

# Why do mental health consumers who receive rehabilitation services, are not using them? A Qualitative Investigation of Users' Perspectives in Israel

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**Abstract** A recovery-oriented approach to mental health involves creating person centered services and enhancing engagement in psychiatric rehabilitation. Israel's Rehabilitation in the Community of Persons with Mental Disabilities Law is a progressive initiative that shifted the locus of psychiatric care to community care supporting individualized rehabilitation and recovery-oriented processes. Yet over a quarter of applicants do not implement their assigned rehabilitation plans and services. This qualitative study investigated reasons and experiences related to lack of utilization from applicants' perspectives. Fifteen service users were interviewed face to face in semi-structured interviews analyzed using Grounded theory approach. Seven categories emerged: (1) Lack of knowledge and orientation; (2) Negative perceptions about rehabilitation services (3) Lack of active participation/shared decision-making; (4) Not feeling heard by the committee; (5) Lack of congruence between participants' goals and committee's final decisions; (6) Lack of escorting professionals' competencies; and (7) Family members' influence. The results are interpreted at the structural and human process levels. Suggestions are provided for augmenting systemic procedures and human interactions processes.

**Keywords** System change · User participation · Individually tailored rehabilitation services · Recovery oriented care

## Introduction

For more than two decades policy makers and service providers are increasingly adopting a person centered, recovery approach in mental health (Anthony 1993; Adams and Griender 2005; Borg et al. 2009; Davidson et al. 2009). Recovery orientation is progressively endorsed, and keeps posing complex and higher demands for increased quality of mental health practices, policy implementation and research (Moran and Nemeč 2013; Slade et al. 2012; USPRA 2009). A recovery oriented approach involves supporting individuals' personal recovery through self-determined processes involving choice and autonomy. Thus, the practice of rehabilitation is expected to allow the acquirement of valued social roles in one's natural environments (Davidson et al. 2009; Deegan 1996; Mancini 2008; New Freedom Commission, 2003; Slade et al. 2014; Tugenberg et al. 2008). Farkas et al. (2005) define this challenge as that of employing a value based practice—in particular the expression of values of personhood, hope, choice and partnerships within mental health and rehabilitation systems. Hunt and Stein (2012) further emphasize how recovery and rehabilitation involve fulfillment of social roles that are collectively valued and embedded in real life contexts (e.g., marriage, childbirth, leaving home as an adult, etc.).

How does this challenge translate in the field? A central aspect involves matching services to mental health consumers' personal goals in community integration processes (Bond et al. 2012; Pratt et al. 2007; Whitley and Siantz 2012) and infusing rehabilitation processes with choice, a

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whole person approach, addressing strengths and capacities (Farkas and Anthony 2010; Moran and Nemeč 2013). Yet often individuals do not have access to personally meaningful services and may be limited by a more traditional variety of existing services, especially in large and conventional services (Green et al. 2014). Indeed, this stands in contrast to an individualized approach and personal understanding required of service users' needs in their often lengthy and non-linear recovery journey. Personal goal matching and quality enhancement in the mental health system have drawn attention in different countries. Studies showed challenges such as diverse levels of concordance between consumers' perceived importance of their goals and the services they received (Lecomte et al. 2005), and lack of consensus and shared understanding between consumers and other stakeholders about outcome and service priorities (providers and family members) (e.g. Fischer et al. 2002). At the same time, efforts were made to improve the insertion and maintenance of innovative rehabilitation practices in day to day regimens (Yeaman et al. 2000) and to strengthen focus on personal goal setting and staff training on goal setting (Oades et al. 2009). In addition, service-engagement of individuals with serious mental illnesses in need of rehabilitation remains a challenge (Smith et al. 2013; O'Brien et al. 2009; Olfson et al. 2009). As a result individuals with serious mental illnesses may continue to suffer from repeated hospitalizations and homelessness (Kreyenbuhl et al. 2009; Fischer et al. 2008). In an extensive review of the literature, Kreyenbuhl, et al. (2009) found that up to one-third of individuals with serious mental illnesses disengage from the mental health system. Discontinuation is reported more salient when engaging in new services or transitioning to services between different phases in recovery (e.g. from an inpatient unit to a community-residential service) (Boyer et al. 2000; Olfson et al. 2009).

In parallel to developments in other countries, policy makers and stakeholders in Israel have been focused on developing psychiatric rehabilitation services in an effort to veer to a recovery person-centered approach. These involve systemic efforts to push for a comprehensive mental health reform that will shift the balance of care from psychiatric institutions to the community. This challenge was practically translated to a need to provide opportunities to achieve maximum degree of functional independence and quality of life for individuals with serious mental illnesses in their natural surroundings. A central part in this initiative is the establishment of the Rehabilitation in the Community of Persons with Mental Disabilities Law in 2000 (RMD 2001; Aviram 2010). The RMD law, is a governmental supported legislation attempted to provide an overall plan for support of adult rehabilitation and community integration. Prior to this law, services available for persons discharged from psychiatric hospitalization to the community were limited, with the

