

# DISCOVERING HOPE FOR RECOVERY

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## ABSTRACT

The concept of recovery and recovery oriented services and practices are well advanced in some parts of the world, particularly in the US and New Zealand. This paper provides a review of the literature upon which hope for recovery is based, and explores the concept in the UK context, where it is now gaining recognition. In so doing, it identifies the background to the development of a consciousness of the possibility of recovery (both with and without mental health services support) and addresses the issues raised by the self-fulfilling concept of chronicity. It further examines the questions of measuring recovery and understanding recovery as a process or goal. It then goes on to identify themes within recovery literature and research, and to focus on recovery skills and self-care strategies for people diagnosed with schizophrenia, psychoses, or other serious mental illnesses. The paper concludes by addressing issues that have implications for more effective policy and practice – most notably resolving the fundamental tension between involvement with and separation from services (a process that will require a better understanding of the role of values in the relationship between those who use and those who provide services).

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This paper is based on a paper originally produced at the University of Central England to introduce the concept of recovery to people in the West Midlands area of the United Kingdom who use mental health services, as well as to their family members and service providers. Its aim was specifically to focus on a selected sample of the vast array of recovery literature and research rather than include the published and unpublished writings that do not directly address the issue of recovery of people who have used mental health services in the UK or other parts of the world. The authors wish to acknowledge the extent and richness of this material that adds depth to the literature and research on recovery. The literature and research included in the review was selected to integrate well-known information with information that has not previously been widely shared. It contains information that we hope will be of use both in providing hope for recovery to people who use mental health services and their family members, and in indicating the direction toward more effective and better quality services that can facilitate the recovery and wellness of people experiencing mental illness.

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## INTRODUCTION

*But now I look back on it with a real sense of achievement. It was a 24-carat crack-up and I'm proud of the fact I got through it, rebuilt myself, did ok as a journalist again, and went on to do what I do now. I couldn't have done what I've done in this job without believing what I believe very strongly, and being tough-minded, focussed, mentally and physically fit. I feel the breakdown and the recovery played a big part in all that (Alastair Campbell, the prime minister's director of communications and strategy in Cantacuzino, 2002 p. 38).*

The concept of recovery, and the development and implementation of recovery oriented services and practices within mainstream services in the United Kingdom are only just beginning. This follows a decade of writing, research and identification of emerging best practices in mental health recovery in a number of States in the US and particularly in New Zealand.

The concept of Recovery was introduced into mental health discourse primarily by individuals who had experienced recovery, rather than by the professionals who had worked with them. At its simplest recovery can be defined as a subjective experience of regaining control over one's life. As their personal definitions of recovery indicate, the achievements of those who have recovered embrace hope, empowerment, and social connectedness:

Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again . . . .The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution (Deegan, 1988, p. 15).

Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort. I believe that if we confront our illnesses with courage and struggle with our symptoms persistently, we can overcome our handicaps to live independently, learn skills, and contribute to society, the society that has traditionally abandoned us (Leete, 1988, p. 52).

Within professional circles in the United States, the concept of recovery became more widely recognised following the publication of *Recovery from Mental Illness: The Guiding Vision for the 1990s*. Drawing upon the writings of people with experience of recovery, William Anthony concluded:

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...a person with mental illness can recover even though the illness is not "cured"... [Recovery] is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993, p. 15).

Recovery, then, is more than a return to a person's previous condition. It is a process of a new self image, an ego that is not completely subjected to the illness. It is a process which leaves the patient not entirely helpless in relation to the illness. (Strauss, Harding, Hafez, & Lieberman, 1987). Many people who were trying to articulate a consumer definition of recovery from schizophrenia, for example, could only conclude that recovery meant that they were able to be 'getting on with their lives' (Tooth, Kalyanasundaram & Glover, 1997).

Warner (1994) distinguished between the concepts of social recovery and complete recovery. Social recovery, on the one hand, implies that the consumer functions socially, but may still display some clinical signs of disorder such as hearing voices or having certain paranoid delusions. It is a process (Deegan, 1988) wherein the consumer can reasonably continue regularly to access psychiatric outpatient care for medication and/or therapy. Complete, on the other hand, implies that the former patient no longer displays any psychotic symptoms and has returned to the pre-illness level of functioning (Warner, 1994).

### **Individual Meanings, Individual Recovery**

Recovery has been described in many different ways - as a process, as an outlook, as a vision, and as a guiding principle. Common to all of these descriptions, however, is a key shift of emphasis: instead of focusing on symptomatology and relief from symptoms, these descriptions support individuals in their own personal development and place the emphasis on building self-esteem, discerning identity and finding a meaningful role in society. In this view, recovery *does not* necessarily mean restoration of full functioning without supports (including medication); it *does* mean building on personal strengths and resources to develop supports and coping mechanisms which enable individuals to become active participants in – as opposed to passive recipients of – their mental health care.

Individual journeys of recovery are not, however, determined exclusively by internal factors. As the U.S. National Technical Assistance Centre (NTAC) attests recovery also is influenced by personal relationships, the physical environment and external resources available to an individual:

Recovery is an ongoing dynamic interactional process that occurs between a person's strengths, vulnerabilities, resources and the environment. It involves a personal journey of actively self-managing psychiatric disorder while reclaiming, gaining and maintaining a positive sense of self, roles and life beyond the mental health system, in spite of the challenge of psychiatric disability. Recovery involves learning to approach each day's challenges, to overcome disabilities, to live independently and to contribute to society. Recovery is supported by a foundation based on hope, belief, personal power, respect, connections, and self-determination (Onken, Dumont, Ridgway, Dornan, & Ralph, 2002, pp. 2-3).

