Learning via participation — a user perspective on user involvement in mental health rehabilitation

Kirsten Petersena,b*, Tove Borgc,d, Lise Hounsgaarde and Claus Vinther Nielsenf,g,h

aThe Institute of Public Health, Faculty of Health Sciences, Aarhus University, Denmark; bThe School of Occupational Therapy, VIA University College, Risskov, Denmark; cHammel Neurocenter, Hammel, Denmark; dUniversity of Southern Denmark, Denmark; eResearch Unit of Nursing, Institute of Clinical Research, Faculty of Health Sciences, University of Southern Denmark, Denmark; fDepartment of Clinical Social Medicine, The Institute of Public Health, Aarhus University, Denmark; gClinical Social Medicine, Central Denmark Region, Denmark; hThe Department of Research and Development, MarselisborgCentret, Central Denmark Region, Denmark

(Received 22 June 2009; accepted 8 November 2010)

The aim of the study is to gain insight into the user’s perspective on user involvement in mental health rehabilitation. The study was designed as a field study lasting 15 months in two supported housing schemes. An ethnographic approach by James Spradley was employed, involving participant observation, informal conversations, and individual- and group-interview. A phenomenological-hermeneutic approach inspired by Paul Ricoeur’s theory on text interpretation was used, including theories of situated learning. The results of the study show that the users experienced their involvement in rehabilitation to be associated with learning processes in interaction with residents as well as professionals. Learning took place via legitimate peripheral participation, via support from and negotiations with professionals and support from peer residents. Both opportunities for and limitations for learning were experienced. The transferability of knowledge and skills to life in a community was questioned, as limited access to participation was experienced.

Keywords: user involvement; rehabilitation; mental health; situated learning; participation

Introduction

Rehabilitation is traditionally associated with the process of regaining lost functions and viewed solely as an individual process (Normann, Sandvik, and Thommesen 2004). Recent literature about client-centred practice and empowerment approaches in mental health rehabilitation anticipates the person’s active role (Roberts et al. 2006; Wilken and Hollander 2005). Taking control over one’s own life and gaining self-determination have been reported in several studies to be important factors in recovery from mental disability (Borg and Davidson 2008; Davidson, Harding, and Spaniol 2005; Onken et al. 2007; Piat et al. 2009). In the literature on rehabilitation of people with chronic conditions there seems to be a shift from a biomedical model.
to a more client-centred perspective where autonomy becomes the ultimate aim of rehabilitation (Cardol, De Jong, and Ward 2002).

A mental disability has a significant impact on individual functioning (King, Lloyd, and Meehan 2007) which often requires long-term support and treatment. Yet, studies have shown that people with severe mental disabilities experience recovery; a mental disability need not necessarily mean a course of progressive deterioration (Robinson et al. 2004; Strauss et al. 2008). Anthony and Liberman (1984) and Liberman and Anthony (1992) have stressed the importance of finding ways to improve the person’s capability and competence to function by bringing about changes in the environment. Limited knowledge exists on how the environment might enable participation during mental health rehabilitation. A study by Ryan and Leci (2000) shows that conditions conducive to autonomy facilitate the vital expression of human growth.

User involvement has been part of Danish social policy since 1998 and recently more attention has been placed on the concept of rehabilitation particularly in the supported housing schemes that offer training for people with mental disabilities. But it is unclear how user involvement is adapted in these housing schemes. International studies suggest that user involvement has a positive impact on rehabilitation and particularly on the development of social skills (Valentine et al. 2003), prevention of helplessness (Greenall 2006), and in reaching higher levels of self-competence (Busschback and Wiersma 2002). Despite the international awareness of user involvement in mental health services limited knowledge exists about the user’s perspective on user involvement in mental health rehabilitation (Petersen, Hounsgaard, and Nielsen 2008). The results presented in this article are part of a study aiming to explore how people with a mental disability experience user involvement in mental health rehabilitation.

Aim
The aim of the study is to gain insight into how the user’s understand and experience user involvement in mental health rehabilitation. This aim implied two research questions: (1) how does the user’s understand and experience user involvement, and (2) what characterises the processes where user involvement takes place?

Methods
Design
The study was designed as a field study carried out by the first author and the analysis was performed by all authors. In order to understand the user’s everyday life during rehabilitation, an ethnographic approach inspired by James Spradley (1979, 1980) was employed; involving participant observation, informal conversations, individual- and group interviews. By entering the user’s environment and taking part in everyday life over a period of 15 months, it became possible to gain a deeper understanding of the user’s perspective of user involvement. In order to gain insight into the user’s perspective the research design was open and explorative without former definitions of user involvement.
**Inclusion criteria**

Settings: supported housing schemes, offering long-term rehabilitation for more than two years, minimum five years’ experience with user involvement as a value and a goal for services.

Participants: people minimum 18 years old, male and female, minimum five years’ experience with mental disability, and at least three months’ stay in the housing schemes.

**Inclusion process**

Purposive sampling was used to recruit and select participants (Kvale and Brinkmann 2009). Variation in gender, age, and time in the housing schemes was attained. The inclusion of new participants stopped when no new information occurred (Wackerhausen 1996).

