# The Rehabilitation-Recovery Paradigm: A Statement of Philosophy for a Public Mental Health System

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The purpose of this statement is to provide an overview of the rehabilitative-recovery philosophy of mental health services. It is an extension of an earlier document that the author was asked to prepare for discussion within the Illinois Office of Mental Health. The use of a recovery philosophy as a general guide for service planning and delivery necessitates a process of interpreting its meaning and exploring its concrete implications for a particular system of services, a process for which this article is only the first step. It is intended to address some common questions regarding (a) the meaning of recovery, (b) the premises for adopting such a philosophy, (c) this philosophy's relationship to various service models, and (d) its implications for policy and program development with examples drawn from the Illinois public mental health services system.

In the words of a recovered consumer, "Rehabilitation refers to the services and technologies that are made available to disabled persons so that they might learn to adapt to their world. Recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of the disability" (Deegan, 1988). There is a rich and growing literature on recovery from the consumer perspective; indeed, one of the foremost professional leaders in rehabilitation points out that the consumer/survivor literature is the source of the recovery concept within the mental health field (Anthony, 1993). Recovery is not the same as cure, but, as another consumer experienced it, "a willingness to change myself to become all that I wanted to be. It was

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accepting the illness, but working toward health" (Schmook, 1994). Recovery involves the idea that consumers assume responsibility for their lives by making choices and learning from that process; the corollary is that professionals must affirm and nurture the process of consumer choice. The consumer literature abounds with examples of the centrality of the experience of choice and responsibility. For example, "Sadly, for years, I had expected someone else to 'fix' me. However, I finally realized . . . that no one else could really make me better . . . for the first time, I finally felt ready to take responsibility for myself" (Leete, 1994).

The emphasis on choice and responsibility is in sharp contrast to much of the professional literature on symptom management, case management, functional skill development, etc., where the strategy is to shape the person's behavior through external interventions.<sup>2</sup> But recovery is more than regaining external roles and functional skills, although these are certainly important; it is also about restoring the self. The consumer movement reaffirms the individual's intentionality, consequently returning the individual to the realm of being and experience and re-acquainting him or her with the inner dynamics of feelings (like shame or hopelessness), internalizations (like stigma or punitive images) and self representations (identification with the illness).

The experiential dimension of psychotic illness, involving the fragmentation of the self and perhaps loss of parts of the self to memory, has not received sufficient attention, preoccupied as we have been with behavior and its management.<sup>3</sup> The partial loss of one's narrative history, and in some cases the wounding of the remaining parts by abusive conduct from others, would certainly tend to disorganize the self structure to the point of undermining intentionality and hope (Deegan, 1996). If in the midst of a disintegrating inner world, the individual encounters a treatment system that over-saturates him or her with the notion of chronic illness, he or she may become identified with the illness. An ethnographic study of persons with serious mental illness, as they participated in various support groups and treatment

activities, demonstrated that mental disorders can become "non-human agents" with which the participants learn to interact and manage by attributing various mental states and impulses to the illness (Weinberg, 1997). While education about the illness is an important component of rehabilitation, some recovered consumers point out that when one attributes everything to the illness, one is always sick. Identification with an illness may feel better than no identity, if that is the choice seemingly offered. As the individual descends into powerlessness and identification with the illness, intentionality is effaced and being is reduced to mere vegetative existence.

Recovery, then, means the recovery of self and hope through exercising choice and learning responsibility (Deegan, 1996; Littrell, Herth, & Hinte, 1996). It is a mode of being that is entered into, an act of conscious volition, not something imposed from without. The process may begin with the person's recognition that he or she is more than the illness, followed by efforts to further restore the capacity for self-recognition and self-regulation. In the view of many recovered consumers, symptom reduction is secondary to improving competencies, and both must be subservient to the recovery of being.

It has also been persuasively argued by Harding (1994) that recovery, from a research point of view, is not an end state and that the notion of recovery as an *outcome* is a research artifact. This is because there is not a scientifically rigorous and universally accepted criterion for defining and operationalizing the concept. In fact, she asserts, "we are actually studying markers in the course of life . . . in which illness is only a part" (p. 157). In other words, these 'measures' are socially-constructed markers devised to anchor the concepts of illness and recovery, concepts whose epistemological status is unstable at best. Therefore, she concludes that the focus should be on the *person* in the context of his or her life course, not on the illness per se. Harding's analysis supports the notion of recovery as a developmental process and is consistent with the consumer-survivor perspective that recovery is a mode of being that subsumes (without denying) the illness/disorder. However, the displacement of end states and outcomes by a *process* 

forces a consideration of how the recovery philosophy interrelates with outcome-oriented services.