It is the uniqueness of each individual's recovery journey that makes finding a generally agreed-upon definition of recovery so difficult. Influenced by unique life experiences and cultures, individuals bring their own systems of personal values to their definitions of recovery. The subjectivity of these definitions is, however, problematic within the field of psychiatry. Conflict arises in the attempt to balance two competing, yet equally compelling, needs: (a) the need to create a common psychiatric language for the purposes of treatment and research and to establish general frameworks of diagnostic categories (as in the current DSMIV and ICD10); and (b) the need to validate and support the individual and experiential definitions of recovery which have personal relevance outside of, and often in spite of, the mental health system.

Although this conflict runs through and is central to an understanding of recovery, it is, of course, not unique to that particular discourse. The importance of meaning-full as well as scientific accounts of mental distress and disorder was emphasised by one of the founding figures of modern psychiatry early in the 20<sup>th</sup> century, the philosopher and psychiatrist, Karl Jaspers (1974). Furthermore, throughout the 20<sup>th</sup> century, interpreting individual experiences continued to be the focus of the phenomenological tradition - a tradition which, as Jaspers would have anticipated, is becoming once again prominent in psychiatry with recent advances in the neurosciences (Fulford, Morris, Sadler, & Stanghellini, 2003).

### **Recovery Themes**

Although recovery is difficult to define, there is a rich literature on the themes that it encompasses. For example, a consumer-run business in Ohio was asked by a county mental health board to develop and implement an evaluation strategy to identify strengths and weaknesses in the county mental health system. The consumers agreed that recovery was important and, accordingly, generated a list of indicators of recovery, and a set of criteria upon which professionals could be evaluated (both positively and negatively) in terms of their impact on the recovery process. These indicators, used in a pilot study in Ohio and in Maine with consumers/survivors who had been admitted to the state institution at least once in the last seven years, were rated from most important to least important: a) the ability to have hope b) trusting my own thoughts c) enjoying the environment d) feeling alert and alive e) increased self esteem f) knowing I have a tomorrow g) working with and relating to others h) increased spirituality i) having a job and j) having the ability to work. The rankings were similar for both groups with the top four indicators being identical for both the Ohio and Maine consumers: (Ralph, Lambric, & Steele, 1996; Ralph & Lambert, 1996).

Analyzing four early consumer recovery narratives (Lovejoy, 1984; Deegan, 1988; Leete, 1989; Unzicker, 1989) with a constant comparative method Ridgway (2001) identified the following recovery themes: a) reawakening of hope after despair b) breaking through denial and achieving understanding and acceptance c) moving from withdrawal to engagement and active participation in life d) actively coping rather than passive adjustment e) reclaiming a positive sense of self and no longer viewing oneself primarily as a mental patient f) journeying from alienation to purpose g) undertaking a complex journey, and h) involving support and partnership rather than working alone.

In a review of recovery literature, Ralph (2000) identified four dimensions of recovery found in personal accounts:

a) internal factors – those factors which are within the consumer, him/herself such as the awakening, insight, and determination it takes to recover; b) self-managed care (an extension of the internal factors where consumers describe how they manage their own mental health and how they cope with the difficulties and barriers they face); c) external factors (such as interconnectedness with others, the supports provided by family, friends, and professionals, and having people who believe that an individual can cope with and recover from his/her mental illness); and d) empowerment (a combination of internal and external factors where the internal strength is combined with interconnectedness to provide the self-help, advocacy, and caring about what happens to ourselves and to others).

Recovery is closely related to the concept of empowerment which grew out of the American and European consumer movements. Although studies are few, some research on self-help touches on the issue of empowerment which is identified as a combination of self-determination to gain control over one's life, the creation of an environment in which such control can be gained, and the building of services and policies which support empowerment. Stewart and Kopache's recent research (2002) further reflected the connection between empowerment and recovery: they found that the degree of empowerment experienced by consumers is a significant predictor of the level of symptom distress.

## **ORIGINS: HOPE AND THE POSSIBILITY OF RECOVERY**

Historically, people with mental illness were not expected to recover. In the 19th century, this negative expectation was reflected in "degeneracy" theories of mental disorder; and the self-fulfilling institutionalisation of the asylum movement. Emil Kraepelin (1919), at the beginning of the 20<sup>th</sup> century, judged the outcome of 'schizophrenia' to be so poor that he named the 'disorder' *dementia praecox*, or premature dementia. People given diagnoses of schizophrenia were thus seen as having a necessarily poor prognosis; their illness was expected to take a uniformly downwardly spiralling course. Negative perceptions of severe and persistent mental illness have been maintained for many years and, it could be argued, have contributed to the development of stigma in western societies. This stigmatization has influenced the public view of people diagnosed as mentally ill: often they are considered to be unable to take control over their own lives and, ultimately, to be dangerous. As a result of these perceptions, public and public service responses to mental illness often have been negative.

Such negative expectations and experiences have had a severe effect on the lives of people who have mental health experiences and those who support them (i.e., their families and friends). Many of the people treated by psychiatry are placed in a position of 'learned helplessness' (Deegan, 1992) by a mental health system within which negative beliefs and attitudes provide little or no hope of recovery.

It is perhaps not surprising, then, that the concept of recovery from severe and persistent mental illness has arisen out of the developing conscientization of the rights of marginalised and socially excluded people. This conscientization began with the civil rights movement in the 1960s and 1970s. Recognition of the disadvantaged position of women and black people in western societies led to a growing consciousness of the need for anti-discriminatory legislation which attempts to redress the balance and ensure protection of the rights of these groups. Similar developments in relation to groups of disabled people have resulted in the Americans with Disabilities Act in the US and the Disability Discrimination Act in the UK.