The role of the included participants was via informal conversations and interviews to assist the researcher in getting to know the setting and learn about the lives of the participants (Spradley 1979). At a house meeting, four residents volunteered to participate and later eight residents volunteered. During the field study all residents in the two supported housing schemes contributed with information about their experience of user involvement via informal conversations. Six participants, three from each setting, were invited to the group interview; four participated, as two participants did not turn up due to illness and hospitalization.

**Settings**

Two supported housing schemes in two different municipalities in Denmark were included as settings for the field study, where staff have had user involvement as a value and goal for their services for more than five years. The two supported housing schemes with the total of 24 apartments were located on the outskirts of a larger city. The housing schemes were part of the social psychiatric services, offering rehabilitation and training in order to better function and capability to move to a less supported living environment. On average the residents stay in the housing schemes between two to five years, though a few had been there for more. The residents share a range of facilities, such as kitchen, living room with television and computers, laundry, and garden facilities. This kind of housing is widely used in municipalities in Denmark, where people who need support and help to manage everyday life can stay for a longer period of time. The institutional setting is the result of past years of decentralization with fever beds in hospitals and development of local services. The main purpose for the stay in the housing schemes is, on one hand, to get the help and support needed for the person to be able to manage everyday life, and on the other to learn how to take care of oneself.

**Participants**

Twelve of 24 residents in the supported housing schemes were included in the interviews, age 22–45 years, three men and nine women, three months to three years stay at time of inclusion. Time since illness onset ranged from 6 to 12 years. The
diagnosis informed by the participants was: schizophrenia \((N = 8)\), manic-depressive disorder \((N = 3)\), obsessive compulsive disorder \((N = 1)\), and depression \((N = 4)\). Four of the participant reported having more than one diagnosis.

**Data collection**

**Field study**

Access to the field was made via the leaders of the supported housing schemes; information about the study was given and inclusion criteria were met. Participants for the interviews were recruited during time in the field and the relationship with participants was developed and maintained over a long period of time (Spradley 1979). After access to the field was ascertained the researcher’s field roles were actively developed (Wadel 1991). In the beginning the role was a ‘visitor’ and an ‘observer’. By the end of the study the role was a ‘student’ and ‘one of us’, as pointed out by participants. The main role was participant observer: at times participating in activities performed by residents, such as shopping, eating, drinking coffee, and watching television; and at other times observing social life and the activities taken place in the settings.

A logbook was made to record the emotional aspects of doing field work, which helped to maintain a critical view of the quality of data collected. The researcher was present between two to five hours a day, various times of the day, and on different week days. There were days with close contact and days away from the field. Distance from the field helped in not getting too involved in the life of the participants (Wadel 1991). Initial data was as Spradley (1980) recommends analyzed continually and used to form guidelines for observations and interviews.

**Participant observation and informal conversations**

The purpose of the participant observation was to locate social situations where user involvement took place and to get a deeper understanding of how the residents experienced user involvement in rehabilitation. Spradley’s (1980) conceptual framework on locating social situations during participant observation was employed. The field study was planned in different phases: firstly a descriptive phase, then a focused phase, and lastly a selective phase (Spradley 1980). In order to gain insight into the user’s perspective the data collected was directed towards the user's understanding of user involvement as openly as possible. Gradually the data collection became more focused as knowledge about the settings and the participants understanding of user involvement was obtained. At the end of the field study observations were selected and focused on issues and situations surrounding user involvement that the participants considered most important. Informal conversations were held with residents about their experience of user involvement in everyday life. Field notes were written within short time after being in the field. A strategy for writing field notes was followed, writing down what people said and did and the exact words and phrases used by participants (Emerson et al. 1995). To increase the trustworthiness of the data collected initial findings form participant observation and informal conversations were used in interviews.
Individual and group interviews

Individual and group interviews were also used to collect data during the field study. Included participants were interviewed five to seven times over a period of three to 15 months. Interviews were conducted until no new information was revealed and rich descriptions of the people’s experiences of user involvement in everyday life were obtained. Ethnographic questioning were used in interviews by asking descriptive, structural, and contrast questions (Spradley 1979) as to gain a deeper understanding of the persons perception of user involvement. Interview guidelines were developed focusing on how user involvement was experienced by participants. In this way, data from former interviews had an impact on the content of the questions asked. At the end of the field study a group interview was conducted with participants from both settings. The purpose of the group interview was to reach a comprehensive understanding of how the residents, in interaction with other users, discuss and understand the meaning of user involvement.

Data analysis and interpretation

A phenomenological-hermeneutic method of text analysis was used, inspired by the French philosopher Paul Ricoeur’s theory of interpretation. The analysis followed three analytic levels of interpretation: naive reading, structural analysis, and critical interpretation (Ricoeur 1976). Field notes collected by the first author from participant observation and informal conversations as well as the audio-taped individual- and group interviews were transformed from talk to text and used as the empirical data material. NVivo, a qualitative research software programme, was used to store and organize data during the analysis.

In the naive reading, the text was read to get an overall impression of ‘what had been said’ (Ricoeur 1976). ‘Units of meaning’ were located during the naive reading containing sentences with related content and meaning. The naive reading gave a firsthand understanding of the meaning of the text and gave an overview of how the users understood user involvement.

In the next level, the structural analysis ‘units of meaning’ were located and used to find out ‘what had been talked about’ and how the users experienced their involvement in rehabilitation. This level of the analysis helped formulate units of significance and corresponding themes. The results of the structural analysis revealed themes and related subthemes which helped to open up for the next level: the critical interpretation.