## Medical Model, Rehabilitation Model and Community Support System (CSS) Model

Illness and Disability: Medical Model and Rehabilitation Model

In Illinois, as in most states, the public mental health system's mission and services are directed toward persons with serious mental illnesses (SMI). SMI involves both a medical illness AND a functional disability. Medical/clinical services focus on reducing the symptoms of the mental illness, while rehabilitative services focus on reducing the level and duration of the psychiatric disability. As others have pointed out, the assumption that serious mental illnesses like schizophrenia typically follow a progressively deteriorating course is no longer supported by research (Corrigan & Penn, 1997; Harding, Brooks, Ashikaga, Strauss, & Breier, 1987; Lin & Kleinman, 1988; McGlashan, 1988). Many mental health services address both symptoms and functional disability and, in fact, there is a significant degree of overlap between these two aspects of SMI and between the two types of services which are applied to them. Given this overlap, Bachrach (1992) has reframed the illness-disability split into one unified concept of primary, secondary and tertiary disabilities. The primary disability encompasses the symptoms and functional impairments (e.g., thought disorder, cognitive impairment, verbal incoherence); the secondary disability is the subjective experience of the illness (e.g., internalized stigma, withdrawal, hopelessness); and the tertiary disability consists of the social consequences of the illness (social isolation, discrimination, unemployment, poverty).

Only after severe psychiatric symptoms (or primary disabilities) are ameliorated and the medical condition is stabilized can rehabilitation realistically begin. This is because the cognitive impairment and affective distress that often result from a psychotic episode can make it very difficult for the individual to focus on recovery

goals (secondary and tertiary disabilities). Indeed, the imposition of such demands during this phase of the illness may aggravate the condition. However, with appropriate timing and if the consumer so chooses, rehabilitative services and the recovery process can help channel energy, focus attention, improve coping skills and bolster self-esteem, all of which accelerate clinical progress and prevent relapse and recidivism.

Literature reviews and meta-analyses of psychosocial rehabilitation (PSR) outcome studies show generally favorable, though not totally consistent results (Anthony & Liberman, 1992; Bond, Drake, Mueser, & Becker, 1997; Cook & Jonikas, 1996; Corrigan & Yudofsky, 1996; Dilk & Bond, 1996; Drury, Birchwood, Cochrane, & MacMillan, 1996; Herz et al., 1997; Penn & Mueser, 1996). However, clinical trials of certain manualized program interventions have achieved significant results (Eckman et al., 1992; Marder et al., 1996; Smith et al., 1996). For example, one rehabilitative approach combines multiple family psychoeducation (about serious mental illnesses and mental health services) with multiple family groups that include the consumers. The group sessions address everything from coping skills to vocational rehabilitation to advocacy. Research on this particular program model has demonstrated an effect size in medicated patients equivalent to that of pharmacotherapy (McFarlane et al., 1995). So, in practice, rehabilitative interventions and medical interventions may be combined to accomplish shared objectives.

The Joint Commission on the Accreditation of Health Organizations (JCAHO) Lexikon defines disability as the "consequences of impairment" and rehabilitation as the restoration of functioning following an illness, including "the combined and coordinated use of medical, social, educational, and vocational measures" (O'Leary, 1994). The JCAHO Accreditation Manual groups medical and rehabilitation services together under the category of patient care (JCAHO, 1996). Consequently, the overlap between illness and disability forms the basis for the complementarity of the medical and rehabilitative models of mental health services.

Integrating the Medical and Rehabilitation Models of Service Delivery

If one accepts Bachrach's (1992) integration of illness and disability (or even the premise that the two are connected), it logically follows that the two types of services should inform one another. For example, the rehabilitative component should be sensitive to the unique character of each consumer's recovery process, including his or her present medical condition and ability to tolerate task demands. The important work of eliciting the consumer's recovery goals and choices should proceed through an individualized and clinically sensitive dialogue that helps the consumer to prepare for and to accept occasional setbacks as part of the process. In turn, the medical/clinical component of services should strive to see the consumer in a holistic way, as a person with goals and aspirations who has a life that extends beyond the illness and beyond the present clinical setting. Clinicians ought not assume that a particular episode is representative of the individual's whole life or of the entire population of persons afflicted with SMI, an assumption that has been termed "the clinician's illusion" (Harding & Zahniser, 1994). This means that medical/clinical staff must be able to imagine the person's life outside the hospital or clinic and to conduct assessment and treatment within that larger perspective. By unifying the clinical sensitivity to the individual's present medical/mental state and the rehabilitative perspective of the whole life, the two models mutually inform one another and achieve maximum results. Therefore, it is critical that the two models not be seen as mutually exclusive or conflicting.