In the UK, as in many other countries, people diagnosed with mental illnesses remain largely marginalized. The slowly developing national and international service user movements are, however, beginning to raise a new consciousness: the possibility of recovery from serious mental illness now is being considered. This shift began in the late 1970s and early 1980s, when people who had experienced mental health problems and had been treated within the mental health system started to record their experiences and tell their stories in books such as Judy Chamberlin's *On Our Own* (1978). Such records have increased significantly in the late 1980's (Deegan, 1988; Leete, 1989) and, with additional growth throughout the 1990s, have led to a very significant literature written by people with recovery experiences. Professionals also have become interested in this rich literature and begun to understand the meaning of 'recovery' more clearly and to seek ways in which this new information can contribute to better and more effective 'treatment'. Much of this new literature is relatively inaccessible, being published in journals that are difficult to obtain, or indeed in papers that remain unpublished. Nonetheless, there have been some landmark publications – most notably from the US (e.g., Carling, 1995; Davidson & Strauss, 1992; Mosher & Burti, 1994), from Australia (e.g., Tooth et al., 1997) and from Sweden (e.g., Topor, Svenson, Bjerke, Borg, & Kufas, 1998).

Within the UK use of the concept of recovery is still very limited: the majority of people served by the mental health system are given little hope of recovery from their experiences and the staff that work with and support them have little, if any, knowledge about recovery or about ways in which recovery can be supported. However, the situation is about to change. The UK Department of Health, in a series of key policy documents "Modernising Mental Health Services: Safe, Sound and Supportive" (1998), "The National Service Framework for Mental Health: Modern Standards and Service Models" (1999a), and the "NHS Plan: A Plan for Investment. A Plan for Reform" (2001a), have set out a clear and comprehensive vision for mental health services – a vision which places people who use services and their family members firmly at the centre of service planning, development and delivery. These policies provide a framework within which recovery orientated services can be conceived, planned and implemented involving service users and family members as equal partners at every stage of the process.

## Breaking the Bonds of Chronicity

As Table 1, which provides results from seven follow-up studies of people diagnosed with schizophrenia, demonstrates, the evidence of recovery from severe mental illness is not new. According to Harding (quoted in Johnson, 2000, pp. 2-3),

These studies have consistently found that half to two thirds of patients significantly improved or recovered including some cohorts of very chronic cases. The universal criteria had been defined as no current medications, working, relating well to family and friends, integrated into community and behaving in such a way as to not be able to detect having ever been hospitalised for any kind of psychiatric problem.

**Table 1: Results from seven follow-up studies of patients with the diagnosis schizophrenia** (Johnson, 2000)

	No. of patients	Study Length in years	% Subjects recovered and/or improved significantly
Bleuler 1968, Zurich	208	23	53-68
Ciampi & Muller 1980, Switzerland	290	37	57
Tsuang et. al. 1979, Iowa, US	186	35	68
Huber et. al. 1980, Germany	502	22	56
Ogawa et. al. 1987, Japan	140	27	57
Harding et. al. 1987, Vermont, US	269	32	68
DeSisto et. al. 1995, Maine US	99	35	49

The question that arises, then, is why it has taken so long for the concept of recovery to become widely recognised. In examining this question, Topor (2001) argues that chronicity, as a feature of conditions such as schizophrenia (as it is traditionally conceived), can become self-fulfilling – that is, traditional theories of schizophrenia, echoing earlier degeneracy models of "madness", assume chronicity; and chronicity is the result. Against this background of expectations, recovery is, indeed, something of a challenge.

The image of the schizophrenic as someone other than, qualitatively different from, other people occurs in diverse psychiatric traditions and underscores the notion that the total breakdown of the ego is the foremost reason for chronicity (Topor, 2001, p. 43).

The difficulties that have been experienced in establishing the concept of recovery within mainstream services are thus closely connected with the problems of throwing off the effects of institutionalisation. The term 'chronically ill' is appropriately attached to people whose illnesses (physical or mental) have become long-term and who as a result, may have to spend long periods in hospital. But merely being admitted to a hospital for psychiatric treatment was, for a long time, enough to attract a label of chronicity Rosenhan's (1973). In recent years it has become possible to offer treatment, care, and support services that are at least as effective as hospitalization through crisis-resolution and home treatment teams in people's natural communities. However, despite contrary evidence, labels of chronicity remain attached to people with

diagnoses of serious mental illness. With deinstitutionalisation and the closure of psychiatric hospitals, "functional disability" has replaced chronic illness as a new criterion.

Topor (2001), further argues that we must recognise, and take a stand on, the idea that chronicity is not, somehow, built-in to people with serious mental illnesses, rather, it is a product of the life-styles which, as a result of societal expectations, they tend to adopt. "The cause of chronicity, which has long been sought within the individual (biological or psychological characteristics) is not inherent in the illness itself, a part of the natural order, but rather is clearly connected with the person's life in society" (Topor, 2001, p. 53). Stigmatisation ensures that people who have been defined as chronic sufferers by psychiatry assume psychiatry's definition of themselves. Thus the biography becomes the biology.

## **MEASURING RECOVERY**

Since the experience of recovery from mental disorder is unique to each individual, its measurement must be approached with great caution. One person's perception of recovery may not be acceptable to another. The central issue is recognising the importance of the subjective experience of recovery. External professional or societal expectations should not be applied to any individual, except when behaviour becomes clearly damaging to that individual or to society.

Attempts to measure recovery are fairly recent and, in terms of the exploration of themes and concepts, are not yet well developed. Some research and recovery models focus more on outcomes, others on recovery as a process. A particular challenge is attempting to quantify and categorise coping mechanisms whilst, at the same time, recognising that "What in one period of life may be helpful or is at least necessary, can become a hindrance/obstacle"<sup>2</sup> (Bock, 1999, p. 166).