majority of individuals depending mostly on hospital services. The law allows persons with serious mental illnesses to receive individually tailored supports and services from a package of pre-determined services and resources. These are provided based on defined eligible criteria and a professional assessment of the individuals' needs. Service and resource provision are related to support in key life domains such as housing, employment, adult education, social and leisure time activities, assistance to family members, dental care and case management (RMD 2001; Shershevsky 2006; Aviram 2010; Aviram et al. 2007). Thus, this law represents a national commitment to improve the quality of life of persons with SMI and facilitate their recovery process (Aviram 2010). Individuals can be eligible for the law's benefits upon a psychiatrist recommendation and by formal acknowledgment of significant reduced work capacity and problems of social adaptation due to a mental disorder. To determine the best matching services, consumers—with the help of an accompanying professional (often a social worker or case manager)—fill in a comprehensive application form and then attend a Rehabilitation Committee (locally termed a "rehabilitation basket committee") which is composed of three mental health professionals. In the committee an individual's rehabilitation plan is finalized and accordingly services can be approved and granted. It is estimated that since the enactment of the law, more than 38,765 rehabilitation basket committees have convened and that 16,493 individuals receive services (Aviram 2010; Ministry of Health 2013). A recent study showed the law contributed in lengthening the stay in the community after discharge from hospitalization, and in shorter durations of next inpatient episodes for individuals who used the rehabilitation committee services compared to those who did not (Lerner et al. 2012), yet despite this positive outcome, additional efforts are needed to enable those engaged to avoid premature attrition and more fully exploit services (Hornik-Lurie et al. 2012). Even more disconcerting is the fact that only 15–20 % of the eligible population is estimated to apply to the rehabilitation committee (Aviram 2010; Struch et al. 2009; Aviram et al. 2012). Furthermore, amongst those who do apply to receive services, a substantial number (25–30 %) end up not using them (Ministry of Health 2009; Israel National Council 2009; Aviram et al. 2012).

Thus, similar to other countries, Israel's mental health system suffers from low rates of engagement as well as disengagement from services despite growing efforts of a mental health reform. The sub-population who disengages from services draws special interest because they involve individuals who have exercised their right for obtaining Rehabilitation Basket services, yet did not continue to acquire them. A few qualitative studies have been conducted about the reasons and subjective experiences of individuals with serious mental illness who disengage from rehabilitation and mental health services. In one study,

individuals receiving assertive community services were interviewed about their reasons for disengagement: participants' voiced different reasons such as having a wish to be independent, having poor therapeutic relationships, and experiencing a sense of autonomy loss related to having to take medications (Priebe et al. 2005). In another study, Smith et al. (2013) examined both the perspectives of consumers and perspective of practitioners about disengagement from services identifying marked discrepancies between consumer and practitioner views: individuals with serious mental illness pointed to services that were not relevant to their needs, inability to trust providers, and a belief that they were not ill. Yet, providers pointed to different reasons for disengagement including lack of insight, stigma, and language and cultural barriers. In another program for homeless people with serious mental illnesses, engagement with services was attributed to severity and substance abuse, perceived kindness, pleasant surroundings, access to one-on-one provider interactions, and fewer rules and restrictions. Three additional studies found that relationship factors were most important for engagement, highlighting the role of consistent relationships with providers who supported "normal" rather than "mentally ill" identities (Green et al. 2008) as well as the treatment alliance and sense of connectedness (Angell and Mahoney 2007). These studies provide some leads regarding the challenges related to disengagement, and together shed light on the complex, multilevel challenge that is at hand for those interested in mental health system transformation.

In the present study, we aimed to broaden understanding related to disengagement aspects by gaining in depth understanding of individuals who were assigned rehabilitation services under the RMD law, yet did not utilize them. We do so by purposely sampling individuals with serious mental illnesses who received yet did not carry out their approved rehabilitation plans and inquiring about the reasons for lack of implementation. In light of expected discrepancies in views of service users and practitioners (e.g. Smith et al. 2013), we were interested to gain insights from service users' experiences. The present study focus can serve an opportunity to learn about generic pitfalls relevant to endeavors in other countries engaged in the process of directing mental health care in a recovery orientation, veered to individualized plans and increasing choice in the context of a national mental health.

## Methods

### Study Design

This qualitative study employed a purposive sampling method which is recommended when the phenomenon of

investigation involves a sample population that exceeds a given criterion (Palinkas et al. 2013; Patton 1990). In the current study examining those who failed to engage in rehabilitation alleged services represented an outlier to the majority who succeed attaining and using services. By focusing on this sub-population of service users we expected to gain a deep understanding of lack of implementation from service users' points of view.

Participants were recruited by the second author who formerly worked as a chief rehabilitation coordinator in the northern part of Israel. Interviewees were traced using a computerized data base available from the rehabilitation committee between March 2011 and March 2012. Inclusion criteria included individuals with a psychiatric disability who had an approved rehabilitation plan that was not carried out in the 6 months to 1 year following approval. Exclusion criteria included individuals who were not fluent in Hebrew. Based on these criteria 23 potential interviewees were screened and contacted by phone calls. The researcher described the study rationale and procedure, as well as anonymity and confidentiality procedures. Participation was voluntary and 8 were not interested in the interview, resulting with 15 participants. Characteristics of those not willing to participate was similar to those who agreed to participate in terms of demographics and pattern of lack of use of the rehabilitation plan. The study was approved by the University and Ministry of Health ethics committees and informed consent forms were obtained.