Each of the mental health disciplines has a unique role to play and special competencies to contribute to integrating these approaches. Rehabilitation is *trans*-disciplinary, meaning that it is competency-based rather than discipline-based. Each of the mental health disciplines can prepare one to *acquire* rehabilitation skills. However, no discipline guarantees that each member of the profession is qualified to *provide* rehabilitation services to persons with SMI; that may necessitate additional training.<sup>4</sup> Even though their emphases may differ, all of the

mental health disciplines are united by the shared outcomes of symptom reduction, functional improvement and achievement of individual consumer recovery goals.

### Community Support Systems (CSS)

The Illinois Office of Mental Health (OMH), in conjunction with its Joint Advisory Council, has followed the lead of the Federal Center for Mental Health Services by adopting the CSS model as the template for the community-based services it funds on behalf of its consumer target population. This model specifies principles and system-level outcomes regarding necessary service components and how they interrelate, with case management at the hub. The CSS model includes rehabilitation and consumer-centered services and thus already points in the direction of the rehabilitation-recovery paradigm. The recovery philosophy is simply the next logical step; it articulates what rehabilitation services are and how they are guided by the idea of recovery as the ultimate purpose of mental health services. Recovery signifies the consumer's effort to regain functional skills, social roles and self and further develop them to his or her highest potential. Since this is the guiding purpose of the community support system, it is a purpose that must be supported by all of its components.

In summary, while each of the three models (medical, rehabilitation, community support system) is responsible for *outcomes*, the recovery philosophy articulates the *process* through which this occurs in partnership with the recovering consumer. From this perspective, the consumer-centered recovery philosophy is the umbrella over all models, disciplines, practices, and activities in the hospital and the community.

## The Recovery Philosophy: Principles and Implications

As previously noted, the recovery-rehabilitation model and the medical model are not only conceptually compatible, they can otentially enhance one another. But, the challenges raised by the ideas

of recovery and empowerment must be candidly acknowledged because they go to the very heart of what is meant by "mental health treatment." As such, these seminal ideas will tend to touch a "raw nerve," however cloaked our responses might be in the language of academic theory, management, or professional guilds. These challenges call our attention to the following values:

- 1. Wholeness means humane and integrated services.
- 2. Client-centered services are those individualized to the consumer's needs (rather than the provider's convenience).
- 3. Hope (not "maintenance" or "custodialism") means that persons with psychiatric disabilities can have a "real life."
- 4. Partnership (not paternalism) means working collaboratively with consumers, their families and other professionals.

The rehabilitation-recovery paradigm compels professionals and policy-makers to take a fresh look at how we structure our accountability, including perhaps in many instances, a re-evaluation and redefinition of our professional identity and role. As managers of a system of professional services, it challenges us to promote, in partnership with consumers and families, an organizational culture of recovery and empowerment, manifested not just in a collection of policy documents but in how we do our daily work. In the sense that a culture is a form of life, we are creating together a new form of life with opportunities for all concerned. Some possible concrete implications and examples include:

- 1. Empowerment refers to staff as well as consumers; a disempowered staff could hardly be expected to act as models for consumers. The implications for both training and organizational development are critical (Corrigan & McCracken, 1995).
- 2. Integration of rehabilitation and medical model services across hospital and community settings may lead to replacing the concept of "discharge" with that of "transition." Otherwise, one is left with the impression (and consequences) of processed

- cases rather than persons returning to their communities and to services that are continuous and consistent with those provided in the hospital.
- 3. Client-centered services means, among other things, that in token economy programs the behavioral targets must go beyond unit management objectives and creating "good patients" (e.g., "brushing teeth in the morning") to targets that are sequential steps in an individualized rehabilitation plan developed with the consumer.
- 4. Validating *client choice* means acknowledging that sometimes those choices will conflict with unit and program management goals (e.g., regarding refusal of medications, seclusion, etc.). It may be useful to develop with consumer advocates a structured method for responding to such situations that honors the individual consumer and his or her recovery process while respecting the professional obligation to offer medical-clinical services in line with current best practices and to maintain a therapeutic environment which is safe and healthy for everyone.
- 5. Hope, in place of custodialism and maintenance, might mean that the consumer's own life aspirations are validated by routinely inquiring about them, empathically listening, facilitating a dialogue that elicits the authentic core of those aspirations, and assisting the individual to translate them into achievable objectives (e.g., a job, a place to live independently, etc.). For a given facility, it might mean that every time an activity is implemented, the consumer participants are asked to remind the professionals present and themselves of their recovery goals and objectives and which ones are connected with the activity. Hope can also be generated when recovered consumers/prosumers are hired in mental health services organizations, helping clients to acquire an expanded vision of their own recovery potential.
- 6. Partnership means that each partner--consumers, professionals, each discipline--accepts that he or she does not have all the

answers and works WITH one another, not doing things TO one another, not competing, not engaging in paternalism. Partnership is also a choice.