However, now that 'Recovery Practices' are becoming policy in developing service systems in a significant number US states and nationally in New Zealand (New Zealand Mental Health Commission, 2001), the need to measure the effectiveness of these systems and practices is pressing. Attempts are being made to develop instrumentation which would make it possible to look more systematically at the factors promoting and inhibiting recovery (Ohio Department of Mental Health, 2003).

### **Factors Promoting Recovery**

A team of mental health consumers, professionals and researchers in the US has developed a compendium of resources entitled 'Can We Measure Recovery?' (Ralph, Kidder, & Phillips, 2000). Among the 19 recovery/recovery-related instruments included in the compendium, the following are particularly enlightening:

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<sup>2</sup> "Was in einer bestimmten Lebensphase hilfreich oder zumindest notwendig war, kann in einer anderen Lebensphase zum Hindernis werden."

*The Recovery Attitudes Questionnaire* measured peoples beliefs about the concept of recovery emphasising that recovery is possible and including such positive statements within the questionnaire as recovery needs faith and recovery is difficult and differs among people (Ralph et al., 2000).

*The Making Decisions Empowerment Scale* (Rogers et al., 1997), revealed five factors relating to empowerment and recovery: a) self efficacy/self-esteem b) power/powerlessness c) community activism d) righteous anger optimism, and e) control over the future

*Segal, Silverman, & Temkin's instruments* (1995) concluded that a) quality of life and independent social functioning are most likely to be related to personal empowerment, and b) organisational empowerment is more related to involvement in work, both paid and volunteer.

*Harding, Brooks, Ashikaga, Strauss, & Breier* (1987) reviewed longitudinal studies which revealed a recovery - or significant improvement - rate of between 46% and 68% of patients with schizophrenia. These researchers identified ways of separating out the residual effects of the disorder from the effects due to institutionalisation and other associated factors. *McGory* (1992) and *Anthony* (1993) also identified stigmatization, restricted choices, and low self-expectation as factors contributing to chronicity in people with serious mental illness.

*Tooth and colleagues* (1997) respected the implications of individual stories, backgrounds, resources and experiences on recovery by using Personal Construct Theory to examine recovery from schizophrenia from a consumer perspective. They identified eight categories (from 111 distinct themes): a) the *process* of coming to terms with the illness, b) the variety of *activities* that facilitated their recovery, c) aspects of the *environment* that facilitated their recovery, d) the effects of *medication*, e) aspects of *self* and coping strategies which helped in recovery, f) the role of various *networks* of people, g) the role of *hospitalisation*, and h) the *non-facilitatory factors* which hindered the recovery process. Of these categories, the role of self – encompassing determination to get better and manage the illness – emerged as the most significant. From responses in focus groups, 53% of participants named optimism and hope for recovery as significant. An equal number reported stigma as a negative aspect. Forty-nine percent identified the importance of spirituality in their recovery and a majority of participants identified a turning point in their journey of recovery.

*The Personal Vision of Recovery Questionnaire* (PVRQ) (Ensfeld, Steffen, Borkin, & Schafer, 1998) was designed to measure consumers' belief about their own recovery. Developed by a team of consumer and professional researchers, it revealed five main factors of recovery: a) support b) personal challenges c) professional assistance d) action and help-seeking e) affirmation.

The Well-Being Project (Campbell & Schraiber 1989), a landmark study conducted by mental health consumers in California, was a multi-faceted study aimed at defining and exploring factors promoting or undermining the well-being of persons diagnosed with mental illness. Using quantitative survey research, focus groups and oral histories, the research found that nearly 60% of the clients surveyed indicated that they could

always, or most of the time, recognise signs or symptoms that they are having psychological problems. The most favoured coping and help-seeking strategies were: a) writing down thoughts or talk the problem out (50%); b) eating (52%); c) calling or seeing friends (52%); d) relaxing, meditating, taking walks or a hot bath (54%); e) calling or going to see a mental health professional (62%)

*The Recovery Advisory Group model of recovery*, a power-point show available on the internet (Ralph, 1999), which focuses both on external influences on recovery and the internal, individual recovery process is a reflection of both consumer/survivor literature (published and unpublished) and the personal experiences of members of the Advisory Group. It recognises that the achievement of well-being or wholeness is not linear but is a process of six stages: a) anguish, b) awakening, c) insight, d) action Plan, e) determined commitment to become well, f) well-being/empowerment. Clearly, everyone may not experience all stages, nor does a person complete one stage before going to another. Recovery is viewed as both internal (encompassing cognitive, emotional, spiritual, and physical aspects) and external (involving individual actions/reactions to the influences of and/or interactions with other people and situations).. Internal aspects of recovery include: cognitive, emotional, spiritual and physical. The external dimensions consist of a person's action and reaction to external influences or interactions with people and situations as they move across, round and through stages of recovery. The internal journey continues within the context of the external world and its influences.

### **Turning Points**

A recurring theme in recovery narratives is the importance of 'turning points' on the journey of recovery from serious psychiatric illness. Topor, Svenson, Bjerke, Borg, and Kufas (1997) made an in-depth study of these turning points. In selecting participants, they only included people who had not been admitted to institutional care for a period of at least two years prior to the interview. Even though, at the time of the interview, some participants were in touch with services, they were living a 'normal lives' in society. Five persons (two women and three men between the ages of 32 and 51 years) were interviewed using a semi-structured interview guide. Three had received a diagnosis of schizophrenia and two were diagnosed with personality disorders and affective psychosis. Two of the informants can be considered as recovered and three as socially recovered. Using grounded theory methodology to analyse the transcripts, analysis showed that 'turning points' emerged as the dominant theme in all five narratives.

