an OT in psychiatric settings but was unfamiliar with the OTIPM prior to the project. The other OT had three years of experience as an OT mainly in rehabilitation for elderly in residential care and was familiar with the OTIPM prior to the project. Both OTs participated in a four day education about the intervention model and training in the instruments used, before the project started. Additionally, both OTs also had a separate five day course on the assessment AMPS and a two day course on the assessment BSI-II.

As residents volunteered for the intervention project, their CCWs automatically became involved in the intervention. Prior to the project all CCWs working in the sheltered and supported housings within the municipality, participated in a minimum of one information meeting and a four hour education about the ELR model; the recovery ideology, client-centeredness, participant driven goals, the OTIPM, the intended collaboration between OTs and CCWs, and how to give rehabilitative support in a day-to-day practice of CCWs.

Settings and participants (II-IV)

Three supported and three sheltered housing facilities became involved in the intervention project. These settings had some differences. The *supported* housing facilities were one person, self-contained apartments

or houses. In connection to one supported housing arrangement, there were also shared facilities for socialising, while the other two had no access to communal spaces. They received outreach support from a group of CCWs who had their group of local for personnel downtown. This group of CCWs was recruited on the basis of a level of education comparable with three year of university studies. Their mission was to support the resident with anything needed in home-maintenance activities such as cleaning, washing, shopping, cooking, hygiene et cetera, and medication follow up.

The *sheltered* housing facilities had between 8-12 residents per unit with small apartments connected to shared facilities in a communal apartment for meal-services, small-talk, TV-watching, and personnel available 24 hours. Residents also received help in their apartments with support similar to that given in supported housing, apart from cooking. Two of the sheltered housing facilities had mixed gender among residents. The third housing was only available for men with disruptive behaviour. The level of CCW education was in general lower in this group, varying between none to four years of university studies.

Residents/participants (II-III)

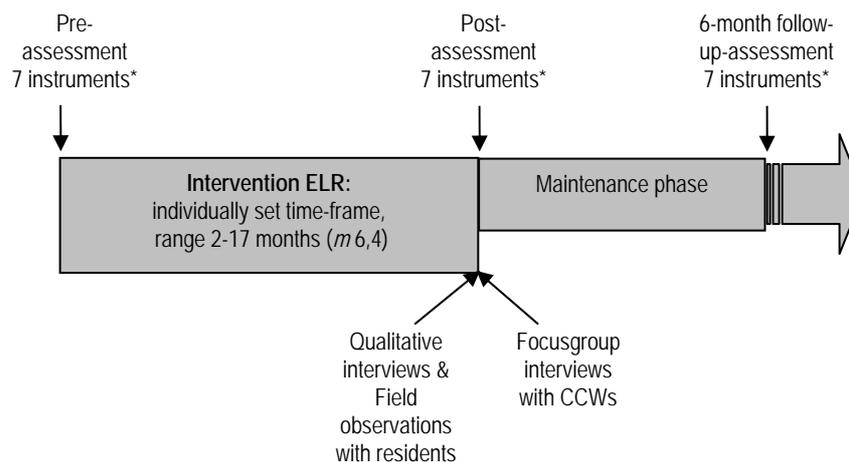
In total 17 residents (seven women) between ages 27 and 66 (mean age 48) living in sheltered (n=14) or supported (n=3) housing agreed to participate in the intervention as well as the research studies. Sixteen of 17 participants completed the intervention program. One participant was unable to finish the program owing to admission to the hospital. The entire group had psychosis-related disorders with recurrent psychoses and a history of 9-48 years of psychiatric disability (mean 22). All of them had high levels of care and support from CCWs in their daily life and a sedentary life-style. Three went to an activity centre part-time and the others had no organized daily occupation.

CCWs (IV)

Each resident who participated in the intervention had one to two contact persons among the CCWs, who automatically became involved in the rehabilitation. All these CCWs were asked to participate in focus group interviews after the intervention was completed. They all (n=21) agreed to take part in the research. Among the CCWs there were sixteen women and five men, aged 24-63, with a work experience from psychiatry varying between 1-20 years.

Procedure for data-collection (II-IV)

During the intervention project, data were collected for study II-IV as described in the figure 3. Data-collection will be further detailed in the following sections.



* Pre-, post-, and 6 months-follow-up assessments included the following instruments: GAS, AMPS, BSI-II, ADL-taxonomy with an effort scale, SDO, SCL-90, and Self-assessment of participation.

Figure 3. Intervention process and research procedures study II-IV.

Study II: Self-report and observation instruments

To understand the cause of problem with performing and participating in meaningful occupations, and to capture changes after intervention, the following instruments have been chosen as relevant:

- *Goal Attainment Scaling (GAS)* (Kiresuk & Sherman, 1968) to measure the degree of goal attainment
- *Assessment of Motor and Process Skills (AMPS)* (Fisher, 2006b) to observe and measure the quality of the participant's performance of daily living activities
- *Assessment of Social Interaction (Swedish version BSI-II)* (Englund, Bernspång, & Fisher, 1995; Fisher & Lindström, 2006) to observe and measure the participant's quality of social interaction in daily living activities
- *Satisfaction with Daily Occupations (SDO)* (Eklund, 2004) to generate scores of perceived activity level and perceived satisfaction with daily occupations
- *ADL-taxonomy* (Törnqvist & Sonn, 1994) using a five-point scale (Hariz, Lindberg, Hariz, & Bergenheim, 2002) to generate scores of perceived effort and independence in predefined daily activities

- *Symptom Checklist – 90 (SCL-90)* (Derogatis, 1992) to measure perceived psychological problems and symptoms of psychopathology

- *Self-assessment of participation* (Granlund, Haglund, Lewin, & Sandlund, 2005) to generate scores of perceived participation in everyday life situations.

The GAS, ADL-taxonomy, AMPS, and BSI-II were administered by the project OTs, as they were also clinically relevant to use within the intervention process of OTIPM (Figure 3). BSI-II was only clinically relevant for a subgroup of seven participants. Specifically for GAS, the OTs referred the individually-set goals to me, who was not involved in the intervention process, to set the scale levels of GAS based on the participants expected progress to ensure the goals were realistically challenging and that all levels of outcome had been identified.

The SDO, SCL-90, and Assessment of participation, were administered by me as researcher. The administration and test scoring were accomplished according to the test manual instructions for each instrument with a supplementary self-rating five-grade scale to the ADL-taxonomy (Hariz et al., 2002) as described above.

Study III: Qualitative interviews and field observations

To gain a deeper understanding of the processes by which residents can benefit from the ELR, the methods must be able to capture the complexities of residents meaning making by detailed personal accounts. Therefore, in this study, I conducted repeated informal interviews (Patton, 2002) and field observations (Hammersley & Atkinson, 2007) towards the end of the intervention program with the participants who had completed the intervention. The informal interviews and field observations were conducted on one to three occasions for each participant and each meeting lasted between 45 minutes and three hours. Interviews were audio-recorded and observational data were recorded in retrospective field notes.

To create an open atmosphere, the meetings often started by having coffee together in the participant's home. During the informal interviews participants were encouraged to tell stories about the process and give concrete examples about the intervention and their personal changes. A specific emphasis was placed on how the ELR participation had impacted on and how the transformations made sense in each person's everyday life and life history. In order to recall resident' memories of events from the intervention, participants were also encouraged to show the settings where the training took place. Field observations added what the participants did to what was said as the field observations provided direct access to the concrete actions of residents' everyday life, allowing for

context-sensitive interpretation of events (Hammersley & Atkinson, 2007).

Study IV: Focus group interviews

The idea of focus-group interviews is to gather people in group discussions to get a broader scope of opinions and ideas about the topics in focus (Krueger & Casey, 2000). Hopefully, when listening to each other in the group, participants will reflect on each others' opinions and express their own views. In this study, all the CCWs who had been involved in the intervention project were asked to participate in focus group interviews after the intervention was completed. Because of the Official Secrets Act, they were interviewed within their own group of colleagues, which resulted in small focus-groups. There were in total seven focus-group interviews and they lasted for 60 -120 minutes each and were digitally recorded.

The focus group interviews were conducted by me as a researcher in the personnel rooms at the housing units or the communal group local for personnel down town. A relaxed tone was initially set by informal conversations and information about the open dialectic and responding dialogue wanted in focus groups (Krueger & Casey, 2000). When discussions came to a close, new topics were raised by me focusing on four main areas: the introduction and implementation process, the actual working and collaboration through the ELR-model, the resident views, and future prospects of rehabilitation.

Study II-IV: Demographic data and basic statistics

To provide characteristics and data for feasibility analysis, the OTs collected some additional data. Demographic data were collected by a questionnaire. Basic statistics and process comments were regularly reported in a study protocol, regarding frequency, attendance, duration, length of intervention, type of strategy, collaboration, and deviations.

Methods of analysis (II-IV)

Statistical analysis (II)

Three of the instruments (GAS, AMPS, and SCL-90) produce linear measures whilst the other four produce ordinal scores. In order to transform the raw ordinal scores into linear measures, different procedures were used to prepare the data before statistical comparisons were conducted. GAS scores were calculated by me according to the statistical formula for GAS (Kiresuk & Sherman, 1968), which produces an overall score adjusted for the relative weighting assigned to goals, the varying number of goals, and the expected inter-correlation among the scales. Regarding AMPS-scores, each OT who collected data entered the raw scores from every individual assessment into the computer software

FACETS (Linacre, 1987-2008). This many-faceted Rasch analysis generated one measure of ADL motor ability and one measure of ADL process ability, adjusted for task challenge, item difficulty, and rater (OT) severity, presented in logits. Regarding SCL-90, I entered the 90 raw ordinal scores from each individual into the computer software (Fridell, 2009). This analysis generated nine measures of symptom structures and three global indexes, presented in linear T-points, and calculated in relation to the sex and age of the individual. In this thesis the Global Severity Index (GSI) is presented, as recommended in several studies as the best overall measure (Fridell, Cesarec, Johansson, & Malling Thorsen, 2002).

After preparation, data from pre-, post-, and follow-up assessments were compared using non-parametric statistics (Wilcoxon signed-rank test) for paired samples. Wilcoxon signed-rank test was used to test if any changes in means or medians were significant comparing before and after the intervention, and if the changes were stable, comparing before and at six months follow-up. Strictly speaking, non-parametric statistics do not test for differences in means, because they use scores turned into ranks, rather they test whether the ranks in one group are typically larger or smaller than the ranks in the other groups. However, the ranks do reflect differences in the means (Howitt & Cramer, 2008). We have chosen to present the results in means, because there are reference values for comparison in means. The significance level was set at $p < 0.05$. The statistical analyses were performed using the SPSS version 17.0 (SPSS, Inc., Chicago, IL).

Narrative analysis (III)

A narrative hermeneutic analysis was chosen to interpret the eventful narrative data to produce explanatory stories (Bruner, 1986; Polkinghorne, 1995). Eliciting a narrative is an open-ended process of peoples meaning making and underlying constructs. Narrative analysis differs from other qualitative methods by its focus on the story. Narrative analysis do not go line by line identifying small units, rather looking for plots and a *how*-focus. It is by creating stories that people experience and understand life (Ricoeur, 1984). The stories put events in relation to other events and thus placed in a temporal and spatial context (Polkinghorne, 1995).