### The Illinois Experience with Rehabilitation and Recovery

While this statement of philosophy might appear excessively ambitious, daunting, threatening, etc., it is important to recognize that in many states, significant progress has been made. Illinois is well past the crisis stage (precipitated by ACLU class action litigation in 1992); a reform (recovery) plan initiated goal-oriented responses. Many system-level problems have been successfully addressed, as evidenced by increased staff/patient ratios in hospitals, reduced incidents of abuse/neglect, reduced census and admissions, implementation of community pre-screening and linkage, implementation of fidelity model Assertive Community Treatment (ACT), intensive case management services, and an ongoing shift in resource allocation from hospital to community services in order to assure treatment in the least restrictive setting.

In the context of this progress, the ACLU litigation was withdrawn in 1997. Upon this stable foundation, the implementation of a rehabilitation-recovery approach is well under way through the following ongoing efforts: (a) state hospital-community services integration through regional networks; (b) rehabilitation paradigm development for the disciplines; (c) CONNECT98, a statewide initiative for funding state-of-the-art psychosocial rehabilitation services (PSR) in the community; (d) consumer-professional partnerships with NAMI-Illinois and the Illinois Mental Health Consumer Consortium, plus ongoing collaborative outreach through the OMH Office of Consumer Affairs (headed by a consumer/psychiatric survivor); (e) an initiative to recruit and train consumer advocates for paid positions in each of the state hospitals; (f) an ongoing contractual affiliation since 1993 with the University of Chicago Center for Psychiatric Rehabilitation for training and technical assistance in implementing rehabilitative services in hospital and community programs; (g) an action plan for

a delicate balance between holding firmly to the core elements of the PSR model while listening, validating and learning from provider input. An overly dogmatic response, besides setting a poor example, might have generated a negative backlash against the very ideas being promoted. A lengthy period of provider-consumer input through regional network advisory councils, combined with education and technical assistance about the PSR approach, helped in addressing most concerns. Resource materials were assembled from the published literature, and exemplary programs as well as new materials developed specifically to address program transition issues. The active involvement of the OMH Director of Consumer Affairs, a recovered consumer, was especially effective in establishing the credibility, or at least the plausibility, of the recovery paradigm among those who were initially skeptical. It is also important to note that most providers responded to this initiative with enthusiasm and that many community mental health service providers were already providing PSR services of a very high quality. Here the principal concern was to support those efforts rather than undermine them with a new set of administrative procedures.

Among the minority of providers who expressed reservations about the PSR model, the concerns were typically framed in terms of risks to the stability of "lower functioning" clients whose condition was perceived to be relatively fragile and ill-suited to a recovery approach. We validated the concern but not the desired response ("Let us retain a traditional day treatment program for those clients."). It is true that consumers who have relied upon a structured day program for 3-5 days per week, which consists of organized social-recreational activities, will need a replacement social structure. Within the PSR paradigm of peer support and socialization, there are opportunities for social activity without the paternalistic or custodial aspects of the previous social structure. This can provide the consumer with an opportunity to experience on a more subtle level the social ecology of choice and to become more comfortable with the process of choosing. It is still a "holding environment," but one which does not "hold back"

integrating vocational rehabilitation and mental health services and for facilitating access to vocational services by persons with serious mental illnesses; and (h) training events in FY1998 and FY1999 featuring national leaders in psychiatric rehabilitation, introductory and advanced community college courses in PSR skills for hospital and community provider staff, and a statewide demonstration project of training for hospital and community providers on the McFarlane model of family psychoeducation.

Despite this admirable record of progress, one should not underestimate the barriers encountered or the remaining obstacles. For example, the CONNECT98 Initiative, which implements state-of-theart PSR services to replace and/or enhance existing day treatment services, leverages the conversion of roughly 60-75% of existing services with a modest amount of new funding. Most, but not all, community providers have embraced the new direction. Due to concerns about Medicaid revenue, some initially perceived their organizational interests to be better served by the status quo. The Medicaid system presented other, more technical, problems as well, including that of designing the PSR services initiative to be consistent with Medicaid categories for those services deemed billable. This necessitated reconciling a rehabilitation/recovery model with one based on the concept of medical necessity. The problem was that of encouraging appropriate levels of Medicaid revenue generation by PSR providers without discouraging the provision of important PSR service components, such as peer support and vocationally-oriented services, which do not generate Medicaid revenue. The Office of Mental Health decided to fund at 100% those PSR services that are not Medicaid billable and to develop a PSR financing model which incorporates variable levels of estimated Medicaid revenue.