Before the turning point is reached in an individual journey, however, there is often a breakdown and "hitting bottom" – that is, a descent to a place which is characterized by feelings of impotence and the loss of a sense of identity (Topor et al., 1997). The façade that had covered the emptiness has collapsed and the individual is left with a feeling of hopelessness and a sense that the gulf between the role and the individual can no longer be bridged.

I saw everything as completely hopeless I didn't have much faith that I could ever come out of it as a whole person ... but I didn't have any choice either ... Stopping therapy and going back to the way it was before wasn't a real option for me ... so I

felt like, all I could do was follow through ... to the bitter end ("M", cited in Topor et al., 1997, p. 16).

At the 'turning point', then, a number of factors stand out as playing a crucial role. These may take the form of a fortuitous external event or a personal decision. Often the catalyst comes from an outside influence – a friend, a relative, treatment staff, a pet, or God. These catalysing factors come together in the form of an unexpected change in circumstances that force the individual to make a decision.

I think it was finally getting the right medication that enabled me to find my way out of this. It helped me to start doing things for myself. Because I didn't feel suffocated by the medication, it didn't rob me of my energy .... I didn't have to be injected, I could take it myself. I was the master over my own medication ("J" cited in Topor et al., 1997, pp. 12-13).

The most significant element of a 'turning point', then, which need not be dramatic, is a change in how individuals perceive themselves in relation to their symptoms, their condition, and their own lives. But the goal of regaining one's self is often a slow process and can take a long time: "the upward journey is not a straightforward or linear process" (Topor et al., 1997, p. 16). In maintaining the journey of recovery, people emphasise the role played by their own will, their own efforts. When these other people are professionals, they often do something more or something different than their professional role requires of them; they break the rules to form a reciprocal relationship. Coincidences can also play an important role. It is highly individual and is closely connected to the person's particular life history.

## RECOVERY SKILLS AND SELF CARE STRATEGIES

Research carried out amongst those who live with psychosis mainly outside the world of "services", reveals that in general self-help begins long before help from others and to a large extent may remain effectively independent of it (Bock, 1999). Self-help is not about coping mechanisms, in the sense of generalised techniques, but about strategies developed within the context of the individual's own complex biography: "from looking carefully at the biographies it is quite clear, that self-help is an immensely complex and very individual process and that the individual protective mechanisms change character in the course of time"<sup>3</sup> (Bock, 1999, p. 164).

Bock conducted in-depth interviews with 34 people who had persistent and recurring psychotic experiences. The group was subdivided into those who previously had no experience of psychiatry and those who had experience of psychiatry or only occasional contact. Using a grounded theory approach, Bock brought an anthropological perspective to bear on psychotic experience and concluded that grasping emerging points is like 'a collage', and within this collage, frank psychotic illness emerges as only one facet of a much wider range of psychotic experiences. According to Bock, "Psychotic experience is recognised as a very specific human

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<sup>3</sup> *"Eine genauere biographische Betrachtung macht hingegen deutlich, dass Selbsthilfe ein ungeheuer komplexer und sehr individueller Prozess ist und dass die einzelnen Schutzmechanismen im Lauf der Zeit mehrfach ihren Charakter veraendern."*

balancing act of contradiction and social compromise, an ambivalent condition of the simultaneously incompatible, finally an illness which contains the seed of health in it"<sup>4</sup> (1999, p. 4).

Psychotic experience, then, is not necessarily an illness, but may be or reflect an existential crisis, providing the opportunity or even the function of encompassing a new inner balance. In this respect, Bock's work is consistent with a position paper from the British Psychological Society, which argues that we should understand psychotic experience as a way of solving problems for which people have different capacities (British Psychological Society, 2000). Sometimes this goes wrong and then help from services, including medication, may be needed. Psychosis in the general community is more common than expected (Van Os, Hanssen, Bijl, & Ravelli, 2000), and as Bock's study shows, while changes or alterations may be experienced as unburdening or even a loss, at the same time they may also be an expression of building a new identity.

Many of the skills required to manage people's own lives and their emotional distress can be acquired once people begin to believe in their own capacity to recover, to develop self belief. Self-managed care may include a range of strategies, including holistic remedies, spirituality, physical exercise, and creativity. Medication may also be a positive tool for many when it is used voluntarily in a personally informed way to assist recovery. The important principles in relation to treatments are those of individual choice and self-determination and are central to an understanding of what helps people recover. One of Campbell and Schraiber's subjects in The Well-Being Project put it like this: "I'm on lithium and I should be coming off it next month. I'm trying to go it alone ... my doctor's agreed to let me try it. I lived without it for 35 years. Why should I accept the fact that I have to take lithium for the rest of my life" (1989, p. 47).

Bock (1999) speaks of 'pragmatic defence mechanisms' that help people cope. These may include smoking, play, work or the absence of work, a reduction in stimulation, meditation and creativity. Reeves (2000) suggests that journaling or keeping a diary may be helpful in making life connections and honouring feelings. Creativity helps with expressing feeling, relaxing and being absorbed. Music, pets, gardening and walking in nature also assist recovery (Mental Health Foundation, 2000). Spirituality and psychosis are closely related for many people (Jackson and Fulford, 2002). And spirituality often plays a role in recovery by providing a meaning or purpose to life, a reason for living, peace and comfort. Recovery itself is a "Journey of the heart" (Deegan, 1996, p. 91)

In addition to lifestyle changes, there are many internal changes in awareness of the self that assist recovery. Self-acceptance, accepting one's own humanity and attaining peace, play important roles: "I have to be kinder to myself and not expect miracles. I know it is about a process of development which requires time, that every

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<sup>4</sup> "Erkennbar wird die Psychoseerfahrung als eine sehrspezifisch menschliche Form der Gratwanderung, des zweifelnden Widerspruchs und des sozialen Kompromisses, als ein Zustand der Ambivalenz und der gleichzeitig von Unvereinbarem, schliesslich als eine Krankheit, die den Keim der Gesundheit in sich birgt."

development has its downside and that I have to learn to live with it"<sup>5</sup> (quoted in Bock, 1999, p. 77).