The critical interpretation which is ‘placed at the end of the hermeneutic arc’ helped create a comprehensive interpretation of the text (Ricoeur 1973). Literature on learning and research evidence from research studies were used in the critical interpretation. According to Ricoeur, the critical interpretation helps in lifting the interpretation from the individual experience to a more common level about ‘being in the world’ (Ricoeur 1973). As such the participant’s individual experiences were lifted to a common level about the role and meaning of user involvement in rehabilitation.

Frame of reference

In accordance with the design of the study, the frame of reference was developed during the analysis, where concepts about situated learning became discernible as a
relevant theoretical frame of reference. The learning theme was identified in the structural analysis and in Ricoeur’s understanding of text analysis this ‘opened up’ the text and showed the way for using concepts and theories about learning in the critical interpretation. Literature on learning by Lave and Wenger (1991) and Dreier (2002, 2008) were read to give a comprehensive understanding of what has been talked about in the interviews. By applying a situated learning perspective the analysis was not only focused on people’s experience of user involvement, but helped to understand how user involvement gave people access to participation in learning processes during rehabilitation.

Ethical considerations

Informed consent to carry out the field study was given by leaders of the two supported housing schemes and after access was given informed consent was obtained from residents on the basis of oral and written information. Confidentiality and anonymity were obtained according to The Ethical Principles of the World Medical Association Declaration of Helsinki. Included participants signed a written informed consent form and they could withdraw freely any time they wished without consequences for their stay. Personal information about the disability was voluntarily provided and solely informed by participants. The project was reported to The Danish Data Protection Agency, journal no. 2007-41-0688 and to The Local Ethics Committee on 5 May 2006.

Results

The study was aiming to gain insight into the user’s understanding and experience of user involvement and what characterises the processes where user involvement takes place. The results of the study showed that the users experienced user involvement as part of everyday life in the supported housing schemes. The users’ understanding of their involvement in rehabilitation was connected to learning processes taking place in interaction with professionals as well as other residents in a ‘training community’. First, the results from the naive reading are presented followed by the structural analysis where the learning theme is identified. At last, the critical interpretation is presented including a discussion of the findings. Words in quotation marks illustrate the expressions used by participants.

Naive reading

The naive reading gave the first understanding of how the users experienced user involvement in everyday life during rehabilitation. User involvement was experienced by the residents as being able to decide and to have influence. Two types of influence were identified; (1) ‘self-influence’ – being able to make decisions about own life and what to work on during their rehabilitation, and (2) ‘house-influence’ – being able to decide together with other residents on issues of common interests.

The purpose of the stay was expressed by the users: ‘to train’, ‘to develop’, and ‘to learn’. Training took place all day in what users called a ‘training community’ where the training was an integrated part of everyday life together with the other residents. As a participant expressed his training: ‘…we are off at night between 11pm and
7am – then we will not be disturbed’. Limitations to user involvement were described by the residents as: ‘...the professionals say now it is time, you can say what you mean now’. The professionals guided the residents in finding out where and when influence was possible: ‘...the professionals say it is now it is happening’.

User involvement was also an issue among residents in the supported housing schemes: ‘...we do involvement together and with each other and for each other’. Residents supported each other in getting their ideas heard by the professionals and in gaining influence especially at house meetings. They exchanged experience of what seemed to work best and how to persuade the professionals. They talked about timing; whom to talk to about what and to be careful not to mention their delusions if they, for example, wanted to go away on weekends. The professionals were considered as ‘the real authorities’; the ones who make the final decisions about the daily activities and rehabilitation in the housing schemes. The users did appreciate that the professionals listened to what they wanted but they knew they could not decide on their own.

Situations were described where it was particularly difficult to decide on their own: after being at psychiatric hospital or after periods of illness: ‘...they don’t really count on you when you have been ill, it takes time before you gain influence’. As one expressed: ‘...this is the worst thing about living such a place or to be at hospital, you are not independent any longer, you don’t have the same control...’

These situations were characterized by losing control and not being able to make own decisions, and when feeling better they felt that they were able to make decisions. But it took time before the professionals showed them the confidence and respect so they could obtain this.

 Structural analysis

During the structural analysis the learning theme and related subthemes contained issues on how the users experienced user involvement as part of learning processes while participating in rehabilitation were identified. As illustrated in Table 1, there was one overall theme: participation in rehabilitation unified the content of all the themes. The identified themes (column 3) originated from the units of meaning and units of significance located in the naive reading (columns 1 and 2).

 Learning via experience and support from professionals and the other residents

The users talked about learning about user involvement from experience, by learning what it is and how to gain influence. Several of the residents had obtained this experience from receiving help from other services or participating in voluntary work. Some users were newcomers and did not have the knowledge. One of the participants said: ‘I think many of the residents are not aware of the fact, that they can have influence – if they just say something’ [at house meetings]. They learned about user involvement by getting support from professionals and residents in the housing schemes. The professionals showed when and where user involvement takes place by saying: ‘now it is time, you can say what you think now’. They also learned user involvement from other residents, by helping each other: ‘...we do user involvement together, with each other and for each other’.
Learning via knowledge and communication

User involvement was experienced as being able to make decisions and to gain influence. Via knowledge about user involvement and how to communicate they could gain self-determination. According to the users it was useful to have knowledge about methods: ‘It is good to know the methods the staff use’. Knowing about the methods used could help them make good arguments for things they wanted to achieve. They talked about certain ways to communicate with professionals so they listened and got their ideas heard more. Being able to argue and communicate were usable skills when trying to gain self-determination, as one expressed: ‘...I know very well how I should talk so they listen and then I might gain some of what I want’. Talking to professionals was also a way to find out about what they wanted to achieve during their stay.