### Study Sample

The sample included fifteen individuals ages 22–65 ( $M = 44$ ,  $SD = 13.8$ ). Most were men and single ( $n = 10$ , 67 %), three were married and two divorced. The majority were Israeli born ( $n = 12$ , 80 %) and three were born in Eastern Europe. Most had 10–12 years of schooling ( $n = 10$ , 67 %), three had less than 10 years, and two had more than 12 years of education.

Eight participants had been hospitalized between 1 and 3 times (53 %), 4 participants had never been hospitalized (27 %) and 3 were hospitalized more than three times (20 %). The participants were sampled from five out of the nine rehabilitation committees distributed in different geographical districts of Israel.

Most participants had received an approved plan once and did not implement it ( $n = 11$ , 73 %), the others had been invited to the rehabilitation committee twice and did not implement their plans in either time ( $n = 4$ , 27 %). Most have been referred through community mental health centers ( $n = 9$ , 60 %), three were referred from psychiatric wards (20 %), and another three either initiated the connection by themselves or with guidance of other health care services (20 %).

Based on the computerized data base, 34 rehabilitation services were approved for this study sample (more than one service approval can be granted per participant depending on their needs and goals). More than half approvals ( $n = 20$ , 58 %) involved sheltered services such as a sheltered workshop, occupational workshop, protected housing, etc. The rest included supported services such as supported employment, supported education, mentorship.

### Data Collection

An initial interview guide was drafted and tested in two pilot interviews with participants who were not included in the final study sample. These were conducted with a 62 year old man, divorced with 12 years of education and a 43 year old man, single man who had 14 years of education, who resided with his mother.

These pilot interviews served to test and further develop the interview guide as well as to allow practice of interviewing skills. The pilot interviews revealed a unique impact on interviewees given the interviewer's previous position in rehabilitation committees as a professional. One participant reacted by being brief and not detailing their experience with the rehabilitation committee because "well you already know—you are part of the system". For the other, the interviewer was identified as an authority figure eliciting their suspicion. In either case this made participants less comfortable and less elaborative in discussing experiences they had in the rehabilitation committee. As a result it was decided the researcher better interview individuals from distant geographical districts while emphasizing her current formal role as a researcher. Interviews lasted between an hour and an hour and a half. The interview began with an open-ended question: "Please tell me about your experience of rehabilitation in relation to the rehabilitation committee". Thus, participants could freely generate salient experiences and memories related to their processes related to the rehabilitation committee and plan. Next, the interviewer asked more specific questions allowing to attain a full and sequential description of the process, such as; "Can you detail what preceded your attendance to the rehabilitation basket committee?", "what made you decide to approach the committee?", "how was the experience during the meeting with the committee?", "what happened following the meeting with the committee?", and finally: "why do you think you did not execute the rehab plan that was assigned to you"?. The interviewer further probed when relevant contents to the research question emerged, for purposes of clarification and elaboration. To guard the trustworthiness of the analytic process the second author reflected on the process and interactions with interviewees with the fourth author after each interview as well as when processing the accumulating and

overall findings. This reflexive process enabled to guard against potential personal biases in data interpretation and resolve different interpretations of the data (Lincoln and Guba 1985; Patton 1990; Patton 1999). Interviews were audio-recorded and transcribed verbatim.

### Data Analysis

Interviews were analyzed using grounded theory approach. First, open coding of each interview was conducted in order to identify units of meaning for reasons and experiences that led participants' not to employ their rehabilitation plans (Glaser and Strauss 1967; Strauss and Corbin 1990, 1994). The second and last author looked for common themes and categories, comparing similarities and differences. In parallel, to better understand the specific context that led to non implementation, a summarizing protocol was constructed for each participant including general background information, application process and the main emerging themes for non implementation. Coding was an iterative, inductive, and reductive process that organized the data (Walker and Myrick 2006). This process resulted in further refinement of themes and the clustering of themes under larger conceptually shared categories. Overall, seven categories were identified that represented over 20 themes about different reasons and experiences that led participants' not to employ their rehabilitation plans and services. To ensure reliability and trustworthiness in the analytic process, special attention was given to the interpretation of the interview narratives by the second author. The researcher who formerly worked in rehabilitation committees was well acquainted with the rehabilitation committee procedures and service providing to mental health consumers. This former acquaintance lends itself to having insider knowledge which facilitates the ability to keep to the focus of the main goal of the study and be aware of relevant nuances that may come up in the interview (Patton 1990). At the same time, the former professional connection to the system and rehabilitation committees also risk potential biases in her interpretation of the interview narratives. To ensure reliability and trustworthiness, two additional coders coded the interviews alongside the second author. After every three interviews the second author met with the last author (and occasionally with the third one) to determine her interpretation of the interview narratives. In these meetings, special attention was given to the identification of reasons provided by participants versus interpretation of the investigator by use of reflexive processes (Denzin and Lincoln 2000). As a result the investigator learned to identify personal biases, such as a tendency to overinterpret some of the contents in the interview narratives. This raised her awareness and helped lend credibility to the study findings.