## IMPLICATIONS FOR PRACTICE AND POLICY

Important as self-care strategies are, research has shown that for the majority of people, relationships with professionals and mental health services can help recovery. Where such relationships are positive, they support the development of people's dreams and the attainment of their goals. "It came through that she wasn't just in it for the money or you know she wasn't up herself, I'm the psychiatrist, you're the patient sort of thing. She treated me like an equal person and just, I always saw her true person coming through sort of thing" (quoted in Tooth et al., 1997, p. 46).

However, it is also clear from the research literature that formal services are often perceived as hindering people's recovery through the "operationalization of society's response to mental illness – that of shame and hopelessness and the need to assert social control over the unknown and uncomfortable" (Onken et al., 2002, p. ix). Deegan (1996) and Glover (1999) both emphasise the importance of hope. This requires mental health professionals to appreciate: "the deep existential struggle that is at the heart of the night of despair" (Deegan, 1996, p. 95) through which the person is living.

A number of models have been proposed in an attempt to capture the difference between services that help recovery and those that hinder. Barker, a professor of psychiatric nursing, with experience as a psychiatric nurse and academic, has developed a conceptual model for the development of acute services that he calls 'The Tidal Model' (Barker, 1998). Within this model, the person is the story and her or his environment is likened to the ocean. It may be calm or stormy. There may be rocks or lighthouses. The purpose of professional intervention is to help the person concerned to understand his or her own story and to assist the person to change the direction the story is taking.

Saleeby (1997), a social worker, drew upon the biological sciences to develop an Ecology Model which emphasises the need for a healthy environment to ensure that organisms can develop well. Saleeby's work was further developed at Kansas University, and is variously known as the Kansas or Strengths Model (Rapp, 1998). It demands from mental health workers a conceptual leap to stop looking only for, and hence identifying, problems, deficits, sickness or being unwell. According to Cowan (1999), "It demands that the created environments for people with severe and persistent mental illness are overtly enabling rather than entrapping" (p. 7). Similarly, "Recovery requires the right atmosphere or organizational climate in your mental health organization – one that is sensitive to consumers, and values independence of the individual. It allows consumers to risk, to fail. It holds that every consumer has a right to the same pleasures, passions, and pursuits of happiness that we have. It looks at potential, not deficits" (Weaver, 1998).

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<sup>5</sup> "*Ich muss gnaediger mit mir selbst umgehen und darf keine Wunder erwarten. Ich weiss ja, dass es sich um einen Entwicklungsprozess handelt, der Zeit braucht, dass jede Entwicklung auch ihre Rueckschlaege.*"

Whatever model is adopted, training will be important in what are becoming known as 'recovery based competences' (New Zealand Mental Health Commission, 2001). Such competencies should not be an add-on to current training; rather, they require a fundamental shift towards user involvement in both development and delivery. Service users in New Zealand, drawing on a range of information sources, have developed a list of recovery competencies. These include a) understanding recovery principles and experiences, b) sustaining a positive focus on equality and social inclusion, c) recognising self-determination, d) acknowledging and supporting the consumer movement and e) having family support.

In addition to the training of professionals, there will also need to be changes in service provision. A study by an independent mental health organisation in the UK, the Mental Health Foundation (2000) showed the need for more easily accessible services in a crisis, particularly out of office hours, for emergency care overnight, for more talking and complementary therapies, and for a greater awareness of the diverse needs of people from minority ethnic communities.

The Ohio consumer group (Ralph & Lambert, 1996; Ralph, Lambric, & Steele, 1996) developed a set of statements to rate the impact of mental health professionals on their recovery. In a pilot study, clients in the mental health system rated these from most to least impact:

1. Encourage my independent thinking
2. Treat me in a way that helps my recovery process
3. Treat me as an equal in planning my services
4. Give me freedom to make my own mistakes
5. Treat me like they believe I can shape my own future
6. Listen to me and believe what I say
7. Look at and recognize my abilities
8. Work with me to find the resources or services I need
9. Are available to talk to me when I need to talk to someone
10. Teach me about the medications I am taking.

Key issues identified in consumer personal accounts are validations of these statements (i.e., offering encouragement, believing in a consumer's abilities, empowering by treating the person as an equal in planning for and delivering services) listening and believing, and emphasising free choice.

### **Building on Self-Management to Implement Recovery Oriented Services**

In the US, the concept of self-management began being applied to people with chronic physical conditions in the 1970's. In the late 1980s and early 1990s, that application was extended to people who experience mental health problems. In the UK, on the other hand, development and evaluation of self-management is in its early stages. In recent policy initiatives – such as "Saving Lives: Our Healthier Nation" (Department of Health, 1999b) and the "NHS Plan" (Department of Health, 2001a) – the initiative has been given the highest priority. These documents set out the

government's vision for a new, more patient-centred NHS, and confirm a commitment to help people with long-term conditions maintain their health and improve their quality of life. Their Expert Patients Programme endorses self-management of mental health issues and wellness as an essential component of recovery-oriented services:

“The era of the patient as the passive recipient of care is changing and being replaced by a new emphasis on the relationship between the NHS and the people whom it serves – one in which health professionals and patients are genuine partners seeking together the best solutions to each patient's problem, one in which patients are empowered with information and contribute ideas to help in their treatment and care” (Department of Health, 2001b, p. 9).

