

Living with a psychiatric disability: lessons to learn and to pass on

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Introduction

In today's Dutch political climate, the emphasis is on accepting personal responsibility. But how people with a psychiatric disability are expected to do so has not been worked out in any detail, if at all. Although a number of initiatives have been undertaken by psychiatric service users themselves, they remain fragmented. No overall picture is available and little is known about their effectiveness or what particular features serve to make them effective. Greater cohesion is now being sought by means of a 'recovery programme', run by, for and involving people with a psychiatric disability. This paper describes the programme, looking first at the meaning of the concept of 'recovery' before going on to consider recovery processes and the factors that may promote or impede recovery. Following a brief description of self-help initiatives addressing recovery, empowerment and ways in which experience-based expertise can be built and put to use, we describe the recovery programme itself. The concluding section presents an account of a effect study recently begun, which looks at certain well-defined attempts by people with psychiatric disabilities to help themselves and fellow-users.

The meaning and of 'recovery'

During the 1990s, Dutch mental health services gave a significant impulse to the *rehabilitation* of people with serious psychiatric disabilities. A relatively new feature was the identification of patients' own life goals, and assistance designed to help them achieve those goals. This opened up the prospect of real change in their life situation. In the mid-1990s, a new word was added to the rehabilitation lexicon: 'recovery' (see Deegan, 1993; Boevink, 1997, etc.) Here, the term is not used in the clinical sense of complete alleviation of symptoms, the 'cure' of the condition or a full return to the patient's previous state. Rather, 'recovery' refers to the unique, personal processes whereby people with psychiatric disabilities attempt to 'pick up the thread' and to give their lives new content and direction. The person concerned may well

benefit from the services of a rehabilitation professional, but the focus is firmly on his own efforts in giving his life a more favourable direction. In this sense, 'recovery' therefore entails the active acceptance of disabilities and limitations, together with a gradual transition from the identity of patient to one of active citizen and member of the community. While rehabilitation is usually geared towards practical aspects such as work, education and social interaction, 'recovery' takes a psychological approach in which the focus is on the change of identity.

Deegan – herself diagnosed with schizophrenia – describes the significance of recovery as follows: "...one of the lessons I had to learn was that recovery is not the same as cure. I have lived with this illness for 21 years and it is still with me today. I can therefore assume that I will never be 'cured', but that I am on the road to recovery. Recovery is a process, not a goal in itself. Recovery is an attitude, a strategy to cope with the day and its challenges. For me, recovery means that I know that I have certain limitations and that there are things that I cannot do. But rather than allowing this to lead to desperation and submission, I have learned that knowing what I cannot do also shows me what I *can* do." (Deegan, 1993).

The most frequently quoted definition of recovery is that offered by William Anthony, Director of the Psychiatric Rehabilitation Center in Boston, USA. He describes recovery as "an intense, personal and unique process of change in a person's attitude, values, feelings, goals, skills and/or roles. It is a way of living, of leading a satisfying, hopeful and useful life with the restrictions that psychiatric disabilities entail. Recovery means growing out of the catastrophic consequences of the psychiatric condition and developing a new meaning and a new purpose in one's life." (Anthony, 1993).

The concept of recovery is a powerful one. At the individual level, it entails a shift of focus from the psychiatric condition, symptoms and passivity to one's own life, possibilities and the resumption of control. An awareness of their personal experience and knowledge enables people with a psychiatric disability to formulate stories in which they can recognize themselves. Those stories are important because they enable people to describe what it is to live with a psychiatric disability, to develop their own identity further and to identify (to themselves and to others) the help and support that will be required in doing so.

The concept of recovery is not only important at the individual level. At the collective

level, it is inextricably linked with self-determination, empowerment and emancipation of people with psychiatric disabilities, and with efforts to counter stigma and discrimination (Fisher and Chamberlin, 2003).

Recovery processes

Recovery is therefore a question of transcending hopelessness and the loss of a meaningful identity, social connectedness, roles and opportunities. Persons with serious psychiatric disabilities must recover from traumatic experiences, from programmes, practices and environments which have stripped them of power, and from stigma and discrimination in the community. Several studies (e.g. Ralph, 2000) have identified phases in this process. Gagne (2004) cites four phases:

1. Feeling overwhelmed by the condition
2. Struggling with the condition
3. Living with the condition
4. Living beyond the condition.