## Results

Seven categories related to lack of implementation of one's rehabilitation plan emerged: (1) Lack of knowledge and orientation; (2) Negative perceptions of the available rehabilitation services (3) Lack of participation and shared decision making process; (4) Not being heard by the committee; (5) Lack of congruence between the goals participants wanted and the committee's final decision; (6) Lack of competencies of the escorting professional, and (7) Family members' influence on utilizing services (Also see Table 1). Each category is depicted next with demonstrating quotes.

### (1) Lack of knowledge and orientation regarding RMD law's essence and process.

Most participants ( $n = 11$ ) were not aware or lacked sufficient understanding and knowledge about the rehabilitation committee; what is it about, in what context it convenes, what are the procedures and services offered by it? This was demonstrated early in interviews in the responses of some participants to the initial introduction of the topic of the interview (the rehabilitation basket) by the interviewer. For example, one participant replied: "what rehabilitation are you talking about?". Another woman said: "I didn't know what this committee is about—I thought it belongs to the [Government's, g.m.] Education Department, and that they do testing [to screen, g.m.] for schools". She remarks that only much later did she receive an explanation about the purpose of the committee and its relevance to her personal rehabilitation process. Another participant described their confusion and lack of information regarding the committee and the content of the law as follows:

I understood that rehabilitation basket is a broad thing, I didn't know from whom [i.e. what governmental office, g.m.] to ask for it. I thought maybe from Social security, maybe from the Ministry of Health, how do you get to them? How do you ask for it? I thought they could offer many additional things, other than sheltered workshops and supported residence.

A participant mentioned that she had no preparation or knowledge prior, during and after the committee:

I didn't know what the rehabilitation basket could involve, I was offered a working position of low wage—5 NIS per hour—and I refused it. Only recently I discovered through the nurse that I see at the Mental Health Clinic that they have another program that offers enrichment classes. During the committee I didn't know there were additional services

Others yet had only a vague idea about its purpose and procedural processes:

I was sent to all sorts of places, and interviewed, and I was asked questions, I answered and they told me, that's it you may go, and I didn't get any answers, did they approve or not, what did I get? I didn't know what they have to offer to me and what I can get, I ended up not getting any answers.

Another participant said: "I know I am going to receive some help but I don't know what I am going to receive, or at least I know it in a very limited way". The following participant mistakenly thought that the committee provides one with a particular rehabilitation program:

to tell the truth, I thought that rehabilitation basket is like day treatment. I missed the day to day encounter, like an open house for a half year or 8 months, with someone who helps, professional help. Someone who listens to you

This general lack of orientation sometimes continued or occurred after receiving rehabilitation and service plans: "and no one came and even told me that I received the basket of services. I feel disappointed of the system". Or: In the committee it was decided that I need a hostel [residential supported services, g.m.] and also sheltered work and then I received the approval notification home, but I actually didn't know what I was supposed to do with it?" Thus lack of knowledge, orientation or follow up about the context, the goal and the procedures related to the rehabilitation plan led participants not to utilize services.

### (2) Negative perceptions of the available rehabilitation services

Despite the lack in knowledge and orientation, a majority of participants ( $n = 11$ ) were assigned rehabilitation services and attempted to use them. However they quickly developed negative attitudes toward them, especially in cases of assigned sheltered services and workshops. For example one participant that was directed to a sheltered factory requiring simple manual labor, said: "it's a kind of work—a little bit like occupational therapy, it's not a job; neither the position nor is the money appealing". Another participant describes his negative views, after visiting three potential work facilities:

... I visited the place and what I saw was far from me, there wasn't even place for consideration, there was nothing there for me. I saw those that for them this was therapeutic, but it didn't fit me. I felt like I was back in the hospital, these places are for persons with serious disabilities—not like me.

**Table 1** Participants themes and descriptions of reasons and experiences for not using rehabilitation plans

Theme (n*)	Description
1. Lack of knowledge & orientation regarding RMD law (11)	Lack of understanding of one's rights and the committee's goal to support one's psychiatric rehabilitation Lack of knowledge about committee procedures and rehabilitation services
2. Negative perceptions about rehabilitation services (11)	Offered service perceived as deficient in terms of promoting personal goals Offered services are perceived as hosting people who are too sick and malfunctioning compared to the participant
3. Lack of participation and shared decision making (12)	Insufficiently involved as an active partner in the decision making process about one's rehabilitation plan and services Feeling a lack of concordance between the person's current motivational state for change and the committee members' motives to change to the person
4. Not feeling heard by the committee (11)	Disrespectful approach of committee members Experiencing the committee as not attuned to one's needs and goals
5. Lack of congruence between personal goals and the committee's final decision (15)	Final rehabilitation plan does not refer to participants' originally intended personal goals
6. Lack of competencies of the escorting professional (15)	Professional practitioner lacks knowledge about available services, the committee and rehabilitation processes Lack of acquaintance with the applicant which limits practitioners' ability to voice applicants' interests to members of the committee
7. Family members' influences on utilization (11)	Family members influence the person's decision to use/not use the rehabilitation plan Family members available resources delay use of assigned rehabilitation services

\* *n* number of service users who mentioned the themes

Others regarded the other consumers with which they would interact in social and residential services negatively. One person described his impressions after his first visit to a daily social club: "I was ashamed; do people also look at me as a sick person? Do I look like them?!. it demoralized me and stressed me... I ran away from there as soon as I could". Another participant refused an offer for a supported housing arrangement. He visited the facility where he met a friend of his. He describes his impressions:

my friend told me he is there in a room. You know, they have all kinds of hostels [supported group housing services, g.m.] over there, where you have roommates, and no one is satisfied about the shared life... my poor friend, he is a good person, it is not nice to laugh about him, I hope I won't get into a similar situation.