The transcripts from interviews and field observations were subjected to a narrative-type inquiry (Polkinghorne, 1995), that is a narrative analysis of eventful data to produce explanatory stories. We also used Clandinin and Connelly's (2000) three dimensions for analysis of narrative inquiry spaces: temporality, sociality, and place.

Core story formation began with a careful review of all interview transcripts and field notes pertaining to a particular resident with a focus on descriptions of events. The next strategy of emplotment included

working with one or more plots of a story to disclose how it was constructed, conveying meaning-making. Emerging plots were formed to understand the story as a whole. Each individual narrative was analysed separately and reconstructed as a coherent story. Subsequently, four of the 16 participant narratives were chosen for closer analysis of the meaning-making and narrative structure. In parallel, connections between participant stories and possible theoretical frameworks were made. Several possible storylines were then analyzed until a negotiated outcome in line with the empirical data was accomplished. Different theories were brought into analysis to explore different understandings of the storylines. Moreover, when we found that the narratives often had the form of a 'success story', subsequent analysis was structured by that notion and further analysed out of the narrative structure. Another major framework for the analysis was how participants' narratives seemed to refer to both *occupational transformation*, regarding capacity to act and to perform desired tasks, and to the start of an *identity transformation* from a passive into an agentic identity (Polkinghorne, 1996). The resulting storylines are representative of all 16 narratives.

Qualitative content analysis (IV)

Qualitative content analysis (Graneheim & Lundman, 2004) was chosen to analyse the focus-group interviews in order to illuminate differences and similarities of the content and the underlying meanings of CCWs experiences.

The interviews were transcribed verbatim and read in their entirety several times to get a broad understanding of the content. All data corresponding to the aim of the study were divided into short textual units and subsequently coded, condensed and categorized out of the manifest as well as latent meaning. More specifically, the condensed codes were grouped by combining similar utterances under a descriptive concept. Further, the grouped utterances were divided into sub-categories by similarities and dissimilarities, which were then given a label that described their content. The analysis was continued by grouping the sub-categories and by labelling the higher-order categories in accordance with the empiric data. Next, we identified two types of disability ideologies and two types of perception of the organisational request, which the different types of reasoning among CCW were based upon.

Ethical considerations (I-IV)

Some ethical considerations were included in the drafting phase of the project while others have been visible during the ongoing project. I have continuously and consciously tried to identify ethical problems and handle them along the research process. Formal ethical approval was

obtained from the Regional ethical review board at the Medical faculty, Umeå University, Dnr 06-069 M.

As researchers, we actively participate in shaping the things we describe (Mishler, 1986). In intervention research we might also make influences socio-politically, economically, materially, and in aspects such as responsibility, power, structure, flows of information, human resources; of which some we may be aware of and others not (Hayden, 2007).

Intervention research in real life contexts are complex per se. There is a difference in implementing an intervention project and conduct research on the phases of the implementation, or on the impact of the intervention. The design that we have used in study II-IV regards the impact of the intervention and involves strong relationships between the project leader, researcher, individuals and the context. In study I, I had in the role of an OT a former relationship with the residents and housing facility. The residents were assured that whatever they said would not have any consequences for their relationship with the coaches or for their situation in the residence. However, trying to understand the residents' and CCWs' perspectives, and contributing to the contextualized knowledge of integrated rehabilitation in the home environment, has been the main argument for the scientific legitimacy of the ethical considerations.

Precautions were taken due to the fact that residents in these studies may have experiences from many years of dependency in the housing facility, low degree of self-determination, meta-cognitive impairments, and a subordinated position in the research. Participants were at repeated occasions carefully informed both verbally and in writing, about their rights and their possibilities to, at any time and without explanation, waive continued participation in the intervention as well as the research. The project included easy to read brochures about the intervention and missive letters about the research. More explicitly, they were informed about the intervention process itself, the purpose of each study, expected use of time, the methods used, voluntariness and the procedures for maintaining anonymity. For study II they were also, along the intervention process, informed about the type of evaluations they would go through and repeatedly informed about the voluntariness of these and how they could be used. Informed, explicit oral and written consent was obtained from all before they began their participation in the intervention. The consent was renewed orally, continuously for each new occasion of data collection. Also, it has been important to preserve confidentiality while the analysis has been conducted and presented as close to the empirical data as possible with direct quotes to add credibility. This has been handled by, for instance, changing certain recognizable facts.

The most pressing question has been whether it is ethical to run an intervention project for a limited time; an intervention that is new to the

participants as well as to the organisation, and not normally offered; an intervention that is designed to allow for meaningful daily occupations and which, according to participants' statements, have generated hope in parallel with the increased awareness of the ordinary gray everyday life in the housing facility, increased and more varied activities, agency and experience of transformative opportunities. One might ask what the changes may result in after a time, when most routines possibly have returned to normal again. However, in future work it is a responsibility for organisations rather than a research question to decide how to best support the residents continued development.

Time passed between the intervention project and publication of research results, which may have increased the possibility of establishing a distance while it may also have posed a risk of disappointment from praxis. The studied praxis usually set high hopes on changes as a result of the research, while in reality more effort from the organisational level is often required in order to really achieve considerable changes (Nilsen, 2010). However, research on essential issues of the target group, facilitates collaboration and the ability to produce materials that can contribute to new and increased knowledge. In that sense, this type of arrangement can be considered a 'joint venture'.

FINDINGS AND REFLECTIONS

Four studies were conducted to understand and evaluate the impact of the housing facility context and intervention using a home-, recovery-, and occupation-oriented focus. These studies illuminate different aspects of the impact and provide a broader understanding of how to support people with severe psychiatric disability to become active agents in their everyday life. The results begin with a summary of each study. In the subsequent sections, an exploration and evaluation of the *impact* regarding resident *changes* from each of the four studies are presented, followed by the *factors of importance* observed in the studies. The theorising of agency-structure is applied in relation to what it means to residents with experiences of psychoses and what it means to be imposed upon by a housing facility structure. A spreadsheet overview (Figure 8, p 69) shows the changes and factors of importance derived from each study and finally, an overarching analysis of the *feasibility* of the intervention, assessments, and collaboration is presented.

Summary of the studies I-IV

Study I: Home bittersweet home: the significance of home for occupational transformations

When exploring the significance of home for occupational transformations, resident experiences illuminate how residential conditions facilitate *trying* interactions which generate occupational transformations. It is developing to try interactions in diverse situations, but it is also trying, in the aspect of having to meet and handle demanding neighbours and new situations. For example, being forced to socialise is demanding, but developing. The findings highlight the benefit of engaging in the social framework of the housing, and aspects of socialisation, contradictions and conflicts, as dynamics for generating change.

Residential conditions appear to provide a complex structure that facilitates rehabilitative interactions in which 'progressive tensions' arise between opposing values; i.e., authentic versus artificial, desirable but frightening, and independence versus dependence, all of which are important in the process of change. The process of being supported in taking personal responsibility for occupations of daily living and increasingly social engagement is reflected in the residents' experiences.

Awareness of the meaning of home also emerges as central. When living in a supported housing facility, the meaning of home appears paradoxical; however, progressive tensions and trying interactions seem to have a rehabilitative impact. This study deals with a home perspective

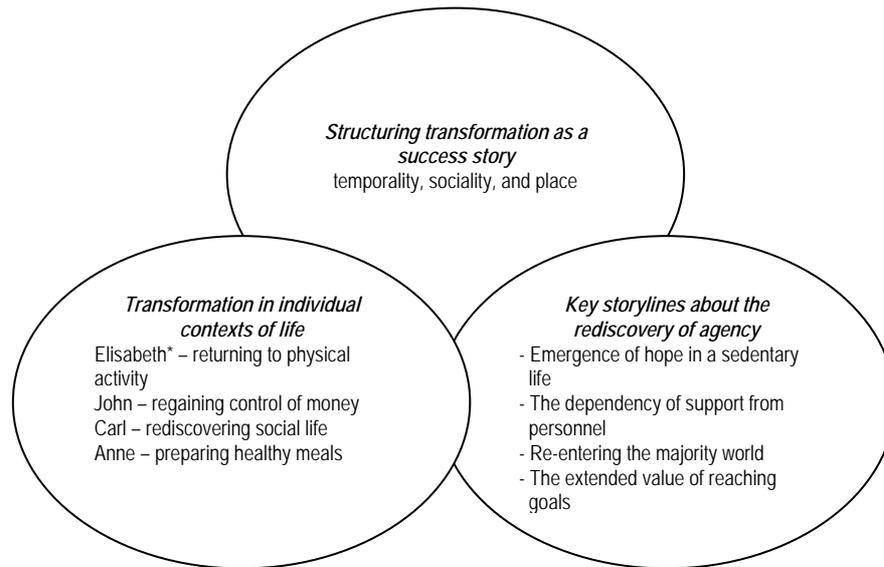
and provides potentially useful findings for professionals working in home- and community-based social psychiatry. The paper concludes with implications about ADL and suggests a new concept useful to occupational therapists; the concept of Social Activities of Daily Living (SADL), in addition to the traditionally used IADL (instrumental) and PADL (personal) concepts. SADLs are highlighted as dynamic spaces for occupational transformations within this context.

Study II: Dealing with real-life challenges: outcome of a home-based occupational therapy intervention for people with severe psychiatric disability

Study II examined the outcome of the ELR intervention for improving occupational and health-related factors among 17 adults with severe and long-term psychiatric disabilities living in supported or sheltered housing. The outcome components measured at baseline (pre-), discharge (post-), and six-month follow-up were goal attainment, occupational performance, activity level, satisfaction with daily occupations, effort and independence in activities of daily living, reduced symptoms of psychopathology, and self-perceived participation. However, the Assessment of participation had methodological concerns (see Methodological discussions), which is the reason that the outcome of this assessment is not included. Statistically significant improvements were found on a group level in most of the variables when comparing pre- and post measures, and good stability was found at the six-month follow-up when comparing pre and follow-up measures. These findings suggest that important improvements were accomplished when participating in the ELR intervention.

Study III: Stories of rediscovering agency: home-based occupational therapy for people with severe psychiatric disability

Study III is based on the same residents as in Study II; residents participating in the ELR intervention. Using a narrative analysis approach provided a deeper understanding of how residents with psychiatric disability make sense of their occupational transformations in the context of their everyday life and life history. The narrative analysis discloses stories of 'rediscovering agency' and addressing occupational and identity transformation. As is illustrated in Figure 4, the narrative analysis made it possible to analyse and present the narratives in three facets: the basis of their narrative structure and the construction of success; the four representative cases demonstrating how transformations occur within individual contexts of life; and four key storylines representing different aspects of 'rediscovering agency'.



* To preserve anonymity personal names are changed

Figure 4. Narrative analysis of 16 participant stories (III)

Study IV: Responsiveness or resistance: views of community care workers encountering a new rehabilitation model

The CCWs who were the contacts for residents participating in the ELR intervention were automatically involved in the rehabilitation and collaboration. Focus group interviews and qualitative content analysis was used to establish categories and patterns describing the CCWs views of the intervention. In analysing and interpreting the empirical data, disability ideologies and organisation theoretical frameworks were used to understand the different views among CCWs.