In the first phase, the person is likely to experience confusion and disorientation as the result of the overwhelming nature of the symptoms. He or she is primarily concerned with mental and physical survival. This phase is marked by feelings of hopelessness and powerlessness. It is marked by a loss of the sense of self (i.e. the 'self' prior to the emergence of the condition), from others and from the social setting. During the second phase, he asks himself how he can live with the condition. Coping strategies are developed, as are ways in which to 'rediscover' oneself. The main struggle is now with the lack of confidence and of adequate responses to the condition. There is still the fear of relapse, of being overwhelmed by the condition once more. This fear abates during the third phase as confidence in one's ability to cope with the condition begins to build. The person in recovery develops a new 'self' and learns to recognize his strengths and limitations. Personal ties with significant others are restored. Old roles are assumed once more, and new roles are explored. The restrictions of the condition are still felt, but a refuge – a niche – becomes available. In the fourth and final phase of the recovery process, the condition is pushed yet further into the background. The person regains a sense of connectedness and can as-

sume meaningful roles. Talents and possibilities are expressed in various areas, and new capabilities are explored. There is room for a new meaning and for new goals in one's life.

Other researchers propose phases very similar to Gagne's. For example, Young and Ensing (1999) offer: (1) 'overcoming *stuckness*', i.e. emerging from the restraints of the condition itself, (2) regaining what has been lost and carrying on, and (3) improving the quality of life.

What helps and what hinders?

An increasing body of research is being undertaken to identify the factors which will promote or impede the recovery process. (See for example Onken *et al.*, 2002, Gagne *et al.*, 2004). The obstacles to recovery range from the lack of basic life requirements to inadequate and ineffective professional help, substance abuse and traumatic experiences. They also include lack of respect or approbation from others, lack of trust and feelings of hopelessness on the part of significant others, lack of opportunity to assume any significant social role, lack of information concerning practical coping strategies, stigma and embarrassment.

The factors which promote the recovery process include acute stabilization in the event of crisis, (access to) effective treatment and therapy, fulfilment of the primary life requirements, the presence and support of a competent, involved person who understands what the person in recovery is experiencing, hope, acceptance, coping skills, the ability to deal with an impending relapse, self-care skills, social skills, someone to represent one's interests, the courage to take risks, assistance ('coaching') in work and education, satisfying work and interpersonal relationships, diversity in significant social roles, financial security, intimacy and spirituality.

In fact, the exact factors at play will vary according to the current phase of the recovery process. Moreover, a factor which promotes the process in one phase may prove an obstacle in another. One example is 'the courage to take risks'. During the first phases of the process, this can serve to impede recovery, while in the later phases it is an essential factor in furthering the process. The sheer number and variety of factors which affect recovery in one way or another serve to underline the individual and highly personal nature of the processes involved.

Several ongoing studies are examining the course of the recovery processes in people with a serious psychiatric disability. As part of these studies, indicators have been developed, using which the progress of the recovery process can be quantified or inferred. Several questionnaires have also been developed and are now in use (see Ralph *et al.*, 2000). However, few indicators have been subject to proper psychometric testing. Recovery is inferred (see Gagne, 2004) from such factors as the re-assumption of socially accepted roles, the subject's success and satisfaction in various social roles, the reduction, control or alleviation of symptoms, increased self-confidence and well-being, increased number and quality of interpersonal relationships, improved mental health, a greater feeling of involvement with oneself and others, the perceived meaningfulness of life, increased self-confidence and access to one's own strengths and abilities.

Recovery programmes in the Netherlands

In recent years, the users of mental health services, particularly those in long-term care, have developed a number of initiatives inspired (at least in part) by the recovery concept (Boevink, 2003). Some of these initiatives have been developed autonomously, others with the help of professionals. All aim to promote individual recovery processes. They also provide for the development and use of service users' own experience-based expertise, and the development of strategies designed to ensure active and significant user input in the professional care services. Various innovative initiatives have been launched to strengthen the position of people with a psychiatric disability to provide a different approach to mental health issues. They include programmes conducted by the Client Interests Bureau in Eindhoven, the 'Wegwijswinkel' in Utrecht and the GGZ Rijnmond User Council in Rotterdam. Users develop training courses for professionals and for fellow users, and start new self-help groups. Examples include a course in Brabant, the Ziezo self-help organization, training for the Anoïksis spokesmen, and the national recovery programme run by and for users in Utrecht, Apeldoorn and Maastricht. Users have also presented our own experiences in a form which will be useful to the professionals. Examples include the courses written by Conquest in Eindhoven and Amsterdam, the 'Working with your own experience' course produced by the GGZ Rijnmond User Council, and the 'Users training professionals' project in Eindhoven. At national level, user organizations such

as Weerklank and the Borderline Foundation have also started processes which will change the way in which psychiatric disabilities are approached, based on the experiences of the users themselves.