Thus, even if participants understood and partook of the services assigned to them, when they perceived the services as lower level and/or involving others who came across as very ill, they dismissed the service as unfit for them and ended up not engaging in it.

(3) Lack of participation and shared decision making process

Most participants ( $n = 12$ ) felt lack of partnership in the process of designing their rehabilitation plan. Often, they

claimed others were deciding for them, only sometimes considering their personal opinion. One participant said "they ask your opinion but in the end they decide". Another described: "and then she [the rehab commissioner, g.m.] decided it will be quick... you can't always ask for everything in these services". A male participant described a similar experience in the committee and this interpersonal process resonated with a sense of meaninglessness in his life:

... they agreed on exactly where I'd go and did not ask me what I wanted and if I wanted... what decisions, what decisions have I made in my life? I have no decisions in life, my life is pointless, its futile.

This person felt a continued sense of lack of partnership with a mentorship service he received through the rehabilitation basket committee: "I don't feel her as a partner, its like she is a stranger that comes and interrogates me, asking me questions to fill time, and I am not really a part of what happens."

Lacking a sense of participation could also sometimes derive from personal factors. For examples, some participants felt they were not ready during the committee to commit themselves to major life decisions. The following quote demonstrates ambivalence about change when a participant was in the committee: "right now I am interested (in pursuing rehabilitation), however at that time [of the committee, g.m.] it was like I do—I don't, I will—I

won't". Another participant for whom it was premature, felt tense and unable to engage in a dialogue while in the committee: "I was very anxious, I only wanted my social worker to speak instead of me".

Thus for both external and internal reasons, participants did not feel that they own the process, or have part in the decision making processes about their rehabilitation plan and services. In such a state, participants were unable to adhere to designated rehabilitation plans

#### (4) Not feeling heard by the committee

Partly related to the previous theme, however broader in its scope, many participants ( $n = 11$ ) complained about having an overall sense of not being heard by committee members, of being "transparent". One participant poignantly described her feeling in the process:

... I came out of there so upset, angry and frustrated. I sat at home and cried to my daughter... she [the Rehab commissioner, g.m.] asked me if I go to the cinema, to restaurants; I tell them—I don't have money—how will I go to the cinema or restaurants?!... and then 'how many times do you shower in a week?'—these kind of questions like I am retarded... I had high expectations from the committee... I want to work with dignity, to see people, talk to people... what is so hard to understand about that? And in the committee they didn't understand these things.

Another participant noted their discontent along similar lines as follows:

there was limited time, and I understood that I need to answer immediately and that's it, and they will be the ones to decide. There was no personal approach, answer quickly and that's it, there is a long cue of people... there was no [opportunity, g.m.] getting down to the details... it felt like a waste of time

Thus, participants felt the professionals at the committee were not listening, in some cases they were experienced as disrespectful, and not seeing them and their needs. This made participants feel frustrated and helpless about the whole process, leading to an attitude of disengagement.

#### (5) Lack of congruence between goals participants' mentioned and the committee's final decision

All participants in the study ( $n = 15$ ) noted a general lack of concordance between their desired goals and the committee's decision about the final rehabilitation plan. Sometimes this was explained by lack of specific services that fit the needs of participants. For example, one participant described:

I received someone to help me during the week, and I don't need that. I might need this help once every 2 weeks or a month. I get along on my own. I need other things that will support me further, like a nutrition group, or a baby sitter to give a free hour once in a while—these things are not in the rehab basket [list of services, g.m.], and the committee decided that I will receive a helper, which wasn't the service I needed at that time.

Another participant said he arrived at the committee and requested both financial and residential help by supporting his move out of his parents' home to independent living. However the committee only approved of a supported employment service:

in the committee I asked for financial and residential support... the relations at home were very tense and it was important for me to get out of the house to independent living. I think if I were out of this tension that characterized home, the decision to go for employment would have been more feasible because I wouldn't have to face my parents' criticism and expectations. As soon as residential support was not approved, that influenced the rest of the process, and nothing came out of it... you ask one thing, they approve something else or part of the plan and then the process is stuck.

Another participant came to the committee with a goal of getting back to the open market to work as a receptionist. She describes her discontent with the committee as follows:

what they decided was that I will go into some workshop or something with allowance payment... I don't want workshops, I want a job, I want to earn money. Look at my house, there is dampness all over the walls; my economic situation is very bad. My son works like a dog, helps me out, my daughter helps a little. But it's not enough, I need to work, I am all day closed between four walls, watching television, I am degenerating, water that don't run—simply become murky. I don't want to swallow pills all day—that is not the way or the solution; it is running away from reality.