CCW statements show varying views regarding the residents' potential, rehabilitation, and their own role. Furthermore, the CCWs display varying approaches to the project and perceptions of the value of the intervention. Their reasoning seemed to depend upon which disability ideology and perception of organizational demands they related to. In turn, this has implications regarding their responsiveness or resistance to the intervention.

Changes in residents (I-IV)

Rediscovering agency – occupational and identity transformations (I-IV)

The narrative analysis in Study III called for a concept to capture the main occurrence in the analysis based on the resident stories. 'Rediscovering agency' was the negotiated conceptualisation we found to be the most comprehensive for this occurrence. Rediscovering agency goes beyond the attainment of specific goals or skills, but rather addresses occupational and identity transformation.

Furthermore, some notions of occupational transformations as described in Studies I, II, and IV could be denoted as 'rediscovering agency'. In study I, agentic rediscovery occurs in the forms of taking personal responsibility for occupations of daily living, taking charge of one's everyday life, motivation through success in occupations, and experiencing increasing social engagement in desired life situations. Furthermore, the core category of 'Trying interactions generates occupational transformations' in Study I, with the underlying categories and tensions, includes aspects that could be further understood using such a framework. These findings are closely related to agency in the understanding of the dialectic interaction between personal agency and the structure under which one is living, acting, responding, and participating. These findings also highlight the benefit of socialisation, contradictions, and conflicts as dynamics that generate occupational and identity transformations. The term 'rediscovering agency' denotes a process of regaining occupational competence and aspirations true to one's personality and as such, the changes described by CCWs (Study IV) as well as the measured changes in goal attainment and occupational factors (Study II) also could fall under the concept of rediscovering agency, pointing to increased capacity to act. In Study II, examples such as attaining person-driven goals, increased satisfaction with daily occupations, improved abilities, and decreased effort and increased independence in managing activities of daily living could be interpreted and understood as rediscovering agency in everyday occupations. In Study IV, increased social interaction, engagement, pride, goal attainments, improvements in specific daily occupations, and self-sustained initiatives were observed as increased self-directedness by the CCWs and as such closely linked to an increased sense of agency.

The concept of agency implies an active human being is one who has desires, makes plans, and carries out actions. Thus, agency contrasts the passive lifestyle as described by the residents prior to the intervention (III). In further elaborating and understanding the process of rediscovering agency, the sense of agency could be especially interesting to convolute in the light of the residents' experiences of psychoses. The

sense of agency plays a fundamental role in personal development including self-awareness, which forms the basis for meta-cognitive capacities (Dimaggio & Lysaker, 2010). The ability to recognise oneself as the agent of a behaviour is the way the self builds an image of an individual person in relation to the external world (Jeannerod, 2003). Jeannerod (2009) proposes that the process of self-recognition operates effortlessly at two levels: an automatic level for action identification and a conscious level for the sense of agency. According to Jeannerod, the sense of agency may explain positive symptoms of schizophrenia such as thought insertion and delusions of control. One core problem often faced by persons suffering from psychosis is a disturbance of the sense of agency; a loss of the ability to ascribe one's own thoughts, internal speech, apparent or unapparent actions to oneself. Non- or wrongly ascribed thoughts and actions then become ideas for delusional interpretation according to this explanation (Farrer et al., 2004).

Residents who have had experiences of psychoses may have the added vulnerability of a disrupted sense of agency due to meta-cognitive severities including integrating a sense of ownership with the sense of agency. Usually the sense of ownership and agency are tightly integrated (Gallagher, 2000). To exemplify, one resident in Study III discussed "the victory of phoning a friend again after 15 years". This example may enhance the understanding of the process of rediscovering and reflecting a sense of agency. This action was one milestone along a transformative process, whereby the resident challenged himself to gradually reach his person-driven goal of meeting a woman. While phoning, one has an enduring, embodied, and tacit sense that their own hand and voice are doing the action; an ownership in the action and agency because phoning is volitionally directed by the individual. Regarding the sense of agency for performing tasks and thoughts, further distinctions may be found in both first-order or immediate experience (Tsakiris, Schütz-Bosbach, & Gallagher, 2007), and higher-order or reflective consciousness (Stephens & Graham, 2000). Further drawing upon the previous example, while phoning, the resident had a sense of control and thus a sense of agency for the ongoing action of phoning; a first-order experience. Subsequently, if asked if he had just performed the action of phoning, he could correctly ascribe agency to himself; a higher-order, reflective, conscious attribution of agency. Furthermore, the narrating itself also provides a reflective opportunity (Mattingly, 1998).

To summarise, 'rediscovering agency' refers to the subjective awareness that one is initiating, executing, and controlling one's own volitional actions; acting as the author of one's actions and thoughts and daring to have aspirations in one's everyday life. Within the studies in this thesis, the process of rediscovery seems to be closely related to facing challenges, opening up to having goals, trying and experiencing progress in daily occupations, gradually increasing one's occupational competence, and thereby, reworking an agentic identity. Giddens (1984:281) considers all

human beings as knowledgeable agents who “know a great deal about conditions and consequences of what they do in their day-to-day lives”. However, their marginalised situation in society and the structural impact of sub-institutionalised housing facilities may deprive their agency and opportunities to fulfill their life goals and social participation. This will be further elaborated in a subsequent section, “The housing facility context”.

Changes among residents as experienced by CCWs (IV)

When reflecting on the impact of the intervention and changes seen in residents, the CCW presented dispersive views on a continuum from none to temporary, sustained, and further gains. Those who reported “none” stated that they had not had time to meet the resident due to other more demanding residents, but in their opinion “changes are rare and not to be expected”. CCWs who observed temporary gains gave concrete examples of changes they noticed such as “she is so happy and engaged about her baking plans in her own apartment, she even picked berries and watched over them as if they were made of gold”; however, these observations were followed up with statements that they did not think the changes would last for an extended period. CCWs who experienced sustained gains exemplified how the resident improved in and attained the targeted daily occupation in the goal area they had set for the rehabilitation. Further gains were exemplified by other aspects aside from goal attainment, such as positive side-effects in other activities including joy, pride, and self-directed initiatives. CCWs also gave examples of increased social interaction and engagement among residents in the communal, shared facilities. This outcome was the most surprising effect experienced by CCWs:

“Yes, they have shared personal experiences with each other around the dinner table. We have heard how they have talked about their difficulties and personal ambitions in a way that they have never done before, and it has come from the residents who participated in the project. You can tell that they have worked and reflected on these skills. Another event that surprised us was when (resident name) suggested to (another resident) that they would go and play mini-golf. Such an initiative has never come from him before. He is usually very introspective.”

Changes in goal attainment, occupational, and health related factors (II)

When evaluating the occupation- and health-related outcome of the ELR-intervention for residents, significant differences in tests scores indicate important progress. As is illustrated in Table 2 and Figure 5, statistically significant improvements were found on a group level in most of the variables when comparing pre and post measures, and good stability was found at the six-month follow-up when comparing pre and follow-up measures. These findings suggest that important changes were

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accomplished by participants in the ELR intervention. The 'after intervention' result of GAS can be compared to a mean value of 50 as the expected outcome if all participants would have reached exactly the expected level of goal attainment. The change in motor ability of 0.5 and process ability of 0.5 logits indicates both a statistically (minimum 0.3) and clinically (minimum 0.5) meaningful change (Fisher, 2006a). Regarding social interaction ability, we did not have reference values. The activity level has a maximum possible value of 63 and a satisfaction score of nine (Eklund, 2004). It is notable that the activity level increased after intervention, but was not stable at follow-up. The GSI-index, a linear measure of the global severity index of psychiatric symptoms, can be compared to the reference values for people with diagnoses of psychoses; 70.1 (Fridell et al., 2002).

Table 2. Changes between measurements (GAS, AMPS, BSI-II, SDO and SCL-90) made before (a) and after (b) the intervention and at a six-month follow-up (c), presented in means, standard deviations and p-values.

Outcome Variable	Before the intervention (a) mean (sd)	After the intervention (b) mean (sd)	Six months after the intervention (c) mean (sd)	p-value a-b (p-value a-c)
GAS (n=17*)	26.1 (0.0)	53.7 (10.4)	52.2 (7.8)	<0.001 (0.001)
AMPS (n=15)				
motor ability	1.6 (0.5)	2.1 (0.4)	2.1 (0.5)	0.002 (0.001)
process ability	0.6 (0.6)	1.1 (0.5)	1.1 (0.5)	0.002 (0.001)
BSI-II (n=7)				
social interaction ability	1.0 (1.0)	2.2 (0.9)	2.1 (0.8)	0.002 (0.001)
SDO (n=17*)				
activity level	5.0 (1.2)	6.0 (1.2)	4.9 (1.2)	0.002 (1.00)
satisfaction score	36.5 (9.4)	40.7 (9.2)	38.9 (9.5)	0.000 (0.014)
SCL-90 (n=17*)				
GSI-index	85.7 (20.8)	69.1 (15.1)	72.9 (18.1)	<0.001 (0.001)

* 17 at a and 16 at b and c

Abbreviations: GAS = Goal Attainment Scaling, AMPS = Assessment of Motor and Process Skills, BSI-II = Bedömning av Social Interaktion (Assessment of Social Interaction), SDO = Satisfaction with Daily Occupations, SCL-90 = Symptom Checklist, GSI = Global Severity Index

Regarding effort and independence in activities of daily living, significant changes and stability at the six-month follow-up were achieved in a majority of the actions that participants had problems with prior to the intervention (Figure 5). To summarise, clear improvements were measured in actions such as walking in the neighbourhood, shopping, cooking, calling for attention, taking part in conversation, phoning, taking out clothes as needed, and areas of personal hygiene such as cleaning and washing.

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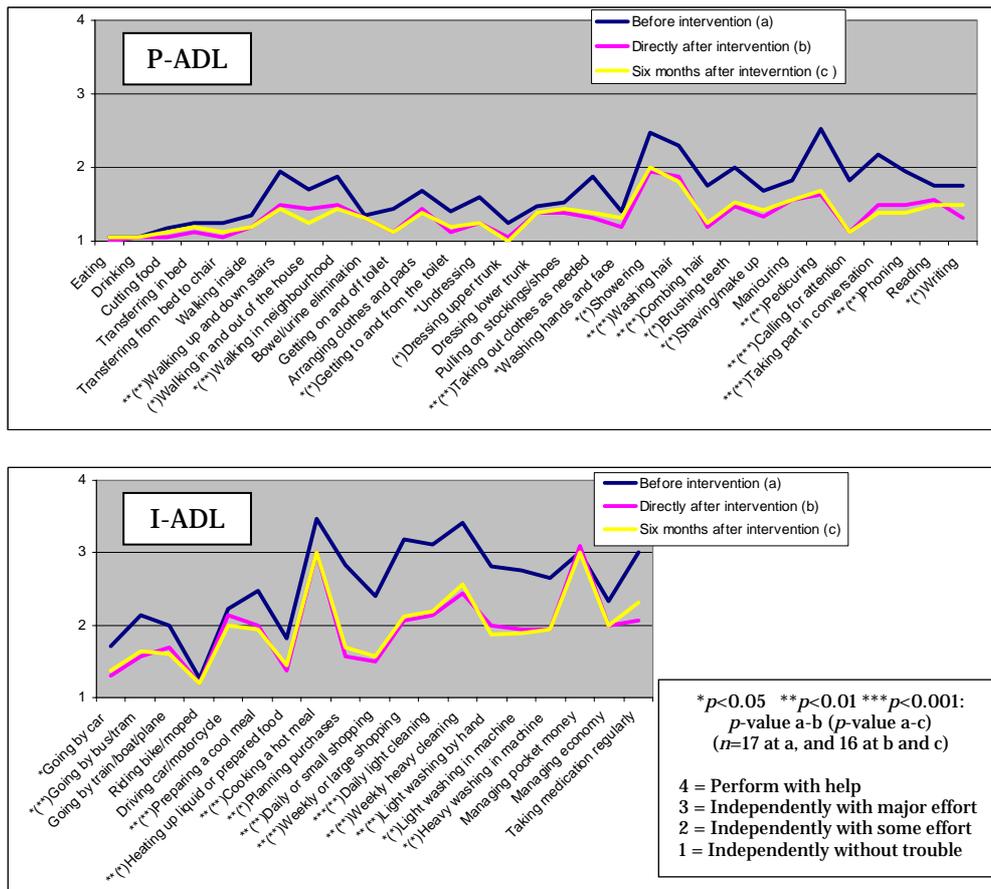