User-run projects are growing in popularity and in substance. In countless areas, new activities are undertaken based on the users' own 'helmsmanship'. The underlying belief is that the use of personal experiences will lead to new insights regarding psychiatric conditions and their symptoms, such as hearing voices or self-harm. The people behind these projects believe that they can contribute to a better type of assistance than the mainstream care services currently available. Self-help programmes and user-run initiatives are a response to the fact that people with psychiatric disabilities rarely see their individuality, experience and knowledge reflected in the standard mental healthcare system. For users themselves, the emphasis is now shifting onto their own strengths and abilities, rather than on railing against the power of others and their agenda.

A recovery programme devised by, for and involving people with psychiatric disabilities

Hitherto, there has been no general overview of the various user-run initiatives in the field of recovery, empowerment and the use of experience-based expertise. There is no account of the methods used, the experiences gained have yet to be collated and no solid scientific basis has been established. To contribute to the development of knowledge in this area, the Trimbos Institute and the *Stichting Beschermende Woonvormen* (Sheltered Accommodation Foundation; SBWU) of Utrecht initiated a developmental project in 1998, bringing together the elements of user-run initiatives which are thought to account for their success.

The basis of the project was formed by a self-help group of SBWU users who regularly met to discuss the recovery concept in general and their own recovery process in particular. Gradually, this self-help group grew to form a group which developed various activities on behalf of other users and the professionals of the SBWU. For example, the group devised a course on recovery for users and professionals, it conducted a 'consumer-directed' survey on the satisfaction of users regarding the assistance provided, and instituted a series of meetings to present and discuss re-

covery themes among the users of sheltered housing. The methods and process are described in detail by Boevink *et al.* (2002) in the book *Samen werken aan herstel*.¹

Based on the results of this project, a recovery programme devised by, for and involving people with a psychiatric disability came into being. The programme targets persons suffering from serious mental illness and facing psychiatric disabilities. In many cases, they face multiple, complex problems in various aspects of life and living, and have impressive patient careers in psychiatry. As a result, they are confronted with dependency, lack of self-confidence and control over one's own life, loss of meaningful identity and a serious social and societal vulnerability.

The recovery programme is intended to counter the marginalization of people with a psychiatric disability and to enhance their ability to manage their own lives. The underlying principle is that the programme helps starting and promotes individual recovery processes, contributes to full and meaningful social participation, and gives those taking part a powerful voice as stakeholders in mental healthcare services. To this end, the programme enables users to exchange experiences and offer mutual support. It also encourages them to develop experience based knowledge, to make it available to others and to capitalize this knowledge. Lastly, the programme triggers change within psychiatric institutions in the direction of recovery-based services.

People with a psychiatric disability can take part as a (self-help)group member, active participant, as a student, speaker or teacher on one of the courses, as a volunteer or as a paid expert by experience. The activities involved include:

- Sharing experiences with others (where these have hitherto been undergone without having words to describe them).
- Distancing oneself from those experiences and reflecting upon them (devising one's own story).
- Placing the personal story ('I and me') in the collective context ('We and us').
- Rendering the story usable by others, by means of a transfer of knowledge to fellow users, professionals and other interested parties.
- Participation as course tutor or speaker in educational programmes.

¹ Boevink *et al.*, *Samen werken aan herstel. Van ervaringen delen naar kennis overdragen* ['Working together on recovery. From sharing experiences to transferring knowledge'] Utrecht: Trimbos Institute, 2002.

Here, the underlying principle is that formulating and telling one's own story forms an important part of the recovery process. Doing so enables the storyteller to cope with something as overwhelming as for instance a psychosis. Moreover, it enables the person to distinguish between and separate the condition and the self, the personal identity. And it enables the person to learn to formulate/articulate what he or she needs to support the recovery process. Formulating one's own story and presenting it to others is the first stage in developing experience-based expertise. The many individual ('I and me ') stories are combined to form a collective ('We and us') story. This involves seeking and identifying the common ground, similarities and differences. The final phase is to convert the story into a form which can be used in the process of (commercial) knowledge dissemination and education of others. In this way participants are supported in their quest for role diversification. They can take part in the programme as a member of a workgroup, a student, speaker, mentor, course tutor, volunteer, or paid 'experience expert'.