An anticipated challenge was that of skepticism among some day treatment providers about rehabilitation/recovery-oriented services and the underlying premises of such an approach. These concerns seemed to arise at the level of day treatment supervisory and line staff and then filter up to the agency executive. The OMH response required

the consumer, i.e. it is a *therapeutic* holding environment which is enabling but not controlling. For professional staff this new approach requires a transition from a directive role to that of a *convener* and *facilitator*, from providing to *training* and *mentoring*, enabling volunteers and prosumers to act as *catalysts* for social structure and support. Concerned providers were reminded that peer support/socialization centers could serve multiple functions including drop-in centers, organized social events on a sign-up basis, formal skills training groups, job clubs, and consumer-run businesses like a cafe or tea room. Similarly, clubhouse models have been adapted for lower functioning consumers with skills training classes for those who choose to participate (Cella, Besancon, & Zipple, 1997). The dominant themes of the technical assistance were individualizing services, maximizing consumer choice, recruiting paid prosumer staff, and developing more flexible expectations among professional staff.

The barriers to rehabilitation and recovery within the state hospitals are complex due to the more formal, discipline-based structure of such settings. The disciplinary specialization combined with a medical model structure has had the effect of compartmentalizing the medical and rehabilitative services as well as splintering the various rehabilitative activities. For example, token economy-incentive programs for behavior change are unit-based, while in most facilities vocational and educational services are centralized and conducted offunit. Unit managers tend to become concerned with issues such as admissions, discharges, census, etc. Nurses and physicians are concerned with monitoring medication response and symptom levels. In addition to implementing behavioral economy programming, mental health technicians are responsible for getting patients to their appointed place on time, whether a group on the unit, an educational service offunit, or a psychiatric appointment. One strategy has been to identify "Champions" within each unit and facility who are the catalysts for rehabilitative programming.<sup>5</sup> Another is to begin implementing assessment, treatment planning and discharge mechanisms that require the integration and individualization of the various services. Each of

the ten state hospitals has a unique history and organizational culture that may, on occasion, tend to resist efforts to impose universal structures throughout the system. Once again, a respect for local determination and empowerment has to be balanced in relation to the need for accountability, in this case, accountability to the consumer's right to integrated, individualized services with continuity between hospital and community settings.

#### Conclusion

A recovery approach is already unfolding within the Illinois mental health services system and its various components. It is parallel to the recovery approach disseminating throughout our national system. Like the proverbial idea whose time has come, its momentum has developed almost to the point of a self-perpetuating process. This is perhaps attributable to the authenticity of this philosophy's roots in the human experience of consumers. In the words of other recovered consumers, "Consumers have always lived with the potential to recover in their lives" (Schmook, 1996).

The recovery philosophy is compatible with the major service models. Indeed, it integrates and grounds them. But obstacles and challenges remain, including challenges presented by the recovery philosophy itself: listening, learning, understanding, sitting with it, making it our own, living it on a daily basis. Professionals cannot merely settle for a philosophy while becoming complacent about its concrete implementation. Perhaps it is time to begin our own process of recovery and self-examination. Those who are serious about the recovery philosophy will need to place sustained attention on generating ongoing leadership from consumers, family members, and professionals at all levels within the mental health services system. Professionals need to learn how to be sincerely grateful when a consumer teaches us something. This will contribute to their empowerment, to our own humility, and to authentic partnership.

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#### **Footnotes**

- 1. A parallel line of descent may be traced from the work of Chicago psychiatrist and neurologist, Abraham A. Low, M.D., who founded Recovery, Inc. in 1937 (Fichtner, Jobe, & Barter, 1991).
- 2. One of the notable exceptions is the approach of Anthony and his colleagues at the Boston University Center for Psychiatric Rehabilitation.
- 3. A recent departure from this pattern is the recently reported three year clinical trials of personal therapy for persons with schizophrenia by Hogarty et al., (1997).
- 4. The International Association of Psychosocial Rehabilitation Services has developed *Practice Guidelines* and a credentialing process for psychiatric rehabilitation practitioners.
- 5. This strategy emerged from the training and technical assistance received from the University of Chicago Center for Psychiatric Rehabilitation, which, under the direction of Dr. Pat Corrigan, has provided a pivotal leadership role in disseminating the rehabilitation-recovery paradigm throughout the Illinois mental health system.