There are a number of developing approaches to implementing recovery oriented practice upon which recovery-oriented services can be established. One of the largest of these approaches is the Ohio Mental Health Consumer Outcomes Initiative (Ohio Department of Mental Health, 2003) which has built recovery into its information technology-based outcomes system. This functions from individual case management and enables the aggregation of information at a state level.

Perhaps the fastest growing individual approach to mental health recovery is the self-management framework developed by Mary Ellen Copeland (2002) in Vermont, USA. The Wellness Recovery Action Plan (Copeland, 1997) is a simple yet powerful self-help system based on increasing awareness, improving self-care and strengthening supports. The following is a brief outline of the framework:

*Five foundations of recovery.* a) hope, b) personal responsibility, c) education, d) self-advocacy, and, e) developing & maintaining a support system.

*Wellness Tools.* Activities, routines, thoughts and behaviours that maximise wellness and minimise symptoms. (i.e., reaching out for support, peer counselling, maintaining an ongoing dialogue with health and social care professionals, planning the day, stress reduction and relaxation techniques, focusing exercises, diversionary activities and fun, journaling, exercise, sleep, being outside, increasing or decreasing stimulation, and the act of stopping to analyse a situation to make a thoughtful decision on how to proceed).

*Writing a Plan.* Writing a plan must be entirely under the control of the individuals who plans to use them, when they are well or feeling all right and with help from their supporters if they wish. Mental health staff, family members and friends can provide support, feedback and encouragement. The process can be lengthy and must be done at the individual's own pace. The plan should include the following: a) daily maintenance (what I do each day, when I am feeling well?); b) triggers (what are my triggers and what is my response to each one?); c) early warning signs (what are early warning signs for me, and what is my action plan for each one?); d) when things are breaking down (how do I know? breaking down list and responses / action plan); e) crisis plan (how to know when I am well, crisis symptoms, supporters' phone list, medications, treatments, treatment facilities and respite care, supporters' roles, what to do if I am a danger to myself or others, and how to know when my supporters no longer need to use this plan?)

In addition to Copeland's plan, a wide range of other self-management information resources and tools are now available in the UK. These include the Manic Depression Fellowship Self-Management Training Programme, and self-management books and resources for people who hear voices (Coleman and Smith 1999) and for those who self-harm (Smith, 1999). Further, Rethink (2003), a national voluntary organisation, has a research and development programme addressing the issue of self-management. There are a number of developing service-user run crisis and recovery support services that operate in 'recovery' oriented ways that recognise the importance of self-management.

Thus, self-management and empowerment are important adjuncts to other mental health treatment approaches, and provide hope for recovery to its service users and significantly increase the effectiveness of services.

The challenge for the NHS, working in partnership with patient organisations and other governmental departments... is to bring about a fundamental shift in the way in which chronic diseases and long-term conditions are managed – a shift which will empower and liberate patients to play a central role in decisions about their illness (Department of Health, 2001b, p. 6).

## **RECOVERY AND VALUES-BASED PRACTICE**

The importance of self-management skills in the development and implementation of recovery-oriented practice highlights a tension that runs through the recovery literature between separation *from* and engagement *with* services. The development of the recovery movement, with its origins in human rights and empowerment of disadvantaged groups has been, to an important extent, outside of and even in contradistinction to traditional models of service orientation and delivery. In this respect, the recovery movement is a "survivors" movement. But recovery is not "anti-psychiatric". To the contrary, as the literature reviewed here illustrates, it acknowledges and endorses the key role that services can play for some people. Recovery, then, is defined not so much by *separation* from services as by the demand for a new *response* from services, a response which is positive, respectful, facilitating and empowering.

The management of this tension between separation from and engagement with services is a central issue for the development of policy and practice in the UK. Other countries - notably Sweden, Australia, New Zealand, and the US – have well developed models but perhaps the UK is first in the field to bring the "user as expert" so fully right into the heart of health policy. Doing so involves "a fundamental shift in the way in which chronic diseases and long-term conditions are managed" (Department of Health, 2001b, p. 6). Such a shift is very much to be welcomed; however, it should be undertaken carefully. With significant and continuing organisational and other challenges to professionals (United Kingdom Department of Health, 2001c) primary care services and patient centredness are at the heart of a developing health service in the UK – so much so that many professionals fear that, in place of disempowered users, we will end up with disempowered professionals.

There may be some in the survivor movement who would see the disempowerment of professionals as no bad thing (on the not unreasonable basis that they equate the empowerment of users with the disempowerment of professionals). Certainly, as the origins of the recovery movement itself show, there has been a need to balance power relationships in health care (McCubbin & Cohen, 1996). And there is good epidemiological evidence (noted above) that many with psychotic experiences may have no need of psychiatric services at all. But those who do need services, need the support of empowered and enabled professionals. Power is not necessarily a zero-sum game, and empowering users, including reducing professional "power over" them and "over" service delivery and policies, can increase professionals' "power-with." Insofar as empowering users aids in their recovery, the professionals have become more effective. As such, though they may have been "depowered" over users and over the service system, they have become empowered in their capacity, as professionals, to play a role in user recovery (McCubbin & Cohen, 2003; Prilleltensky & Nelson, 2002).

Many different strands of policy, practice, training and research must come together if we are to build the balanced and mutually respectful partnership between users and providers of services to which the recovery movement points. A variety of (not necessarily exclusive) approaches are on offer here: for example, critical psychiatry (Bracken and Thomas, 2001), discursive psychology (Sabat and Harré, 1997) and, in Continental Europe, hermeneutics (Widdershoven and Widdershoven-Heerding, forthcoming).