Figure 5. Changes between measurements (ADL-taxonomy: effort and independence) made before (a) and after (b) the intervention and at a six-month follow-up (c), presented in means and p-values

Factors of importance (I-IV)

In Study II, the outcomes rely on the intervention in accordance with the core principles of ELR. By using qualitative methods to identify categories, mechanisms, and other dimensions (I, III, IV), the inductive approach illuminates several additional factors of importance, or illustrates them from another angle. These factors add a deeper understanding of the dynamics involved in the interventions, transformations, collaborations, and context. In this section, the context will be further explored in a theoretical light of agency-structure, focusing on a possible understanding of the structure given a housing facility.

The housing facility context (I, III, IV)

Notably, the CCWs did not reflect upon the impact of the housing facility structure or power relations influencing resident agentic potentials or possibilities for change. On the contrary, residents reflected on different aspects of the housing facility and dependency in both Studies I and III. One interpretation is that it is more likely that a repressed person will notice and reflect on the oppressive structure in the housing facility, giving rise to reflection and awareness of one's changing situation. In Study I, residents exemplify both hampering and developing facets and several *tensions* become apparent by their stories (Figure 6). One example is the tension between authentic or artificial; residents expressed wishes of living in an ordinary home, but on the other hand required the support supplied by a housing facility. Another tension is managing with and without coaches; this refers to the need for support during the process of change towards managing oneself as well as the continuing need for support in other situations and daily occupations. This is in accordance with the findings in Study III. These tensions seem to facilitate awareness and self-reflection when residents are engaged in discussion about them.

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Core category	Category with progressive tensions	Sub-category
Trying interactions generate occupational transformations	Constructing frameworks <i>- authentic or artificial</i>	Spatial: home as place Organizational: Structuring living conditions
	Being forced to socialize <i>- difficult but meaningful</i>	Exposure to conflicts Having something in common Widening views on self and others
	Being promoted by coaches <i>- managing with and without</i>	Giving it a go Respectful attitude with explicit roles Being acknowledged
	Facing challenges <i>- none or over-ambitious</i>	The right levels of demand Pressures to face reality
	Change leads to further change <i>- desirable but frightening</i>	Key transformative insights Motivation through success in occupations Increasing social competence

Figure 6. Overview of core category, categories with progressive tensions, and sub-categories (I).

Residents in both Studies I and III also reflect on the *approach* of personnel. It is distinguished in the empiric material that the client-centred approach of the OT with a thorough goal-setting process, structure, and openness is a new experience from what the residents have experienced with the CCWs (III). Some residents are surprised by the OT approach, but find it beneficial. Resident comments regarding the CCWs was limited. According to resident excerpts, the housing inhibits the residents, and the structure within the housing hampers individually-directed activities outside the housing. Both CCWs and residents state that support from the CCWs is mainly provided inside the housing facility. Residents expressed a desire to be active outside of the housing facility to a greater extent. Furthermore, it was noticeable that residents were not accustomed to being asked about their own values or expressing what they wanted. From a CCW perspective, it was for example considered very strange that one resident was allowed to have a goal of meeting a woman. CCWs highlighted the positive response observed in the resident afterwards, but also voiced concerns about “what if he really meets a woman and then after two months she breaks up with him? What would happen to him then?”. CCWs seem to have a great influence on what type of goals are considered suitable for the residents. This is explicitly exemplified in the following excerpt: “The OT must understand that the resident has to learn how to clean up first, before he can go outside and do the fun things”. These excerpts show a contradictive ideology among some CCWs which conflicts with the intentions of the ELR-project.

Upon further examination into the social practices of a housing facility, a structural analysis can be used to present a possible understanding of how the power relations, norms, resources, organisation, wording and content of certain passages such as rights and rehabilitation develops

within the housing facility. Using an agency-structure frame (Giddens, 1984) can help explain how supports or lack of supports at a resident level, including structure and cultural norms, can promote or hamper agency.

Foucault (1980) and Giddens (1979) propose that structures can be simultaneously constraining and enabling; multi-faceted and dynamically interrelated. Applying these theories to the findings within this thesis, the structural forces from both the housing arrangements and the rehabilitative interventions may have conflicting impacts on the residents' daily lives. It appears that the intervention gives hope and facilitates agency and community integration in some aspects. Simultaneously, the housing facilities seem to sustain marginalisation, passivity, dependency, and stigma in other aspects. In Study I, residents point to the overarching tension between normalisation and acceptance; for instance, they reflected on the wish to be normal, being accepted for being I, while also needing certain structures. In Study III, the occupational and identity transformations gave rise to reflections about their grey and sedentary life in the sheltered housing facilities prior to the intervention. Since this rehabilitation is conducted in a housing facility context with *long-term perspectives* of psychiatric disability, this perspective also becomes important to agency and identity. The rehabilitation efforts seem to have brought hope and concrete changes to their life situation and they talk about them as successes, but they still have limited future life aspirations. Being offered rehabilitation itself brought hope for change in their life situation, as one resident stated: "someone believed in us after so many years". It is common for individuals with long-term psychiatric disability to have reduced future prospects (Kielhofner, 2008). In part, this may have to do with a disrupted sense of self and deprived agency, but also of not being offered rehabilitation, as reported in other studies (Rosenberg, 2009).

There seems to be differences in disability ideology when comparing the housing facility, as reflected by residents in Study I, and the housing facilities involved in the ELR-project, as reflected by the CCWs. Based on the focus group interviews with the CCWs in different housing facilities, it becomes apparent how different norms have been developed within certain housing facilities. The framing is weak in regards to the directives given about how to work. Also, support from the head of the housing facilities is weak according to CCWs. The head of housing is seldom personally situated in the CCW workplace, but work from an administration office. Thus, the CCWs perception of their mission and priorities seems to differ depending on cultural norms in certain houses. The mission and priorities are also unclear in the governing documents. There are frameworks outlining the overarching ambitions, but without specified content regarding work tasks.

As a consequence of weak frameworks, it is probable that it is instead the personnel who influences the norms of care and support. Our empiric

material points to two different norms in the different housing facilities. In some housing facilities the dominating norm is as stated: 'Our responsibility is to take care of the residents, secure calmness, provide them with a basic standard, and also help them develop, but another profession is unnecessary, we can handle this by ourselves'. This norm is protective towards the basic rights of residents and the CCWs tasks. They clarify that they do not want their work inspected and feel threatened by another profession entering the housing facility with another rehabilitation approach. Another type of norm in some housing facilities was: 'This is a group with complex problems and within the residents service we want to embrace a recovery-oriented approach to help them develop through a concrete work process. It is meaningful to help them develop and we have already seen progress'. This norm seems to emerge from reflective practitioners who perceive problems and are open to change and new input. Within each of these approaches, the structure or individuals are given their social bearing depending on what resources are regarded as valuable and desired in a certain context. In regards to experiences and individual factors, CCWs have developed individual preparations, reflective abilities, openness to influence, and capacity to act. In regards to structure, social practices develop different values and tensions to change depending on signals of what is important and the support and resources given, which influence the cultural norms among CCWs.

Notably, the intervention project is something new to the social practice of the housing facility. Hence, this project can be viewed as a sub-structure within the ordinary structure of the housing facility practice. Also, the OT professionals are temporary elements added to the housing facility, influencing the on-going practices. Accordingly, the structure of a housing facility will not facilitate the implementation of a recovery ideology, but rely on individual CCWs who are open to change due to their reflective abilities and responsiveness on an individual level rather than due to organisational request.

ELR with its core principles (II)

The intervention was based on the ELR model including eligibility of occupational therapy, recovery-focus, collaboration between resident, OT and CCW, partnering client-centredness, goal setting based on resident choices, occupation-based training in real life settings, individually set timeframes, and support during a maintenance phase after goal attainment. The results when measuring pre, post, and six-month follow-up indicate that significant changes were obtained in a majority of the pre-chosen variables. However, we cannot say from this study design, which had few study participants and no control-group, if it would have been as positive with another intervention. Also, we cannot conclude which principles of the intervention were more or less active ingredients. In this kind of real life intervention, there are most often a complex series

of interactions between the active ingredients (Hohmann & Shear, 2002). Furthermore, the factors of importance (process factors) and changes (outcome factors) sometimes overlap and thus the same variable can be both a process and outcome factor in a complex, dynamic intervention (Craig et al., 2008). However, we can assume that the identified core principles were beneficial, as the findings show positive tendencies and suggest a need for further studies of the ELR model.

Doing transformations (I, III)

In both Studies I and III, the residents point to experiences of transformation generating change; change leads to further changes. The act of doing, such as managing occupational performance, and learning by social activities in interaction with the environment, reproduces occupational and identity transformations. Within these studies, aspects of increased communal living, recovery, and trying interactions are enclosed by the constructs of 'occupational transformation', 'rediscovering agency', and 'progressive tensions'. Accordingly, participating in occupations means dynamic interaction with the environmental and personal components. In Study I, resident experiences illuminate active involvement in doing transformations when living in a supported housing facility. This is reflected in the categories of constructing frameworks, being forced to socialise, being promoted by coaches to give it a go, facing challenges, and change leading to further change. In Study III, the meaning of the transformation is reflected in a life context and life history perspective. The resident narratives highlight the importance of being supported in realising change and hope in one's life situation. The narrating itself also provides the opportunity for an inhibited resident to conquer success in one's own life (Mattingly, 1998), which may be regarded as an additional factor of importance in line with doing transformations. The narrating provides self-reflection and ascribes agency to oneself (Polkinghorne, 1996). Experiencing occupational and identity transformations allow residents to relate back to experiences in their former 'good' life when they had active identities prior to their psychiatric disabilities. The transformations also disclose awareness regarding the passive life in the housing facility. The key storylines of the residents transformations give implications for four active mechanisms: 1) being offered rehabilitation together with instances of progress create a sense of hope; 2) goal attainment is a mechanism affecting the broader end of achieving an agentic identity; 3) venturing out of the housing facility and entering the majority world have strong symbolical meanings in spatial, social, and mental notions, referring to conquering new places, establishing new relationships, and expanding the notion of one's limitations; and 4) listening attitudes of the OT, transparency about the intervention process, and attunement to the individual is important for the transformative process.