Another participant felt the committee did not see his vital need for work in the open market and regarded him as lower functioning than he was:

I was expecting something else, I am a regular guy, my life is normal, indeed something happened to me [mental breakdown, g.m.]... and I am slowly rehabilitating myself, time had its effect, the support I received, faith in the path I walk, but I needed in

addition... some additional side support... if I could engage in normative work, or something more or less similar with other people who went through what I went and got back to healthy functioning life...

Finally, others referred to personal assistance appointed to them, that was not compatible with their needs and wants: “I didn’t want a person coming into my house, someone walking around in my house, it connotes that I can’t function, I knew I wouldn’t get along with that kind of arrangement”. Another participant was offered someone to pay home visits to him, said: “I find it hard to trust people, I didn’t want someone coming into my house, I don’t need that, I have friends where I work. Rather I wanted to hear about other work places”.

Sometimes, even if services were available, disagreements regarding the timing and ways to obtain them resulted in conflict between participants and committee professionals and led to elimination of provision of desired services. One participant described:

In the committee she [the rehab commissioner, g.m.] tells me go work in a clothing store saying ‘if you prove yourself for a month we will refer you to work’—What’s this non-sense!? What do I have to do with selling clothes? I need a course for refreshing my typing skills... I am in very bad economic state and after that [taking a typing course, g.m.] I will receive a certificate and be able to go look for work in human resource—I told her I am a secretary by profession... I am a wasted potential for work. ... I came out of the committee very angry.

Thus, when participants appointed rehabilitation plans did not fit personally aspired and immediate goals, they abandoned the plans and services assigned to them by the committee. This is especially evident in cases of economic hardships that exert immediate pressures for income and professional training.

#### (6) Lack of competencies of the escorting professional

Twelve participants felt the provider escorting them in the process lacked knowledge and/or professionalism in preparing, guiding and following up with them regarding the rehabilitation committee. One participant said: “she wasn’t a social worker with a lot of knowledge and experience, she didn’t know what was needed and what’s the right thing to do”. Another participant said: “she [the social worker, g.m.] tried to understand. She herself wasn’t sure what exactly is going to be there [re in the committee, g.m.], what exactly will they ask. So she came to provide support”.

The next 2 quotes further demonstrate such disappointment:

if you ask me, I see here a young woman, a social worker, that at the time it was very important for her to help, because I was in her ward, and she wanted the best for me, however, on the way she missed out on some things.

Until I brought the forms from home and explained them to her—I am disabled with such and such problems—you had to explain to her how to read the document, which is funny at some level... but I guess she wanted to learn this herself, and she didn’t really know me and what I need

Some participants noted a sense of lack of knowledge of the committee professionals: “I said I have a problem that I have a lot of free time and I don’t know what to do with that, I feel lonely... and the psychiatrist said there are social clubs, but the feeling was that he only had general knowledge and he is looking for a solution... maybe he didn’t know about what exists”.

A few were frustrated to have had graduate students escorting them who were lacking competences and continuation. One participant described: “last year I was appointed a student. What’s the idea about that?... it felt like she didn’t have enough knowledge and she can’t really help me”. Another referred to his escorting student as a “kid”: “he is a kid, a kid trying to gain expertise for his degree. This is not a professional. It is not someone I can count on; he is soon leaving, he has a couple of months or so”.

#### (7) Family members’ influence on utilizing services

Finally, participants also noted that family members, influenced their decisions to accept as well as to execute designated rehabilitation plans. This influence was mostly related to residential issues. A participant said:

The social worker offered all sorts of residential options in the mental health system... then my mom stopped her, saying I will not have my son there... he will live independently in his own apartment, like they do with old age persons, I noticed there are many living in such an arrangement at his age too.

Another participant mentioned her ambivalence after visiting a potential supported residential service and the influence of her dad over her decision to move out of her parental home into it:

I am not sure, he [the father, g.m.] may not approve, and it would be new to me, to leave home... even though the people over there were nice, but I think he wanted me to first try it out gradually, from home

In other instances families served as a substitute to using residential services “why move if I have all the comfort at



home?’. In other instances, participants goals were defined by positive or negative familial considerations; wanting to move away from a violent parent, or asking for a paid job in order to take off burden from the off-springs: “the children need money for themselves, they also have debts, and expenses. And future plans, they are saving for their future, I can’t take the money from them and tell them ‘buy me this, buy me that’... the fact that I am dependent on them pushed me to refuse working in a sheltered workshop, I knew it wouldn’t provide the solution, I want a job that pays, so I am not dependent on my children”.

Thus family members’ presence, support (or lack thereof) and connections had impact on lack of implementation of rehab plans, either by objection of family members or by providing an alternative which was perceived as better than that offered in the rehabilitation plan.