One approach to resolving the tension, which we believe has not been sufficiently highlighted, is through a more mature understanding of the way in which values come into decision-making in healthcare. This approach, paralleling as it does the more mature understanding of the role of evidence captured in the concept of Evidence-Based Practice (EPB), has been called Values-Based Practice (VBP, see Fulford, forthcoming).

Values-Based Practice (VBP) has many similarities to recovery: a) it starts from respect for the values of each individual (in this VBP differs fundamentally from "ethics", in so far as ethics aims to tell people what is right); b) it emphasises the importance of strengths and positive values rather than focusing on deficits and negative values; c) it is concerned as much with process as with outcomes, building on skills of communication, awareness and engagement; d) it provides options in care - genuine choices that are built on the diverse skills and resources of different disciplines, and that reflect the strengths and resources of each individual rather than the demands of "authority" (professional, ideological or political); and e) it puts decision-making firmly in the hands of those most directly concerned, individual users and providers working together in the real-life contingencies of day-to-day care.

Although a relatively untried approach, the potential of Values-Based Practice is already being explored through a number of initiatives in the UK. The first action of the National Institutes for Mental Health in England (NIMHE), the government agency responsible for implementing policy on mental health in England, was to launch, by Ministerial Announcement in July 2001, a Values Project Group. The need for such a group was made evident by feedback reported to the web site of the National Director for Mental Health (2003) (NIMHE's pre-launch website) showing the extent of the many

gaps (gulfs, really!) between the values — the needs, wishes and expectations — of the different stakeholders in mental health. The draft NIMHE Values Framework, then, produced by the Values Project Group, rather than attempting to reconcile (still less to rule between) these different values, is process-oriented. It is a framework that aims to support the VBP-skills of effective healthcare decision-making, where "effective" means, as in Onken et al.'s (2002) definition of recovery, empowering the individual in "a personal journey of actively self-managing psychiatric disorder while reclaiming, gaining and maintaining a positive sense of self, roles and life beyond the mental health system ..." (p. 2).

Only time will tell how the UK government's new user-centred approach to policy and practice in mental health will work out. As contributions to this approach, both recovery and VBP are open, experimental, and responsive to experience. They are ready to be judged by results rather than driven by received wisdom, however well-founded theoretically. NIMHE, although primarily a policy-implementation rather than research-funding arm of government, is providing significant preliminary support for the research on which future developments will be based. Initial experience of training programmes in Values-Based Practice, developed by the Sainsbury Centre for Mental Health in partnership with Warwick University, suggests promise for this approach (Fulford, Williamson and Woodbridge, 2002). New programmes, focusing particularly on values in recovery practice, are planned at Wolverhampton University; and similar developments are anticipated in other areas of NIMHE's work (such as the Equalities and Black and Ethnic Minorities programmes).

There are, however, also significant challenges for the user-centred approach, notably in how we respond to societal concerns about public safety, for example, and in how we overcome the continuing (even deepening) negative stereotypes of mental distress and disorder. At best, in meeting these challenges, a genuinely new paradigm of user-provider partnership will emerge, in which the tension between engagement with and separation from services is successfully resolved. Failure to meet these challenges could result in a return to an adversarial relationship between users and providers - with users "surviving" by escaping from services, and with providers reluctantly drawn into coercive regimes, reinforcing dependency, and stifling the spring of recovery.

## **CONCLUSION**

The research and narrative reports reviewed in this article make clear the extent to which the recovery movement, led by people with experiences of mental disorder and their family members, can make a very positive contribution to the development of policy and practice in mental health. This highlights the importance of the UK government's commitment to, and the investment of resources in, employing "experts by experience" in statutory as well as independently run services, to carry out research into what helps people's recovery from mental disorder (including self-management) and to develop and deliver effective recovery-oriented services.

Resolving the tension implicit in the recovery approach, between engagement with and separation from services, will take time and patience. A better understanding of the role of values in mental health policy, service implementation and practice, together with improved skills as the basis of services that focus on the strengths and uniqueness of each individual, may be one way in which this tension can be successfully resolved.

## RÉSUMÉ

Le concept de “rétablissement” et les pratiques et services orientés en ce sens sont reconnus dans certaines parties du monde, particulièrement aux États-Unis et en Nouvelle-Zélande. Cet article donne un aperçu de la littérature traitant de la possibilité de rétablissement pour les personnes atteintes de problèmes psychiatriques sévères, et examine la signification du concept de rétablissement dans le contexte de la Grande-Bretagne, où ce concept reçoit une reconnaissance grandissante. L'article trace les bases du développement de la conscience de la possibilité de rétablissement (avec ou sans aide des services de psychiatrie) et clarifie les enjeux du concept auto-entretenant de chronicité. Il traite aussi des modalités permettant de mesurer le rétablissement et du concept de rétablissement en tant que processus et objectif. Il identifie les thèmes principaux présents dans la littérature et la recherche pertinentes, pour traiter ensuite plus spécifiquement de la capacité du rétablissement des personnes ayant reçu un diagnostic de schizophrénie, de psychose ou d'autre problème psychiatrique sévère et des stratégies employées par ces personnes pour s'aider elles-mêmes. Finalement, l'article aborde des questions touchant l'amélioration des politiques et des pratiques – surtout la résolution de la contradiction primordiale entre l'engagement dans les services et l'éloignement des services. Pour faire de progrès dans ce sens, une meilleure compréhension du rôle des valeurs dans le rapport entre le clientèle et les intervenants et intervenantes sera nécessaire.

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