These findings from resident experiences of how doing creates change and that change leads to further changes of both identity and occupational character could be mirrored by the OT models of how person, environment, and occupation constantly interact (Kielhofner, 2008; Law, 2002; Townsend & Polatajko, 2007). Change in one component may result in change in the others. Also, change in one subsystem; for instance, a person's identity or competence, may result in change in other subsystems, as well as in the person as a whole. The constant comparative and the narrative analysis approaches provide critical thinking on factors of importance by voicing experiences of people with severe and long-term psychiatric disability, which can increase the knowledge and understanding of barriers and possibilities for doing transformations within this context.

Collaboration using a shared framework (IV)

When illuminating the CCWs experiences of collaborating with residents and occupational therapists using the ELR, two overarching perspectives seem to have had an important impact: the disability ideologies and the organisational aspects influencing the tensions to change. The ideologies and perceptions of organisational request represented among the CCWs (Figure 7), seemed to characterise the different outlooks influencing personnel involvement, resistance, or responsiveness to the intervention.

Findings

Disability ideologies

	Stabilisation	Recovery
Resident progress	No significant gains Temporary gains	Sustained gains Further gains
Rehabilitation	No potential Steady structure Stepwise progression	Resident motivation path
Own role	Upholding minimum living conditions Upholding psychiatric well-being	Encouraging change

Organisational aspects

	Resistance	Responsiveness
Commitment to change	Alienation	Embracing the intentions of the intervention Commitment costs
Collaboration	Conflict with ordinary duties Inter-professional discrepancies	Inter-professional appreciation Perceiving merits of a shared framework
Consequences of resident progress	Disrupted routines Increased bureaucracy	Positive dynamics
Resources	Waste of time	Meaningful use of time

Figure 7. Categories and sub-categories derived from the focus group interviews with CCWs (IV).

The intervention project informs the CCWs on a shared framework according to the recovery paradigm. However, as previously noted the weak support provided by the head of the housing facilities together with weak project organisation allow CCWs who are strong bearers of traditional values tend to maintain to these standards of care and also influence colleagues to do the same. These CCWs will act according to their routines and defend their perspectives when challenged by new perspectives. On the other hand, CCWs who are open to change will interact with the new perspectives and collaborate within the shared framework.

Within the intervention project, the framework is clear and the work process is specified in different steps along the intervention process guiding the OT. The process is less clear regarding how the CCW should work. Within the project, the OTs and CCWs are assigned to collaborate; however, how this should be done is not clear. According to the ELR model, the OTs are responsible for the intervention process and sharing information with the CCWs. The CCWs are responsible for sharing ideas

on resources and problems they have noticed in the daily occupations of residents and support the intervention process by helping the residents to integrate new skills into everyday habits. A similar process guide as the one used by the OTs, but designed for CCW rehabilitative actions, would probably add clarity to CCWs.

OTs and CCWs who share the recovery ideology seem to develop their common rehabilitation practice in a productive, inspired manner driven by the individual wishes of residents, rather than their own ideas. This rehabilitation ideology challenges the traditional stabilisation ideology. Interestingly, the clear and specified framework for this approach opens up for more allowing and resourceful practices, according to the CCWs. A shared model seems to provide a way of thinking and acting that helps facilitate hope for change and an agent-supported rehabilitation among the parties who commit to the model. One CCW stated: “The new input from the intervention project have created an awareness of the own role and inspired sharing experiences between each other to deepen the understanding of the residents’ complex situation.”

In conclusion, OTs and CCWs who do not share the same disability ideology and framework will have difficulties understanding each other, while those who share similar frameworks will develop their collaboration in a productive way. The weak organisational framework does not inform or guide CCWs in their practices, but rather relies on individual bearers of what is regarded valuable and desirable within the housing facility norms. Some CCWs tend to base their reflections on their own needs and perspectives while others tend to base their reflections first and foremost on the resident perspectives, the disability ideology, and the organisational request.

In conclusion, a spreadsheet summarising the changes and factors of importance derived from each study is presented in Figure 8.

Findings

Impact evaluation of context and intervention				
	Housing facility context	Everyday Life Rehabilitation (ELR)		
Study and main focus	I The significance of home for occupational transformations	II Outcome on occupation and health variables	III Meaning making of occupational transformations in a life context	IV Involvement and experiences of CCWs
Changes	<p>Personal experiences of:</p> <ul style="list-style-type: none"> - taking agentic responsibility for occupations of daily living - occupational transformations - increased motivation - easier to get things done - easier to get out of the apartment - increasingly social engagement and social competence 	<p>Significant changes in:</p> <ul style="list-style-type: none"> - goal attainment - motor ability - process ability - social interaction ability - satisfaction with daily occupations - psychiatric symptoms - effort and independence in a majority of activities of daily living, i.e. walking in neighbourhood, taking part in conversation, phoning, managing hygiene, shopping, cooking, cleaning 	<p>Rediscovering agency:</p> <ul style="list-style-type: none"> - returning to physical activity - regaining control of money - rediscovering social life - preparing healthy meals <p>Key storylines:</p> <ul style="list-style-type: none"> - emergence of hope in a sedentary life - the dependency of support from personnel - re-entering the majority world - the extended value of reaching goals 	<p>Changes among residents as experienced by CCWs:</p> <ul style="list-style-type: none"> - none: have not met the resident, not thought of it - temporary: happy and engaged in doing but experience say it will not last - sustained gains: attained specific goal area and continues to pursue this - further gains: positive side-effects in other occupations, joy, pride, self-directedness, increased social interaction
Factors of importance	<p>Trying interactions:</p> <ul style="list-style-type: none"> -constructing frameworks -being forced to socialize -being promoted -facing challenges -change leads to further changes (doing change) <p>Progressive tensions:</p> <p>i.e. authentic or artificial, difficult but meaningful, managing with or without, independent – dependent</p>	<p>ELR with its' core principles:</p> <ul style="list-style-type: none"> - collaboration between resident, CCW, and OT - recovery focus - occupation-based training in real-life settings - partnering client-centredness - goal-setting of resident wishes - individually set time-frame - support during maintenance phase 	<p>Mechanisms enhancing rediscovering agency:</p> <ul style="list-style-type: none"> - infusing hope - transparency in process and attunement to the individual - out-of-housing strategies - extended value of reaching goal / thorough goal setting process <p>Doing transformations Agent-supported rehabilitation</p>	<p>Disability ideology: stabilization/ recovery</p> <p>Organisational aspects: resistance/ responsiveness</p> <p>Shared framework:</p> <ul style="list-style-type: none"> - enhancing collaboration - help focusing the right things - using client-centredness - recovery-focus - promoting person-driven goals

Figure 8. Overview of findings in Studies I-IV – Impact evaluation of context and intervention.

Feasibility of the intervention, assessments, and collaboration (I-IV)

Feasibility, specifically analysing and evaluating the practicability and potential impact of an intervention and the methods used, aims at determining if the investment in time and other resources has or will generate a detectable and pleasing result (Craig et al., 2008). When considering an overall picture, the explorative approach used in this thesis provides measured and narrated changes as well as factors of importance. These findings can inform the design of the continued development of the intervention and future research suggesting added variables of interest to consider. The positive changes in residents, as observed by both the residents and CCWs, and measured by the included assessments suggests that the intervention is advantageous to residents. The outcome also indicates that the assessments are feasible and responsive to change. Furthermore, the OTs report clinical relevance in using the interventions and assessments.

Regarding the OT-led intervention, the attendance rate of residents was almost 100 percent indicating a worthwhile investment of time, energy, and focus from the resident perspective. The frequency varied from one to two meetings per week with a mean duration of 60 minutes (range 20 minutes – 3 hours). The length of intervention varied from 2-17 months (mean 6.4 months). The types of strategies used by the OTs were mainly restorative, but also acquisitional, compensatory, and psycho-educational. Using a home context as a meeting place for the rehabilitation was very appreciated by the residents. Residents expressed surprising and grateful statements regarding the OTs coming to their home.

Occupational therapy balances both medical and social perspectives, some more normative than others. In a feasibility consideration, one might ask if the norms and ends provided by the actual intervention and the assessments used are wanted in the context of persons with psychiatric disability living in sheltered or supported housing facilities. According to the findings in this thesis, the residents were very pleased overall. In the qualitative studies, there are progressive tensions. In the progressive tensions regarding normalisation or acceptance, residents reflect upon both wanting to be normal and wanting to be accepted by society. Following this line, rehabilitation should both continuously offer opportunities to develop abilities and roles as desired by the residents, but also focus on creating enabling and accepting environments in society. Another facet of balancing medical and social perspectives was illuminated by the CCWs commenting on the amount of time that the OT spent on documenting assessments, interventions, etcetera in the resident files. This issue reflects how the regulations demand certain

efforts within the medical paradigm that is unusual in the social paradigm.

In regards to assessments, the residents were content with the assessments overall. Two residents did not want to take part in the AMPS in reference to personal integrity. Others underscored how important the process was with clear evaluations and transparency of the process. This indicates that it is very important to be sensitive to resident preferences regarding the intervention, assessments, and the process steps. One assessment of this study, the Self-assessment of participation, was not feasible to use for this group because 40 percent of the residents did not complete this assessment. When analysing the completed assessments (60 percent), we found an inconsistency in the answers given, indicating a misunderstanding of the construction. A few residents also raised questions about the content and that it demanded too much concentration to complete. A possible explanation may be that the lay-out was too compact and unclear.

The CCW opinions were diverse. In general, they thought the intervention project created extra work in their already heavy workload, which they were not prepared for. Some CCWs highly valued the intervention and collaboration and perceived the intervention as feasible, successful, and important to both residents and their own work, while other CCWs thought it was disturbing and unnecessary to have outside professionals in the housing facility. Some CCWs reflected on the competition between CCW and OT responsibilities. The analyses point to the disability ideology and perception of organisational conditions represented among the CCWs as crucial for responsiveness or resistance towards the intervention. Further research is needed to study if these differences in ideology and approach are due to personal, intervention, collaborative, organisational, or implemental factors.

The OT reports from the study protocols describe the difficulties informing and sharing experiences regarding a specific resident, and in reaching out and collaborating with CCWs with a more traditional standard of care perspective. Furthermore, the OTs reported on their difficulties in making themselves understood and advocating for a recovery approach to the CCWs holding onto the more tradition stable ambition versus the CCWs open to new input and a recovery ideology. An additional structural limitation influencing collaboration is that there are few formalised meetings for rehabilitative issues and for collaboration between OTs and CCWs. OTs report that they sometimes have to pursue the CCW and suggest a separate room to be able to inform them about the process and progress of a resident, and to suggest forthcoming supportive strategies of the CCW.

In regards to the OTs impact, factors of social influence, communicating specific perspectives and knowledge, and being situated within the housing facility seemed to have a positive impact. Finally, factors of

collaboration in the rehabilitative and planning situations seem to depend upon authorised meetings regarding rehabilitative issues, a specified place and time, and shared perspectives.

The implementation process of this intervention project was not studied separately, but in the focus group interviews with CCWs, some aspects regarding implementation were discussed. CCW statements indicate that the implementation could have been better planned, anchored, and conducted. The implementation process should have been clearer from both the municipality organisation and the project organisation regarding CCW involvement and work process, and the intended content of the ELR model (Nilsen, 2010).