## Discussion

As mental health systems and services in different countries are investing efforts veering toward a person centered and recovery orientation (e.g. Adams and Grieder 2005; Borg et al. 2009; Malinovsky et al. 2013; Tondora et al. 2012), they continue to be challenged by the practical translation of recovery as a guiding vision for mental health care (Slade et al. 2014). In particular disengagement from services continues to be a central challenge to this endeavor. In Israel, despite a progressive approach by governmental initiatives to support a recovery oriented and person centered approach to rehabilitation and community integration as manifested through the RMD Law, over a quarter of applicants who receive services do not utilize them (Roe et al. 2010). The findings of this study point to possible reasons for lack of utilization of services from applicants’ perspectives that emerged from in depth interviews with fifteen mental health consumers who had disengaged from services. In general, they correspond with reports of experts who previously claimed that the RMD’s rehabilitation plans are not sufficiently in concordance with personalized goals (Aviram 2010; Drake et al. 2011; Goldman and Frank 2012; Roe et al. 2010). They also correspond with similar problems of disengagement as well as a need for acceptable, accessible and available services noted in other countries (e.g. Padgett et al. 2008; Smith, et al. 2013; Smith et al. 2014). The current study further sheds light on users’ perspectives and fleshes-out a series of reasons and experiences for disengagement that can be interpreted at two levels: a. participants’ experiences of system difficulties related to implementation of basic values of recovery/person centered care (i.e. the *structural level*), and b. human factors (interpersonal and intrapersonal) related to the process and procedures of

obtaining rehabilitation plans (i.e. the *human process level*). As such the findings have value to other international system transformation endeavors as they provide a multi-level approach to guide the understanding and strategies pertaining to *structural* and *human process* levels. *Structural* challenges pertain to system level issues such as workforce competencies and services (i.e. reflected in the categories of Lack of knowledge and orientation; Negative perceptions about rehabilitation services; Lack of congruence between participants’ goals and the committee’s final decisions; Lack of competencies of the escorting professional) and *human process* challenges pertain to intrapersonal and interpersonal factors (Lack of active participation and shared decision making; Not feeling heard by the committee; Family members’ influence on utilizing services). While structural and human challenges may not always be exclusive of each other, for the most part this distinction places each of the challenges expressed by the participants in its salient feature as was emphasized by the participants. We next interpret the finding according to this distinction and provide suggestions as to how these challenges might be addressed.

Structural level challenges involve issues that can impact the successful access to the Rehabilitation basket committee, including provider competency aspects: Lack of knowledge of rehabilitation services and procedures related to the committee, and having a sense that the escorting practitioners could not support them sufficiently in content and the related procedures- often rendered participants feeling unprepared for the task of planning a personal rehabilitation plan. Other mental health systems have similarly recognized the central role of information technology to continuity of care (Belling et al. 2011). Furthermore, participants’ sense of their providers’ lack of professional competencies is disconcerting. Development of provider competencies in mental health are essential in order to appropriately support the complex processes of rehabilitation (Belling et al. 2011; Hoge et al. 2005). Unfortunately the Israeli government is rather limited in its power to demand high-level professional personnel and the majority of mental health professionals and rehabilitation practitioners receive traditional mental health trainings (Sher-shovsky 2006; Aviram 2010; Aviram et al. 2012). Similar challenges can be found in other mental health systems, where staff is under trained and/or often over worked and burnt-out which negatively impacts the quality of services (Zayas et al. 2013). Yet, some of these challenges can still be addressed by creating a structured orientation and actively involving applicants in site-visits relevant to their specific rehabilitation interests (i.e. living arrangements, work settings etc.) prior to the committee meeting.

Another structural concern voiced by participants, involved negative perceptions of services. This experience

countered individuals' sense that the rehabilitation offered is relevant to them and/or supporting their recovery processes. Indeed, often the degree to which the system is responsive to mental health consumer's needs is limited. For example, in a recent study consumers reported their needs were only partially addressed by services and the mental health system (Werner 2012). When services are experienced as segregating and stigmatizing they pose a barrier for personal redefinition outside the patient role, and to seeing the illness as just another aspect of one's whole identity (Anthony 1993; Davidson et al. 2007; Deegan 1993; Drake 2000; Slade 2010). One possible way to address this problem with services is to employ "personalization"—an open and flexible approach that allows individuals to develop a personal rehabilitation plan with its own designated budget. The budget allows freedom to choose services, resources and supports specifically tailored to one's personal needs and wants, ensuring a match, and given their personal nature—allowing effective social integration (Mind 2009; Spandler and Vick 2006).

In addition to structural challenges participants reported feeling tension or conflict related to the *human processes* experienced in the rehabilitation basket committee and overall process. Many felt not listened to or not fully understood in regards to their wants and goals lacking a sense of dialogue and partnership with professionals. Such user's experiences of practitioner relationships also lead to disengagement from services in other places in the world (e.g. Smith et al. 2013; Ware et al. 2004). The role of the consumer-practitioner relationship in recovery is central (e.g. Moran et al. 2014). Thus, training in relational skills can enhance collaboration, partnership and shared decision making (Linhorst et al. 2002; Matthias et al. 2012; Russinova et al. 2011), and may be in particular a noteworthy investment for enabling rehabilitation processes to develop more positively. Veering efforts to enhance the relational aspects, such as participation and person centeredness are perhaps what drives transformation processes of mental health workforces (Davidson 2012; Linhorst and Eckert 2003; Malinovsky et al. 2013; Roberts et al. 2008; Schwartz et al. 2013).