### Table 1. Excerpts from the structural analysis

| Units of meaning: ‘What is said’ | Units of significance: ‘What is being talked about’ | Themes |
|---------------------------------|-----------------------------------------------------|---------|
| ‘I have learned user involvement from being in other psychiatric places and through voluntary work’ | Learning from experience | – experience |
| ‘... the professionals say it is now it is happening’ | The professionals say when and where user involvement takes place | – support from professionals |
| ‘... we do user involvement together, with each other and for each other’ | – support from residents |
| ‘... you need to know what it is’ | How to learn user involvement: | Learning via: |
| ‘... it is good to know about the methods the staff use’ | – know what user | – knowledge |
| ...I know very well how I should talk so they listen and so I might get some of what I want’ | – know about methods | – communication |
| ‘... you need to be able to argue’ | – know how to talk | |
| ‘It has a lot to do with self-development I think, that there is someone who listens to you’ | – know what works know how to argue | |
| ‘... now I have learned that they listen to what you have to say’ | User involvement is self-development | Learning means: |
| ‘... we talk about what I need to train’... it takes time before you get influence’ | Learn that people listen to you | – self-development |
| ‘... before, I was very focused on doing the right thing in the eyes of other people instead of doing what I feel like’ | Talking with professionals about what to train | – being listened to |
| ‘... they ask about our opinion’ | Finding ways to get influence | Learning to: |
| | Finding out what they want to do and feel like. | – talk about what to train |
| | The professionals ask about your opinion | – gain influence |
| | | – be aware of own desires |
| | | – say your opinion |

**Learning via knowledge and communication**

Residents helps each other

Talking to professionals was also a way to find out about what they wanted to achieve during their stay.
Learning means self-development and being listened to

The users talked about what it meant to be able to make decisions on their own: ‘... it has a lot to do with self-development’. That the professionals listened and asked what they wanted to do had a positive impact. Being listened to by the professionals made the users feel respected: ‘... now I have learned that they listen to what you say’. According to the users it was not always possible to make their own decisions. When the users had experienced illness or had been at the psychiatric hospital, situations occurred with ‘no-user involvement’ and coercion.

Learning to talk about what to train, to gain influence, and to be aware of desires and opinions

The users talked with professionals about the content of rehabilitation. They learned to identify what to train and what goals to reach, and to be aware of own desires and opinions. The users found ways to gain influence but often it was a struggle: ‘... they don’t really count on you when you have been ill, it takes time before you get influence’. Some residents talked about moving, getting a job or taking an education. Talking about what goals and what to develop helped in being aware of own needs and opinions.

Critical interpretation and discussion

The identified themes from the structural analysis ‘opened up’ for the critical interpretation where themes identified in the structural analysis are interpreted and discussed in dialogue with concepts from the theoretical frame of reference, other theories, and research findings.

The results from the field study showed that user involvement was experienced by users as learning processes taking place in interaction with professionals and residents in a ‘training community’. The way the users understood their involvement in rehabilitation were comparable to the concept: participation in communities of practice (Lave and Wenger 1991). The study showed that learning user involvement became a way for users to learn to obtain self-determination via participation in communities of practice in the supported housing schemes. Being able to participate in communities of practice and take part in decisions in relation to everyday life and issues related to rehabilitation were viewed as very valuable.

Rehabilitation was situated in a context where residents and staff shared a variety of everyday activities as: preparing meals, doing housework, and leisure activities. During the day a few residents participated in supported employment or went to school outside the supported housing schemes. Most residents stayed in and took part in the activities inside the housing schemes. Each of these communities of practice requires mastery of particular knowledge and skills (Lave and Wenger 1991). By being involved in activities and participating in communities of practice in the housing schemes, the residents had access to learn a particular knowledge and skills required in this particular context. There seems to be limited access to take part in communities of practice ‘outside’ the housing schemes which could constrain ‘full participation’ in society. As knowledge and skills required in one context might not be transferable to others, means that access to more intensive participation in society
outside seems to be reduces. Peripheral participation can be an empowering position were growing involvement in the community can suggest an opening towards community membership (Lave and Wenger 1991). There seemed to be undeveloped areas for user’ involvement in the local community.

From the users’ perspective participation in communities of practice in the supported housing schemes was pivotal for gaining self-determination. Knowledge on how to gain self-determination seemed to be essential for getting in control of life. To gain influence had a great value for obtaining what they wanted. Borg and Karlsson (2009) emphasize that we need to critically assess the relation between knowledge and power as the users are not always accustomed to and comfortable with all aspects of user involvement. In the housing schemes the staff showed where and when user involvement should take place but they seemed to underestimate their own power to define user involvement. According to the users the staff had the power to define where user involvement should take place and they had the power to judge if they were capable to make own decisions.