In conclusion, the ELR principles and methods seem to have helped facilitate the development of abilities, competencies, rediscovered agency, and environmental resources necessary for goals attainment among individuals with psychiatric disability. However, the implementation process could have been clearer.

GENERAL DISCUSSION

This thesis provides knowledge about the impact and feasibility of applying recovery- and occupation-oriented interventions to the 'real-life' of residents living in sheltered or supported housing. It reflects on the relevance of rehabilitation efforts in municipal psychiatry services to the realisation of disability rights and on ways, in which recovery- and occupation-oriented intervention's potential to influence change in the lives of people with severe psychiatric disabilities, may be enhanced. Previous research has problematised but offered few solutions concerning the risk with institutionalisation and a sedentary lifestyle when living in sheltered housing or being dependent on support in daily occupations. The overall aim of this thesis was to understand and evaluate the impact of recovery- and occupation-oriented interventions in a home context for people with severe psychiatric disability. Therefore, we explored the significance of home for occupational transformations (I) and offered an occupation-based intervention to study the outcome of (II), and used narrative analysis to contribute with a contextualised interpretation of the participants' narratives from these experiences (III), as well as the CCWs experiences (IV). The thesis also shed light on possible understandings of the agency-structure within the social practice of a housing facility.

Main findings

One central aspect in the material is that the rehabilitation is conducted in the context of home and housing facilities. Another central aspect is the client-centred praxis for enabling meaningfulness and agency in daily occupation of participants. A third central aspect is the long-term perspectives of the residents' lives as opposed to short-term rehabilitation. Thus, this general discussion will be structured according to the aspects of home and housing, understanding transformations, client-centredness, and long term perspectives. An overarching finding that became visible was how the agency of people with psychiatric disabilities can be supported by positive experiences of daily occupations and in social interactions with rehabilitative professionals (I, III), peers (I), and the 'majority-world outside' (III). The studies show different aspects of occupational, identity and health changes, with the overarching denotation 'rediscovering agency' in everyday occupations (I, II, III). It becomes evident that these residents benefit from support in their transformative processes (I, II, III, IV). Also notable is that even if residents make observable changes, a need for support may still remain over a longer time period, and emphasised: a support that is receptive to ongoing transformations and attentive to progressive tensions from the resident's perspective (I, III, IV). I argue that professionals, especially in home- and community-based rehabilitation, need to reflect on both

individual and structural perspectives, as well as abilities in and meaning of daily occupations, to help people with psychiatric disabilities lead a good life, reintegrated in society.

The following discussion sections will further examine some of the micro-contextual factors that promote residents' opportunities of meaningful daily occupations, or hinder them from fully participating in everyday decisions of their life context, and some of the mechanisms of the intervention.

The housing facility - home, housing, workplace, and arena for rehabilitation

The housing facility can be viewed from different perspectives: it constitutes both a home and housing for residents, a workplace for CCWs, and an arena of rehabilitation for residents, CCWs, and OTs.

The meaning and impact of home appear multifaceted when living in a supported housing facility (I). Furthermore, the content and nature of occupations and time spent at home may be such that the occupations, or lack of occupations that takes place, leads to negative consequences for the individual (I, III). Study I brought together both positive and negative aspects that were experienced by the residents in the process of individual occupational transformations. The findings are discussed in two head-lines; a home and a paradox perspective. It is important to consider resident wishes of sensing a home rather than a housing facility. In study I residents revealed how important the home was for the sense of having an own home, an enjoyable environment, pride in creating a personal style, safety, and to be responsible for taking care of it. They connected well-being and comfort to a cosy and tidy home. They also displayed home as a place to which they could invite visitors. These aspects echo the findings from other studies on the meaning of home (Padgett, 2007; Sjöström, 2008). However, residents are also very aware of the constructed framing for support (I, III). This paradox gives rise to progressive tensions, as described in the next paragraph. The analysis lays stress upon the complexity and variety of how occupational transformations come through. The studies also show how the personal transformations lead to reflection on the conditions of housing, both the needing aspects and the hindering aspects, such as passivity trends in the so-called "gray existence" (III).

Diverse types of communities impart unique social dilemmas and their understandings. Thus, it is relevant to ask what common tendencies and dilemmas we can discern in sheltered and supported housing facilities and how these may cause changes in peoples' everyday life and housing facility work. Such tendencies are for instance 'disturbing residents', 'calmness', 'order', 'routines', and 'basic needs', influencing both the residents and the work of CCWs (I, III, IV). In study III and IV, the

housing facilities is referred to as sameness, safety, personal limitations and inside constrains, both from the perspective of residents and CCWs. Some CCWs underscore the striving to help residents, while a few imply that if the residents are calm, they will have a calm workplace with stable routines (IV). Both these views are understandable when reflecting on the housing as a workplace for CCWs. Their working conditions indirectly influence the residents. These findings indicate a need for supporting CCWs to handle the complexities and different perspectives of their work tasks. In contrast, experiences of residents in study I also highlight many tensions and conflicts within the housing. However, they describe the conflicts as tiring and demanding but also developing regarding social skills and learning conflict solving (I). These tensions have had a rehabilitative impact on the residents, when used as progressive means. Residents have been forced to socialize, learnt how to handle social situations, and been engaged in discussions about the progressive tensions within a housing and along the own development and changing conditions (I).

Residents in study III emphasise the importance of entering the 'majority-world' outside the housing while residents in study I hover between managing with and without support, authentic or artificial home, etcetera. Rediscovered competences in rediscovered venues (III) seem to recall a self-determined will from former life, and an opening towards a wider world with possibilities rather than hindrances. This seem to highlight a paradox of needing and valuing some of the residential benefits, but simultaneously experiencing some hindering and stigmatizing facets, pointing towards entering the outside world as the ideal and also possible main track. This kind of paradox is also found in another study describing how residents prefer independent housing but still want the benefits of supervised housing (Tsai et al., 2010).

The home or housing facility has also proven feasible as an arena or starting point for rehabilitation as it provides real life challenges and meaningfulness to residents (I, III). Home and community contexts are also found to enhance occupational engagement and enable the path towards recovery (Bonney & Stickle, 2008; Borg & Davidson, 2008). Furthermore, rehabilitative use of meaningful occupations in real life situations seems to encourage an agentic identity (III). This is in contrast with current main-stream rehabilitative approaches, which often neglect considering an agentic and changing perspective of the residents in sheltered or supported housing, as indicated by some CCWs in Study IV and by comparable notions in other studies (Nelson, Sylvestre, Aubry, George, & Trainor, 2007; Wong, Filoromo, & Tennille, 2007). In addition, rehabilitative professionals are often used for measuring residents' need for services (Coster, 2008) rather than focusing on residents' subjective experiences and on enabling meaningful occupations in a home and community context (Doble & Santha, 2008). For instance, the assessment of limitations and needs are regularly

handled as a one-off and unconnected matter in psychiatric services, directing the amount of services needed, thus influencing the potential in providing support and rehabilitation personalised to their individual, collective and changing conditions in a changing context. Similar notions are compiled by Rosenberg (2009). The outreach and societal contexts are also often not considered or bypassed.

Yet another perspective that the thesis illuminates is the bureaucratic and practical issues and the traditional stabilisation ideologies in residential care, as hindrances in the development of residents (IV). The ideal would be a flexible system, constantly supporting changes and an agentic drive in residents, to enable active citizenship (UN, 2006) among people with severe psychiatric disabilities living in sheltered or supported housing. A stronger organisational emphasise is needed to integrate rehabilitative interventions into the context of CCWs daily work situation (IV).

The findings from study III underscore how residents appreciate the home-based interventions and the success of it, and yet how 'out-of-housing' is one of the main ends. This thesis highlights the significance of coming out of the housing, in supporting an agentic identity, and supporting a reintegration into the 'majority-world' (I, III). Outdoor occupations are also suggested to improve quality of life (Frances, 2006) and social inclusion (Heasman & Atwal, 2004) for people with psychiatric disability. The findings from study I suggest that the home context within a supported housing facility provides dynamic interactions that are significant for occupational transformations and entering the outside world, why this should be considered in home based rehabilitation. Therefore I propose the ELR as a framework for dynamic collaboration in sheltered and supported housing, focusing on recovery- and occupation-oriented modeling to promote agency by meaningful daily doing. Specifically, I propose 'agentic-supported' and 'out-of-housing' strategies to enhance the communal and societal outreach initiatives.

The importance of understanding the transformative processes of the residents

The findings in this thesis suggest that having opportunities to engage in meaningful occupations is having opportunities to, in some sense, take control of one's own life, making choices and simultaneously renegotiating one's identity (I, III). Inter- and intrapersonal influences are significant contributors to the course of events (Bandura, 1986). People who develop their competencies and beliefs in their efficacy, can generate a wider array of options that expand their freedom of action. They are also more successful in realising desired futures than those with less developed agentic resources (Bandura, 1986).

Various processes contribute to the quality and character of the agentic self, and numerous factors can influence the development of these

processes. Also, societies differ in their institutions of freedom and in the number and type of activities that are officially exempted from social control. The less social jurisdiction there is over certain activities, the greater is the contribution of personal influence to choice of action in those domains (Ryan & Deci, 2000). Rediscovering capacity of doing as described in the residents' stories, started as a limited attempt to reach a goal but gave unexpected gains along the non-linear path of rediscovering competence and reworking of an active identity (I, III). 'Entering the majority world' (III) seems to stem out of enacted outreach from a closed minority perspective towards an opening into the majority world, positioning oneself from an alienation standpoint.

The findings within this thesis (I, II, III, IV) also point to openness to differing values of occupation and to non-linear processes of change. The incipient motivation in the resident is important to encourage, no matter what occupational domain it concerns. At another level, the risk with norms and cultural values also need to be highlighted as wider political and cultural trends. When normative assessments and individualistic frames of references are blended with personalised and collective values, the rehabilitative approach sometimes raise ethical considerations. One risk raised is for instance when a resident obtains an agentic identity and social participation outside the housing, if she/he still is entitled the same amount of support in the housing. Another risk that needs to be raised with an agentic perspective is the risk of further individualising the responsibility of each person to take charge of one's own health, as seen in late modernity trends. Therefore it is important to view the dialectic of agency-structure together and not merely focus on the agency as an individualistic responsibility. I argue that in some cases it is inevitable to apply normative models and assessments, for example in a society where justified decisions and services are considered essential or as regards professionals requested to entail best treatment, but it is important to both research and practice raising awareness regarding these views. There is a risk with concepts, theories and models, including those applied in this thesis, being used as authoritative means. Therefore it is essential for practitioners to constantly reflect upon perspectives and concepts used, and especially in the support of an individual resident to share his/her views, perspectives and wishes.

Client-centred praxis needed for enabling meaningfulness and agency in daily occupation of residents

The findings indicate that choice, control, being heard, and involvement in decision-making were emphasised through the enactment of client-centredness (III). The role of the occupational therapist is important for the release and enablement of meaningful and engaging activities. Those who are accustomed to seeing themselves as less successful need to be

aware of how the negative image may hamper development and instead think progressive. The professionals' role and challenge is to get individuals to instead start thinking "maybe I can". The theory of transformative learning by Mezirow (1994) provides a client-centred perspective for understanding the process of changes in occupational performance. This theory is defined as a "social process of adopting, construing and appropriating a new or revised interpretation of the meaning of one's experience to use as a guide to action" (Mezirow, 1994: 222-223). In line with the findings on transformations (I, III), this theory describes how the process of transformation leads to new learning that supports personal change (Mezirow, 1994; Mezirow, 2000), that may explain the spiral of positive development experienced by the residents.