Our study also showed another human process challenge which involved the internal- intrapersonal aspect of participants. Some described that when embarking on the formal rehabilitation process, they experienced strong fears of change, low motivation, or were otherwise too preoccupied with different things in their lives. As a result they were inhibited, lacked involvement and were passive in the decision making processes of the committee. Thus, these applicants approached the committee whilst not ready to engage in the demanding process of rehabilitation. Persons challenged with psychiatric conditions can often feel stuck or ambivalent about pursuing change in their life ('not

necessarily as a result of negative symptoms) (Lecomte et al. 2005; Rogers et al. 2001). This is understandable as the process of reentering employment, engaging socially and/or acquiring new skills after one has drifted from normative developmental stages in life, can be a daunting and tedious task requiring personal investment and persistence. One way to address this problem is using Readiness rehabilitation intervention which helps clarify sources of and current goals in a structured process supporting self exploration. Consumers identify their interest in and willingness to engage in the process of rehabilitation in a specific environment (i.e., living, learning, working, and social) assessing their (a) need for change, (b) commitment to change, (c) self awareness of role related interests, values, and preferences; (d) awareness of options and role characteristics; and (e) willingness to establish personal closeness and therapeutic alliances (Farkas et al. 2000; Farkas and Anthony 2009; Roberts and Pratt 2010). Addressing one's state of readiness is an important part of rehabilitation which can empower and motivate individuals in their overall process of rehabilitation (Corrigan 2002; Farkas et al. 2000; Sheldon and Elliot 1999; Fischer et al. 2002; Moran et al. 2013).

Finally, another aspect of the human process challenge involved the role of family members in engagement and disengagement from services. Family members had influence over their loved ones which sometimes manifested in pushing participants to look for change in their life, and in other times prevented such pursuits because families provided a strong substitute or alternative to rehabilitation (often more in the case of living arrangements). As a family centered culture, taking into account family members in the process of designing the rehabilitation plan with consumers will likely help facilitate the process. We suggest that in collectivist and family oriented cultures, psychiatric rehabilitation systems need be sensitive to families' central role in the life of their mentally ill loved ones and include them (with permission of the applicant) in the process. Families often carry more information and knowledge about the applicants' history, strengths and interests. Thus they can play an important role in having creative suggestions and providing contexts that practitioners do not have to support rehabilitation and recovery processes (Lefley and Johnson 2002; Melamed 2001; Solomon 2012; Spaniol 2010).

The study findings need to be examined with consideration of its limitations. For one thing, the sample was limited in terms of maximum variation given that participants included were only Hebrew speaking, leaving out Arab speakers and other minorities. In addition participants were recruited from a limited number of geographical regions where the committees are most active. More studies should focus on other minority sectors (i.e. Arab

population, Ultraorthodox Jews, etc.) and additional rural district areas in Israel to maximize variation in cultural backgrounds and location (Palinkas et al. 2013). In addition, future studies should include service users who used their rehabilitation and services to determine if they too share similar perceptions regarding the experience with the committee and services, and address their needs as well. Furthermore, the study did not collect perspectives of professionals in the committees, escorting practitioners and/or family members. Obtaining knowledge about these perspectives can help provide knowledge that will complement and may point to discrepancies across the different levels of analysis (systemic, interpersonal and personal challenges). For example, Smith et al. (2013) collected both consumers and providers' perspectives and found marked differences between them. In addition, investigating service users who do use services to compare their points of view with those who disengage, may further shed light on shared and distinguished difficulties in both of these sub-populations, as well as point to what might be positive aspects of the current system. Finally, recently it has been suggested that reasons for disengagement and engagement strategies may vary among age groups (e.g. Green et al. 2012). Thus, addressing larger samples and distinguishing between age groups can provide valuable knowledge with practical implication for system and services in psychiatric rehabilitation.

## Conclusions

Recovery orientation continues to pose a challenge to rehabilitation systems across the world, as manifested in light of disengagement rates that continue to be high. In Israel, the Rehabilitation in the Community of Persons with Mental Disabilities Law in Israel (RMD 2001) has pushed the development of personalized psychiatric rehabilitation services in the community. Yet the challenge of achieving individually tailored rehabilitation plans is yet to be realized as a substantial number of eligible applicants who are assigned services, do not utilize them. The current study investigated perspectives of 15 non-utilizing applicants pointing to multiple challenge-experiences and reasons that resulted in a lack of concordance between personal goals and the designated rehabilitation plans. Challenges were conceptualized as structural (preparation and knowledge of applicants, lack of sufficient professionalism of providers, lack of services that match diverse personal goals) and human process challenges (lack of readiness for change, consumer-committee interpersonal aspects including lack of communication, collaboration, and involvement of family members in the process). We provide suggestions to approach structural challenges by infusing a structured

preparation and orientation process, focusing on developing provider competencies and a more collaborative approach as well as introducing personal budgeting to personalized plans. We also suggest addressing the consumers readiness for rehabilitation. This study contributes to the continuing emphasis on international mental health recovery orientation and person centered trends, by providing service user perspectives and multi-level implications for understanding and supporting such system transformation efforts.

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