The results showed that learning about user involvement and how to gain influence was not only viewed as an individual process or as ‘internalized learning’ by the users. Lave and Wenger (1991) point out that if we focus on internalization of learning we might overlook the value of the social context. The results show that learning was situated in a variety of social situations. Dreier (2002) headlines that people are participants in structures of social practice where they can reproduce, unfold, and change their lives by taking part in social practice. People come to be and know themselves through participation in contexts of action (Dreier 2002, 2008). Lave and Wenger (1991) adds that humans develop in social situations where learning is situated in certain forms of social co-participation and communities of practice involve a set of relations among persons, activity, and the world, over time in relation to and with other communities of practice (Lave and Wenger 1991). According to the users, learning took place in social situations primarily in the supported housing schemes and situated in certain forms of social co-participation with residents and staff but with limited participation in society. The study showed that residents were involved in social practices with professionals and residents for an extended period of time during rehabilitation which gave access to learning via participation.

Newcomers in the supported housing schemes were encouraged by professionals to move from peripheral participation to further engagement. Lave and Wenger (1991) emphasize that at first participation is legitimately peripheral and then gradually increases in engagement and complexity. While participating in communities of practice during rehabilitation, the users found ways to gain self-determination and control. They described it as a struggle when trying to move from legitimate peripheral participation to full participation where influence was possible. User involvement became a way for users to increase their engagement and learning of knowledge and skills via participation. Several users reported periods of illness when support and help from professionals were necessary. In these situations, they experienced limited access to participate and to make own decisions and then it was necessary to start all over and try to become full participants again.

The results showed that the users learned user involvement from interacting with the staff in the housing schemes. Yet the interaction with the staff contained certain contradictions; on one hand they could negotiate about things they wanted but on the other hand they knew that the staff had the power to make the final decisions.
The professionals showed when and where user involvement took place. As one of the users expressed it: ‘the staff say when there is user involvement’, and when it takes place, e.g. by saying ‘...now it is time’. The users understood this as ways in which the staff encouraged them to participate in making decisions, though they knew they were dependent on approval. Moving from legitimate peripheral participation to full participation could always be restricted by the staff.

User involvement was part of the information given to new residents as well as newly appointed staff. In this way the professionals gave newcomers access to participate. The findings from this study showed how users negotiated with the professionals and learned how to communicate: ‘...now they all begin to talk about how they think I am ready for it [to move out] ...and now I come and try to get influence on their attitude, views, and ideas which I finally have achieved’. This user negotiated and struggled to get the staff to believe that she was capable to move to her own apartment. Lave and Wenger (1991) emphasize that participation is based on situated negotiation and renegotiation of meaning in the world. Social interaction is a critical element in situated learning as the person gets involved in a practice that requires certain persuasion and behaviour (Lave and Wenger 1991). The study showed that certain behaviour was not legitimate when negotiating. The users felt they had to communicate in certain ways to get what they wanted.

The users learned user involvement by interacting with other residents; exchanging experience and helping each other. This kind of learning took place when participating in everyday activities in the supported housing schemes, and the ‘peer residents’ were described by users as resources for learning. By participating together with ‘peer residents’ the users learned the communication skills required to be able to communicate with the professionals of things they wanted. In this study the users informed new residents as well as staff; sometimes it was formally arranged that one of the ‘older residents’ made an introduction and at other times it happened via informal conversations between residents. This way knowledge was transferred from ‘old timers’ to ‘newcomers’ (Lave and Wenger 1991). Master–newcomer relationships are also one of the characteristics of apprenticeships (Lave and Wenger 1991).

A study on relationships and culture among patients in hospital showed that patients relate, help each other, and develop social relations (Album 1996). Knowledge about illness and daily life in the hospital was collected, created, and exchanged among patients (Album 1996). Knowledge seems to be enhanced on how to relate to staff and everyday life. The exchange of knowledge seems to take place in social contexts despite being in a hospital or staying in a supported housing scheme. This study showed that the users helped each other to get their ideas heard by acting as ‘peer helpers’ and resources of learning. Learning by replicating others was also used, but they had to be careful about imitating other residents as it was not accepted by staff. Similar results were found in a study investigating the kind of learning that takes place when wheelchair users interact in a rehabilitation context (Standal and Jespersen 2008). The study by Standal and Jespersen (2008) showed that the community of practice established by the participants represented a critical corrective to the instructions provided by professionals. The users helped each other to find solutions to common challenges by both giving and receiving help from each other. Peer users can be an overlooked resource for learning during rehabilitation.

The users experienced limitations in making their own decisions, especially while being ill. In these situations it was difficult to obtain self-determination as the professionals did not rely on or trusted their capability to make their own decisions.
When they experienced these limitations the users in this study found ways to convince the professionals. In a social context there is a range of possibilities of what may be done at a given time; social contexts offer different possibilities that may be restricted to a greater or lesser extent (Dreier 2008). As shown in this study the users experienced both possibilities to learn via participation and limitations. In social contexts power relations occur which can imply unequal scope for participation and there may be conflicts and enduring struggles (Dreier 2008). It can be a challenge especially to mental health rehabilitation when people do have periods during their rehabilitation when they can’t take control of own life.