Using a client-centred approach in this context include awareness on many levels to really help people, oppressed by sub-institutional structures, to stay true to their inner self and develop their agentic identity. Awareness of the common problem with meta-cognition is one facet (Dimaggio & Lysaker, 2010); referred to as the ability to monitor the mental and emotional states of oneself and others, which addresses a number of important areas to understand and consider for service providers in relation to agency. These areas of common problem include for instance reflective functioning, engagement, attachment, and affect regulation. They all together influence the approach in the therapeutic relationship, assessments, goal-setting, and collaboration. An understanding of these problems is needed to be able to attune to them. Another facet that emerged in the data was the importance of transparency during the transformative process. The client-centred interaction used in the ELR, can be illustrated as agent dialogues throughout the rehabilitative interventions, supporting the resident developing an agentic identity in their daily occupations in a home and community context. Listening, encouraging change, providing hope and a transparent process, and supporting the agentic possibilities, seem crucial. A third facet identified in the studies (I, III), is providing opportunities to work with the agentic identity by doing. In this process hope, person driven goals, and occupation-oriented training have been substantial. Using a client-centred approach during a goal setting process and the training towards attaining the goal, include balancing both resident motivation and encouragement of change.

Late rehabilitation perspectives

The findings from the four studies (I, II, III, IV) suggest that late rehabilitation efforts can be very important for people who have lived with psychiatric disability for many years. The necessity of long-term perspectives are also emphasised by Malhi et al (2010). According to resident statements in Study III, it is unusual to be offered rehabilitation, particularly in the home and their own environment. The described lack of autonomy and motivation to manage to go out of the apartment, or to

get up off the couch (III), seems to be explained as due to both the psychiatric illness itself and due to lack of access to meaningful occupations associated with significant institutionalised constraints. Being in a marginalised existence requires adaptability. Because long term psychiatric disability risk becoming a stigmatizing state influencing the occupational identity (Anspach, 1979; Putnam, 2005), it is likely that individuals in need of care or living in housing facilities will go through a process of identity transformation as they are socialized into passivity (Goffman, 1961). Returning to a former, or developing a new, identity requires hope and belief in own agency (III). These findings challenge the still dominant cultural expectations that people with disabilities are passive, dependent, and incapable; expectations that are also in part internalised by our participants. The transformation from relatively passive individuals, who have accepted their care as a usual part of the disability experience, into assertive individuals, who challenge dominant views of disability and become active agents in daily life with positive outcome (I, II, III), call for a continued use and development of late rehabilitative interventions offered in sheltered and supported housing facilities.

The fact that rediscovering agency was made possible by actually raising own wishes of meaningful daily occupations, enabled by professional support in the rehabilitation and transparency of the process, suggest that this group should be offered this type of intervention on a regular or standing basis (I, III, IV).

From a service provider perspective, it should also be noted that this type of action brought insight and hope for a different life and opened the eyes of a more active and healthy life for the residents (III). Study II also shows significant changes in both occupational and health factors. The long history of psychiatric disability without notable change, according to the CCWs, points to the need for resident support in order to take advantage of operating occupation and health promotion. One might also relate these findings to a context of health-literacy (Jorm, 2000), indicating that this group needs professional and societal support in being offered and taking advantage of rehabilitation efforts towards personal agency and participation in life situations, which they are entitled under existing disability policies (UN, 2006). Supporting the health-literacy (Mårtensson & Hensing, 2011) could be used as a strategy to facilitate for individuals to think of their daily occupations as means to increased agency and participation in everyday life and society.

On a societal and policy-level, an occupational justice perspective (Nilsson & Townsend, 2010) could provide the arguments needed to change how institutions choose to take care of people in residential facilities. Occupational justice implies rights of occupational wellbeing such as meaningfulness, enrichment, variation, choices, and equal privileges for diverse participation in occupations (Nilsson & Townsend, 2010; Townsend & Wilcock, 2004). This is of certain importance in the

long-term perspective. Also, as occupational justice actors work to transform a frame from personal tragedy to occupational injustice and to shift attribution from the self to society, they identify features for decision makers. A frame serves as a representation of interpretation that enables individuals to perceive and label occurrences within their life space (Goffman, 1974), and frames function to organise experience and guide action (Snow, Rochford, Worden, & Benford, 1986).

Development of the ELR

One important point with the ELR is to be well-defined in principles and well-structured in process-steps but individually flexible regarding the content of each step, in a client-centred manner. The studies within this thesis give some implications for further development of the ELR intervention used, but there still remains a need for further research approaches to gain a deeper and wider understanding of the impact and dynamics involved in the ELR. Based on the results in studies reported here, I believe the ELR would gain from emphasising an agency- as well as an 'out-of-housing'-perspective within the model. The ELR should underscore residents' possibilities to reach outside the housing facilities by enabling residents to 'enter the majority world' again. Also, the potential of using progressive tensions need to be highlighted. This would help viewing the intent and approach from both OTs and CCWs to set even more personalised and encouraging ambitions alive. Furthermore, I believe the CCWs also would gain from having model-counseling/supervision on a regular basis, and not only the OTs as the ELR model prescribes. That would help CCWs to reflect on their own role, views on rehabilitation and how to go about supporting meaningful daily occupations among the residents. The ELR should also contain clearer implementation elements regarding the instructions to the organisation embracing ELR, about the importance of giving enough resources for the OTs and CCWs, to learn how to collaborate, and how to use the intervention (Fixsen et al., 2005).

Scientifically, we need to know more about the dynamic processes of implementation (Damschroder et al., 2009) as well as intervention and the views of the OTs. It would be important to know more about the mechanisms or active ingredients, duration and location of the interventions as well as the education and model-counseling for professionals. At a later phase, efficacy and effectiveness of the intervention could be evaluated. The findings from this thesis suggest a continued development, use, and research of the ELR.

Methodological considerations

Overall study design

We conducted one study focusing on the context to understand the significance of home for occupational transformations (I) and three studies (II, III, IV) focusing on the intervention using ELR. We used individual level as well as group level design, and included views from both residents and CCWs. In comparison with study II-IV, the intervention in study I did not differ much, even though the intervention was clarified and collaboration added by the model ELR in II-IV.

Recommendations for the design of early phase research of new interventions have been followed in this thesis (Johnston & Case-Smith, 2009; Johnston & Smith, 2010; Portney & Watkins, 2009). The mixed methods approach (Mortenson & Oliffe, 2009), combining qualitative and quantitative study designs, have added knowledge to the understanding of occupational and identity transformations in people with severe psychiatric disabilities and to the development of recovery- and occupation-oriented interventions.

Qualitative methods are preferred when unexplored areas are to be studied (Kvale & Brinkmann, 2009; Öhlander, 1999). We used three types of qualitative methods for the different research purposes. Grounded Theory (Strauss & Corbin, 1990) proved suitable for providing in-depth knowledge about social processes and interactions in the context of a supported housing. Especially, the constant comparative analysis helped exploring the conflicting perspectives within the housing context, which we captured in the categories as well as in the 'progressive tensions'. Narrative inquiry (Clandinin & Connelly, 2000; Polkinghorne, 1995) fruitfully captured personal dimensions of residents' meaning-making of the intervention and transformations that cannot be quantified. Furthermore, the narrative analysis enabled an exploration of the processes of enactment in interaction with culture and context by examining how it was told, and provided stories in a constructive format that give suggestions on how to understand the dynamic complexities. Qualitative content analysis (Graneheim & Lundman, 2004) provided a suitable method for illuminating similarities and differences in the content of CCWs reasoning and an understanding of the underlying disability ideologies and organisational aspects in their work.

The quantitative approach, using a one-group pre-post-follow-up test design provided knowledge about feasibility and tendencies of change among residents on a group level. One strength in the design was the six-month follow-up to enable comparison if the changes were stable over time. Although, the length of follow-up could have benefit from being longer.

One limitation in Studies II-IV is that we do not have the exact number or details of how the recruitment were carried out or how many potential numbers of recruits we could have had, because of the open procedure and because many people helped distributing information and that some participants also recruited neighbors. During the recruitment 17 residents volunteered, which may be regarded as a total sample. Out of these, 16 residents fulfilled the intervention. The recruitment of CCWs was depending on the residents. In study I, we wanted to study the social processes within one housing facility context, and thus we were limited by the number of residents who agreed to participate. Therefore we were unable to follow the strategy of saturation, as suggested within the GT method (Strauss & Corbin, 1990).

All together the studies shed light on different aspects from different perspectives, enabling an overall evaluation of the impact and feasibility of the intervention. The qualitative studies also add new categories, dimensions and mechanisms, which are important to consider in the forthcoming development of the ELR intervention.

Assessments and statistical analysis

Most assessments within OT have an individualistic and medical focus (Coster, 2008). There is a lack of instruments capturing processes, dynamic changes, and societal influences on disability. Thus, we chose best available instruments based on research criteria, and resident relevancy focusing on occupational and health factors. Although the focus of occupational therapy is not on remediating symptoms, we found it motivating to study some health-related aspects as well, which motivated the use of SCL-90. Interestingly, this measure was very responsive to change in this intervention context.

The GAS, AMPS, BSI-II, the satisfaction score of SDO, and the ADL-taxonomy also proved to be responsive to change in this study. According to Turner-Stokes et al (2009), the GAS, with individually prioritised goals used in rehabilitation, has been shown to be more responsive than conventional summary scores. Also, GAS added gains in participants with complex disability by structuring the goals very clearly (Turner-Stokes, Williams, & Johnson, 2009).

Some of the instruments we have used produce linear measures (interval scales) and could have been analysed using parametric statistics, but because other instruments within the same study have ordinal scales, a decision was made to use the same analyses for all scales, for pedagogical reasons. Non-parametric statistics were chosen because: they make fewer assumptions about the characteristics of the population from which the data came; they do not depend mathematically on standard distributions such as normal distribution and are less prone to the influence of outliers (even though we have analysed the distribution and know that we have

bell-shaped curves); they are less powerful than their parametric equivalents; and parametric statistics require interval scales (Howitt & Cramer, 2008).

Using non-parametric statistics, it would be most correct to present the outcome in median and inter-quartile-range values, but because most reference values in previous research are presented in mean values, the same was done here. The median and mean values in our analysis are similar.

When it comes to adjusting for the risk of mass significance, I argue that we have made two comparisons for each scale (comparing pre-post, and pre-follow up for each score). We could consider dividing by two, but we find it unnecessary for this kind of outcome study, where we only can talk about tendencies and feasibility.

Voices of persons with severe psychiatric disability

The voices of persons with severe psychiatric disabilities are often unheard or neglected. This might be due to described difficulties in reflective functioning or expression of reasoning - the so-called metacognition severity (Dimaggio & Lysaker, 2010) - which is common among people with psychotic-related disorders. It might also be due to the gap between political conventions and practical circumstances, leaving marginalised people in isolated isles of society instead of forwarding integrated citizens. The residents participating and sharing their voices in this project (I, II, III), had in general very rich expressions of reasoning and rich symbolic language. A few were problematic to understand, as they had mumbling expressions, most likely influenced by medication and their illness. Nevertheless, all personal narratives and statements were considered equally important in the analyses.