Programme components

The recovery programme explicitly attempts to explore the experience-based expertise of the participants, make this transferable and put it to use in practice. The participants themselves undertake the necessary activities, sometimes as a paid employee of the own psychiatric service organisation (where they are a client as well) conducting the programme. To date, five programme components have been developed and implemented in practice: recovery workgroups, a one day recovery masterclass for users and professionals, a low-threshold 'Making a start on recovery' for users, themed meetings for fellow users, and the training-programmes for professionals.

A recovery workgroup is a group of no more than eight people who meet every two to three weeks to exchange experiences relating to recovery and reintegration. They also develop further knowledge and devise initiatives whereby this knowledge can be used by themselves, fellow users and their mental health care institution. The recovery workgroup has a twofold function. During the initial stages of its existence it is primarily a self-help group. Gradually, the function of initiator is added. The members of the group are paid for their input from the very beginning. This is based on the principle that the exchange of personal experiences is an essential basis for the long-

term development and use of experience-based expertise and that this exchange should therefore be facilitated. A handbook for setting up recovery workgroups is currently in preparation. Workgroups are led by users with experience-based expertise.

The one-day 'recovery' masterclass is for partnerships of user and professional. Users may only take part if they bring their professional caregiver, and *vice versa*. A team of experience-based experts offers information about recovery by means of personal accounts, a moderated discussion, exercises and a game.

The 'making a start on recovery' course is a readily accessible course for groups of no more than five people. It is led by two experience-based experts. Each session will also involve the input of experience-expert guest speakers. There are five two-hour sessions examining a number of key topics, such as possible pitfalls and the sources of support. The main aim of the course is to facilitate discussion and understanding of individual recovery attempts on the part of those taking part.

The recovery workgroups regularly make an inventory of the topics which have been covered, what was said about them, and what information from external sources has been collected in relation to these topics. Some topics are then incorporated into training sessions for fellow clients, the 'themed meetings' by means of a set template. The recovery group members can thus use and test various forms of communication when presenting their experiences: alongside the discussions in the workgroups themselves, they can also develop the skills required to lead discussions or to speak in public. At the same time, the main topics are integrated into a general 'recovery vision' for the use of a wider audience of fellow users.

Finally, the recovery programme also includes training sessions conducted by service users for the benefit of professionals. One objective is to promote relevant experience-based expertise among the professionals, thus creating opportunities for new roles and new forms of communication for the users taking part. At the same time, this is seen as a necessary precondition to the development of care services which seek to promote recovery. The sessions are varied and may include presentations about the recovery programme itself, accounts of personal experiences of the recovery process, and training in support for recovery and in rehabilitation.

Towards a scientific basis?

The project started in 1998 in collaboration with long-term mental health service users has been described in detail in Boevink *et al.*, 2002. A number of the project elements assumed to be effective were then elaborated to form the components of a recovery programme. In 2004, a three-year study into the effect of this programme was commenced. It will monitor progress and results at three specific locations in the Netherlands: Utrecht (Stichting Beschermende Woonvormen), Apeldoorn (RIBW Oost-Veluwe) and Maastricht (RIBW Heuvelland en Maasvallei, RIAGG Maastricht and Vijverdal, the Karwei day centre and the Social Psychiatric Centre). At each location, recovery workgroups will be set up and facilitated, and the one-day recovery course and the longer 'Making a start on recovery' course will be offered.

In Utrecht and Apeldoorn, the study has a quasi-experimental design, while in Maastricht it will be in the form of a randomized clinical trial. An initial group of users taking part in the programme from its inception will be compared with a group joining the programme one year later. All participants will then be monitored for two years: during the second year, the subsequent group will be introduced to recovery activities. There will be a zero (reference) measurement, and further measurements at the end of the first and second years. The outcome indicators relate to identity development, confidence in personal mental health, empowerment and connectedness.

Parallel to the effects study will be a number of more qualitative research components, including a longitudinal study in which individual recovery processes are described and the differences in perception between users and professionals made visible. There will also be a process evaluation of the trial implementations and a study of the defining characteristics of recovery-oriented mental healthcare. Eventually, the results of all part-studies will combine to provide new knowledge concerning strategies and activities, both individual and collective, which are successfully undertaken by people with psychiatric disabilities in order to (re-)build their lives around, and on the basis, of those disabilities, about what others can do to support this process, and about the significance of the findings in terms of the design and structure of professional services.

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