Studies has shown that services do not always live up to the users’ expectations of being involved in planning and in having influence (Graham, Denoual, and Cairns 2005) and barriers to user involvement has been identified among professionals (Anthony and Crawford 2007; Goodwin and Happel 2006; Greenall 2006; Lester et al. 2006). In this study the users talked about the struggles which they had trying to convince the professionals about things they wanted. At times the relationship with professionals was viewed as unequal and the professionals were viewed as ‘the real authorities’ and no-user involvement was experienced. As soon as the users were able to make their own decisions they felt respected and relied upon and the relationship with the professionals was then described as more equal despite the power differences.

The results from this study seem to contradict with the intentions about partnership and corporation between user and professional in the literature (Hammel 2006; King, Lloyd, and Meehan 2007; Wilken and Hollander 2005; MarselisborgCentret 2004). Studies confirm that psychological stress is reduced and treatment outcome improved through the use of client-centred communication and involvement in decisions (Adams and Drake 2006). Self-determination is valuable in psychiatric rehabilitation; having the right to choose where to live, learn, socialize, and work (Schauer, Everett, and del Vecchio 2007), and autonomy is claimed to be the ultimate aim of rehabilitation (Cardol, De Jong, and Ward 2002). Being able to make decisions and gain self-determination is viewed by the users as having an influence on their personal development. Being listened to by the professionals, made the users feel like equal partners. The user’s involvement is crucial to the relevance and effectiveness of rehabilitation, but not only at the level of the professionals’ efforts to interest and motivate but by involving the person in every stage of the rehabilitation process (Borg 2002). As this study indicates, user involvement might have an impact on personal development during rehabilitation by giving the person access to gain self-determination and to take control of life.

The results of the study contained little information about how the competences gained could be transferred to other social contexts. Knowledge and skills could be valuable in supporting the success of rehabilitation as it can be crucial to the person’s capability to function in society afterwards. The fact is that if transferability is not obtained rehabilitation has to start all over if the person can’t manage life in another social context. During rehabilitation, residents lived in a ‘training community’ which gave them access to learning via participation, but they had limited access to participation in e.g. work and education. Participation was limited to services especially for people with mental disabilities. Supported employment in direct placement in community jobs has been successful in helping individuals with mental disabilities to secure competitive employment (Ahrens, Frey, and Senn Burke 1999). Supported Employment is better at supporting and keeping people in employment
than Prevocational Rehabilitation (Burns et al. 2007; Lehmann et al. 2002; Crowtler et al. 2001). There is a need to address participation and involvement in society as important aspects of mental health rehabilitation. The social psychiatric services in the municipalities should not be the end station for users (Bjerborg 2006). Research is needed on how people manage after participating in rehabilitation and we need to know more about how knowledge and skills are transferred into a life in the society.

As the study points out, access to relevant participation in and among multiple communities of practice during rehabilitation is important for the development of knowledge and skills. User involvement becomes particularly important as identity is also closely linked to learning. It is generally assumed that people are able to transfer insights and advice from therapy into everyday lives (Dreier 2008). Learning to become a full participant in life involves the construction of identities (Lave and Wenger 1991). Lave (2001) argues that social identity is negotiated, obtained, and changed in the conflict of everyday practices. In a study by Tanggaard (2006), learning was closely related to the development of identity and determined by access to personal relevant participation in and among multiple communities of practice. User involvement becomes not only a tool in learning but also a tool in developing social identity.

Limitations of the study

The qualitative field study design provided insight into the users’ experiences and everyday life in the context of rehabilitation. The results might not only to be of local interest but can be transferable to other subjects in similar situations (Kvale and Brinkmann 2009). The identified themes from the study are viewed to be of interest to similar rehabilitation contexts as it highlights some of the dilemmas that might occur during rehabilitation. The context for the data collection was settings that had worked with user involvement for several years, which limit the transferability. The sample size was satisfactory, though only a small number of participants were included. Selection of two different contexts for the field study, that differed geographically, produced a detailed data material. The results are based on a rich and comprehensive data material and a systematic data analysis, supported by studies which have an impact on external validity.

During the data collection, a total of 12 residents were included in the study. In addition, 24 residents contributed by giving information about their views on user involvement. This provided the study with a rich description of the user’s perspective on user involvement as seen from different people’s viewpoints. The ethnographic approach gave insight into the social context of rehabilitation and gave access to explore the user’s perspective. Spradley’s concepts about social situations (Spradley 1980) made it possible to identify issues of importance related to user involvement. Having an open and explorative approach produced rich data that could help open up new insights and understandings of the meaning of user involvement in rehabilitation. The limitation of the study is that it solely represents the user’s perspective interpreted from a situated learning frame of reference and does not include the professional’s viewpoint. This could have given a deeper understanding of some of the difficulties which the users experience in gaining influence.

The interpretation of the results was inspired by Ricoeur’s theory of interpretation (1976). This particular phenomenological-hermeneutic approach made it possible to create a comprehensive interpretation that helped in lifting the analysis...
from the subjective experience to a common level about learning via participation. When comparing the results of this study with other studies on user involvement in mental health, the contribution made in this study is a rich description of the user’s experience related to rehabilitation. The interpretation has solely been conducted from one learning perspective which could be too confined. Although learning in rehabilitation differs from learning to become, for example, a carpenter, it is both aiming at getting knowledge and skills to become participants in communities of practice. McReynolds (2002) emphasizes that rehabilitation professionals can play a valuable role for people with mental disabilities by integrating strategies to increase community integration (McReynolds 2002). This study opens up future discussions of how user involvement can be developed so that it can enable learning via participation during rehabilitation and involvement into society.