Some participants claim that they have not received any prior rehabilitation. We argue that the importance here is not whether they have received prior rehabilitation or not but how the experience of a rehabilitation occurrence is told, that is how it becomes meaningful. Claiming no prior rehabilitation indicate valuing the intervention as something important and unusual. Occasionally, the participants also use a quasi-professional language, which we regard not as a methodological problem but as an empirical observation which is interesting in itself. For instance they all talk a lot about the goal process. This use of language indicates that they have been receptive to the intervention process.

Voices of CCWs

The voices of CCWs are also often unheard or neglected. Illuminating CCWs reasoning in study IV turned out very important, highlighting the different views among CCWs and the weak organisational structure

guiding their work. Giving voice to CCWs also provide knowledge about their complex work, indirectly impacting on residents everyday life and opportunities.

Researcher approach

When meeting residents or CCWs, a conscious use of the following approaches has been helpful to me in the sometimes difficult interview or observation situations: clarity concerning research aims, procedures, time, and voluntariness; 'impression management' in trying to minimize myself in talk, outfit, space and positions; fairness in trying to be open, sensitive, curious, and tolerant during the interviews; criticality in trying not to accept things too easily; and usefulness in trying to think about what may be best for the participants regarding the expansive aspects of the home conditions, work conditions, and intervention.

Trustworthiness, reliability and validity

In the qualitative studies (I, III, IV), trustworthiness was considered for, by using several strategies (Graneheim & Lundman, 2004; Polkinghorne, 2007) such as recurrent interviews and field observations, the amount of data, thick descriptions, iterative processes of back and forth comparisons of data, triangulation, and direct quotations. The findings are the endings of negotiations between the authors of the papers, based on different steps of triangulation throughout the analysis. The second and third authors of the papers were not involved in the intervention or in contact with participants.

Quotes allow informants, both residents and CCWs, to speak for themselves and thereby providing an emic; that is insider, perspective on the impact of recovery- and occupation-oriented rehabilitation. For theory development to occur data also had to be considered from an etic; that is outsider or researcher perspective (Lincoln & Guba, 1985). As a researcher though, in some aspects I also represented an insider perspective, because I am a registered OT; because I had previous involvement in a supported housing facility; because I was the developer of ELR; and because I was the project leader. In all research situations, I presented myself as a researcher and the residents in study II-III only knew me as a researcher. Naturally this may have both facilitated and biased the quality of the findings (Kvale & Brinkmann, 2009), and thus must be considered when drawing conclusions of the studies. Nonetheless, in qualitative research, the research processes, including data collection and analysis, are viewed as co-constructions between the participants, the researcher, and the context (Mishler, 1986).

For the quantitative study (II), instruments were chosen on the basis of the variables we wanted to study, the validity, reliability and responsiveness to change. Most of the instruments had good validity and

reliability. The Self-assessment of participation (Granlund et al., 2005) was however newly developed and lacked research on validity and reliability. This instrument was later excluded because of low response rate and concerns about the construction, which became evident when looking at the responses of the residents. The GAS, AMPS, and BSI-II were administered by the OT as these instruments were also clinically relevant in the intervention process. The goals were however referred to me, as a second part aside the intervention, to set challenging levels for GAS. The SDO, SCL-90, and Assessment of participation, were administered by me as a researcher not associated with the clinical staff, to reduce inaccuracy of participant answers in relation to the therapist. It would have further strengthened the reliability of the outcome if the observer and analyst were blind to the timing of the evaluation (pre, post or follow-up).

Generalisation/transferability

The possibilities for generalising the findings from this thesis are limited, due to the study design rather aimed at providing a contextualised understanding to gradually being able to refine the intervention (Polit & Beck, 2010). However, the possible understanding presented in a thorough way and in a theoretical light, facilitates analytical and theoretical transferability although the participants and contexts are local (Lincoln & Guba, 1985)

When considering implementing a similar program, it is relevant to reflect on the context, the participant characteristics, and the intervention and take into account whether there are any particular differences.

These studies are conducted in Sweden, in the context of relatively small sheltered and supported housing facilities. The target group is persons with severe and long-term psychiatric disability, with the common denominator of having recurrent psychoses. The mean age of residents in study I was 31 years and in study II-III 48 years. They had experiences of psychiatric disabilities for a mean of 13 years in Study I and 22/23 years in Study II-III. The interventions offered, were recovery- and occupation-oriented interventions. In study II-IV, the interventions were further clarified by the ELR-model, including collaboration with CCWs and the manualised process steps of OTIPM (Fisher, 2009).

The disability ideologies used by the coaches in study I versus the CCWs in study II-IV were somewhat different. In study I the coaches provided both rehabilitation and support with the recovery ideology internalised in both the rehabilitation and daily support given. In study II-IV, the disability ideologies differed, according to the CCW statements, influencing the involvement in the ELR, the view of the residents, the rehabilitation, and the own role, as shown in study IV. These differences

need to be considered when drawing conclusions of the studies. The consequences of the organisational and structural weakness and poor condition in housing facilities as described in study III-IV are considerable. And yet, the organisations we have studied are well-financed by international standards.

Implications for practice

The UNCRPD (2006) provides new opportunities for people to lead good lives and to be accepted as full citizens. Yet, there is often a gap between the statement of rights and their effective implementation in practice. This thesis has, however, shown that occupational and identity transformations are possible to obtain by client-centred, recovery- and occupation-oriented interventions (I, II, III, IV).

Action is required to address the occupational justice and rehabilitation crisis for people living in housing facilities, and a clearer and more substantial focus on both qualitatively studied interventions and RCTs are needed. This thesis supports the use of the ELR intervention for these purposes, but requires further studies.

These intervention studies (I, II, III, IV) also point at improving municipality capacity to organise rehabilitative services integrated into supported and sheltered housing, provision of reflective situations for practitioners and users, as well as provision of information about and availability of rehabilitation strategies for users.

'Out-of-housing' strategies

Based on several excerpts from the studies within this thesis (I, III), the residents emphasise the value of coming out of the housing from different perspectives. This seems to be symbolised as entering the majority world, positioning oneself in the minority world with wishes and experiences of entering the majority world.

These studies seem to recommend using the home as a springboard in rehabilitation context, but simultaneously this entails a clash of views. In Study I the significance of home for occupational transformations show that the supported housing context facilitate trying interactions, which stand out as beneficial for changes, but on the other hand many residents emphasise the 'out-of-housing' wishes, indicating that this should be the ambition of rehabilitation. The meaning seem to differ when using a home or housing expression. The housing conditions seem to be related to certain stigmatising structures, that the residents want to get away from, while the home seem to relate to having, valuing, and taking care of an own home.

Referring to literature, the out-of-housing strategies are in line with the intentions of social participation in wanted life situations and in society (Yilmaz et al., 2008), whilst the home perspectives are in line with the personal and social meaning of home (Després, 1991; Sjöström, 2008). Yilmaz et al' (2008) study also points to the location of social participation. Occupations outside the home facilitated participation while occupations inside together with personnel hindered participation, according to the participants.

Agent-supported rehabilitation

This thesis points to the benefit of agent-supported rehabilitation for personalised daily life in sheltered or supported housing. The housing facility context is quite unique, influencing residents' participation in everyday life, when living in place and depending on home service delivery (I, III). However, it is important to reflect on the societal and professional values impacting the individual's sense of value, and the risk of normative values also in the ambition of supporting the personal agency.

The mechanisms in agent-supported rehabilitation as identified within this thesis, point to emergence of hope in sedentary life, the extended value of reaching goals, re-entering the majority world, and the dependency of support from personnel (III). The doing and the goal attainments provided opportunities to rediscover agency and rework the identity. Furthermore, during the rehabilitation process it seemed important to enable people to construct things from different viewpoints, offer listening, and to use a transparent process. The transformations narrated by the residents point to a non-linear process and that positive spin-off effect from rather small changes were common (I, III). An important issue seems to be the attunement to constantly changing conditions and preferences along the recovery and succeeding development of an agentic identity.

Using 'progressive tensions'

A third implication for practice, based on findings in several of the studies, is the beneficial use of progressive tensions. Rehabilitative ambitions have to come across different boundaries in the housing facilities (I, III, IV). The common understandings of certain aspects have to be constantly challenged. There is a risk that this will not happen with CCWs striving for consensus and calmness within the housing facilities. There is also a risk with residents settling down because of inhibiting conditions in the housing. Therefore reflective situations should be prioritised both by residents, CCWs and OTs (I, III, IV). Our studies show that practitioners should not be afraid of tensions (I), but instead being encouraged by the organisational structure to reflect on daily issues as well as overarching phenomena. Tensions may generate puzzlement as

well as awareness so as to trigger further development and further conversations, between residents as well as professionals (I). The 'progressive tensions' are constantly ongoing dynamic interactions, that professionals as well as residents need to be aware of and use as natural ingredients in the transformative processes (I).

Implications for future research

This thesis provides initial support for the use of ELR-interventions and proposes continued research. In the future, longer and larger RCT trials are needed to establish the effect and cost-effectiveness of the intervention. Before doing that, further qualitative aspects need to be explored. One aspect is the perspective of OTs providing the services. Also, it would be important to study the impact of adding model-counselling to the community care workers. Specifically, it would be interesting to understand more about how to support practitioners to develop 'shared risk-taking strategies' in line with a recovery-paradigm and agent-supported rehabilitation. A deeper understanding of using the progressive tensions would also be relevant. Yet, another interesting focus would be studying gender aspects of living or working in sheltered or supported housing. The empiric material contains some gender aspects implying that it must be further studied. Also, implementation aspects would be important to study on a deeper basis.

One mechanism that occurred in the findings from several studies was the positive aspects of social interaction with others. Thus, rehabilitation programs need to consider and support social interaction (Yilmaz, 2009). There is a continued need of more research examining how social aspects can be used to support social interaction in real life situations. If more data were available, it would be interesting to see if social activities of daily living (SADL) would be a separate parameter, as suggested by the findings from Study I.

Rigorous research is crucial to the development of a new rehabilitative model, to understand, evaluate, and evidence the work. Whilst evidence-based practice gives practitioners access to information about 'universal' best practices, it does not prioritise practitioner-generated knowledge or promote new research-based interventions relevant to their own practice circumstances as a Practitioner Based Research (PBR) does (Rolfe, 1998). Viewing the practitioner as central to the research process, and research as a necessary component of practice, the integration of practice and research could enrich the continuing development of the ELR by using a PBR approach prior to an RCT-study.

After the initiation of the intervention project that formed the base for this thesis, there have been a few municipalities in Sweden who have

implemented similar intervention projects inspired by the ELR. In the future research on ELR, it would be very useful to engage these municipalities in the development. To serve as a clear practice framework, outlining the process as well as understanding more about how to use the therapeutic mechanisms, it would be substantial developing the ELR as client-centred services for people with severe psychiatric disability on an evidence-based ground. A thorough case study (Yin, 2009) from both a resident, OT and CCW perspective could provide a critical discussion of the pros and cons of the particular mechanisms or approaches used.

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