Conclusion

The users experienced user involvement as learning via participation in multiple communities of practice in the context of rehabilitation in the supported housing schemes. User involvement was experienced as a learning process taking place in interaction with professionals as well as residents in a ‘training community’. User involvement was experienced as a way to obtain self-determination and control via participation in decisions about everyday life and rehabilitation. Being able to have influence on everyday life and issues related to rehabilitation were valuable to the users, as it helped them move from peripheral participation to full participation and gave them access to learn independent living skills.

The context of rehabilitation provided both possibilities for and limitations of learning. When experiencing periods of illness, support and help from professionals was necessary and limited access to participate and to make decisions were experienced. The process after being ill was very distinctive of moving from peripheral participation towards full participation and described as a struggle. Limited possibilities to participate in making decisions were experienced and the professionals were considered as the real authorities. Interactions with the professionals were characterized by contradictions where both negotiations and conflicts occurred. ‘Peer residents’ acting as peer helpers were experienced as resources for learning. Limited access to participation in communities of practice ‘outside’ the supported housing schemes seems to restrict transferability of knowledge and skills.

Acknowledgements

The results are part of a PhD project at the Institute of Public Health, Faculty of Health Sciences at University of Aarhus, Denmark. The project is funded by the School of Occupational Therapy, VIA University College, Aarhus, Denmark in cooperation with the Department of Clinical Social Medicine, Centre of Public Health, Central Region Denmark. A grant was awarded by the Danish Association of Occupational Therapy.

References

Adams, J.R., and R.E. Drake. 2006. Shared decision-making and evidence-based practice. Community Mental Health Journal 42, no. 1: 87–105.
Ahrrens, C.S., J.L. Frey, and S.C. Senn Burke. 1999. An individualized job engagement approach for persons with severe mental illness. The Journal of Rehabilitation 65: 17–24.
Album, D. 1996. Nære fremmede. Patientkulturen i sykehus [Close strangers. The patient culture at hospitals]. Oslo: TANO A/S.

Anthony, W.A., and R.P. Liberman. 1984. The practice of psychiatric rehabilitation: Historical, conceptual and research base. Schizophrenia Bulletin 12: 542–59.

Anthony, P., and P. Crawford. 2007. Service user involvement in care planning: The mental health nurse’s perspective. Journal of Psychiatric and Mental Health Nursing 7: 425–34.

Bjerborg, M. 2006. Nye brugere – nye udfordringer [New users – new challenges]. Socialpsykiatri 3-2006.

Borg, M., and L. Davidson. 2008. The nature of recovery as lived in everyday mental health. Journal of Mental Health 17, no. 2: 129–40.

Borg, M., and B. Karlsson. 2009. User involvement in community mental health services – principles and practices. Journal of Psychiatric and Mental Health Nursing 16: 285–92.

Borg, T. 2002. Livsførelse i hverdagen under rehabilitering. Et socialpsykologisk studie [Conduct of life in everyday during rehabilitation]. PhD diss., Institut for Sociale Forhold og Organisation, Aalborg Universitet.

Burns, T., J. Catty, T. Becker, R.E. Drake, A. Fioritti, M. Knapp, C. Lauber, et al. 2007. The effectiveness of supported employment for people with severe mental illness: a randomized control trial. The Lancet 370, no. 9593: 1146–52.

Busschbach, J., and D. Wiersma. 2002. Does rehabilitation meet the needs of care and improve the quality of life of patients with schizophrenia or other chronic mental disorders? Community Mental Health Journal 38, no. 1: 61–70.

Cardol, M., B.A. De Jong, and D.D. Ward. 2002. On autonomy and participation in rehabilitation. Disability & Rehabilitation 25, no. 18: 970–4.

Crowtler, R., M. Marshall, G. Bond, and P. Huxley. 2001. Vocational rehabilitation for people with severe mental illness. Cochrane Database System Review 2001, no. 2: CD003080.

Davidson, L., C. Harding, and L. Spaniol. 2005. Recovery from serious mental illnesses: Research evidence and implications for practice, vol. 2. Boston, MA: Center for Psychiatric Rehabilitation, Sargent College of Health and Rehabilitation Sciences, Boston University.

Dreier, O. 2002. Psykosocial behandling. En teori om et praksisområde [Psychosocial treatment. A theory about a praxis area]. Virum, Denmark: Dansk Psykologisk Forlag.

Dreier, O. 2008. Psychotherapy in everyday life. Cambridge: Cambridge University Press.

Emerson, R., M. Fretz, I. Rachel, and L.L. Shaw. 1995. Writing ethnographic fieldnotes. Chicago: The University of Chicago Press.

Graham, J., I. Denoual, and D. Cairns. 2005. Happy with your care? Journal of Psychiatric Mental Health Nursing 12, no. 2: 173–8.

Greenall, P. 2006. The barriers to patient-driven treatment in mental health: Why patients may choose to follow their own path. International Journal of Health Care Quality Assurance 19(1): xi–xxv.

Goodwin, V., and B. Happel. 2006. In our own words: Consumers’ views on the reality of consumer participation in mental health care. Contemporary Nurse – A Journal for the Australian Nursing Profession 21: 4–13.

Hammel, K.W. 2006. Perspectives on disability and rehabilitation. Contesting assumptions; challenging practice. Philadelphia: Churchill Livingstone, Elsevier.

King, R., C. Lloyd, and T. Meehan. 2007. Handbook of psychosocial rehabilitation. Oxford: Blackwell Publishing.

Kvale, S., and S. Brinkmann. 2009. Interviews. Learning the craft of qualitative research interviewing. 2nd ed. SAGE Publications.

Lave, J. 2001. Getting to be British. In History in person. Enduring struggles, contentious practice, intimate identities, ed. D. Holland and J. Lave, 281–324. Oxford: School of American Research Press.

Lave, J., and E. Wenger. 1991. Situated learning: Legitimate peripheral participation. Cambridge: Cambridge University Press.

Lehmann, A.F., R. Goldberg, L.B. Dixon, S. McNary, L. Postrado, A. Hackman and K. McDonnell. 2002. Improving employment outcomes for people with severe mental illness. Archives of General Psychiatry 59: 165–72.

Lester, H., L. Tait, E. England, and J. Tritter. 2006. Patient involvement in primary care mental health: A focus group study. British Journal of General Practice 56: 527: 415–22.
Liberman, R.P., and W.A. Anthony. 1992. Principles and practice of psychiatric rehabilitation. In *Handbook of psychiatric rehabilitation*, ed. R.P. Liberman, 95–126. New York: Macmillan Publishing Company.

MarselisborgCentret. 2004. *Rehabilitering i Danmark: hvidbog om rehabiliteringsbegrebet* [Rehabilitation in Denmark: The white book on the concept of rehabilitation]. Århus: Marselisborg Centret.

McReynolds, C.J. 2002. Psychiatric rehabilitation. The need for a specialized approach. *The International Journal of Psychosocial Rehabilitation* 7: 61–9.

Normann, T., J.T. Sandvik, and H. Thommesen. 2004. *Om rehabilitering. Mot en helhetlig og fælles forståelse* [About rehabilitation. Towards a holistic approach to rehabilitation]. Oslo: Kommuneforlaget.

Onken, S.J., C.M. Craig, P. Ridgway, R.O. Ralph, and J.A. Cook. 2007. An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatric Rehabilitation Journal* 31, no. 1: 9–21.

Petersen, K., L. Houngaard, and C.V. Nielsen. 2008. User participation and involvement in mental health rehabilitation – a literature review. *International Journal of Therapy and Rehabilitation* 15, no. 7: 306–13.

Piat, M., J. Sabetti, A. Couture, J. Sylvestre, H. Provencher, J. Botshner, and D. Stayner. 2009. What does recovery mean to me? Perspectives of Canadian mental health consumers. *Psychiatric Rehabilitation Journal* 32, no. 3: 199–207.

Ricoeur, P. 1973. *Filosofiens kilder* [Philosophy sources]. Copenhagen: Vintens Forlag A/S.

Ricoeur, P. 1976. *Interpretation theory. Discourse and the surplus of meaning*. Fort Worth, Texas: The Texas Christian University Press.

Roberts, G., S. Davenport, F. Holloway, and T. Tatten. 2006. *Enabling recovery. The priciples and practice of rehabilitation psychiatry*. London: Gaskell.

Robinson, D.G., M.G. Woerne, M. McMeniman, A. Mendelowitz, and R.M. Bilder. 2004. Symptomatic and functional recovery from a first episode of schizophrenia or schizoaffective disorder. *American Journal of Psychiatry* 161: 473–9.

Ryan, R.M., and E.L. Leci. 2000. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55: 68–78.

Schauer, C., A. Everett, and P. del Vecchio. 2007. Promoting the value of practice of shared decision-making in mental health care. *Psychiatric Rehabilitation Journal* 31, no. 1: 54–61.

Spradley, J.P. 1979. *The ethnografic interview*. Wadsworth: Thomson Learning.

Spradley, J.P. 1980. *Participant observation*. Wadsworth: Thomson Learning.

Standal, Ø.F., and E. Jespersen. 2008. Peers as resources for learning: A situated learning approach to adapted physical activity in rehabilitation. *Adapted Physical Quarterly* 25: 208–27.

Strauss, G.P., M. Harrow, L.S. Grossman, and C. Rosen. 2008. Periods of recovery in deficit syndrome schizophrenia: A 20 year multi-follow-up longitudinal study. *Schizophrenia Bulletin*, 36, no. 4: 788–99.

Tanggaard, L. 2006. *Læring og identitet* [Learning and identity]. Aalborg, Denmark: Aalborg Universitetsforlag.

Valentine, G., B. Jamieson, A.M. Kettles, and M. Spence. 2003. Users’ involvement in their care. A follow-up study. *Journal of Psychosocial Nursing in Mental Health Services* 41, no. 4: 18–25.

Wadel, C. 1991 *Feltarbeid i egen kultur* [Field work in own culture]. Flekkefjord: Seek.

Wackerhausen, S. 1996. Kausalt-felt metoden – en metode til udvælgelse af personer i kvalitative undersøgelser [Kausalt-felt method – a method for including people in qualitative studies]. Institut for Filosofi, Aarhus Universitet, Artikel I: *Dansk Selskab for Sygeplejeforskning*, no. 2/1996.

Wilken, J.P., and D. Hollander. 2005. *Rehabilitation and recovery. A comprehensive approach*. Amsterdam: SWP Publishers.