



Board of
Behavioral
Sciences

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MEETING NOTICE

Marriage and Family Therapist Education Committee June 15, 2007

University of Phoenix, Sacramento Campus
2860 Gateway Oaks Drive, Room 101
Sacramento, CA 95833
800-266-2107

10:00 a.m. – 3:00 p.m.

- I. Introductions
- II. Review and Approval of March 9, 2007 Committee Meeting Minutes
- III. Discussion with Clients and Family Members Regarding Therapy Experiences
- IV. Discussion of Increasing the Minimum Unit Requirement for Qualifying Degrees
- V. Presentation on Draft Revisions to Curriculum Statutes by:

Warren Hayes, Chief
MHSA Workforce Education and Training
California Department of Mental Health
- VI. Discussion of Draft Revisions to Curriculum Statutes
- VII. Future Meeting Dates
- VIII. Suggestions for Future Agenda Items

Public Comment on items of discussion will be taken during each item. Time limitations will be determined by the Chairperson. Items will be considered in the order listed. Times are approximate and subject to change. Action may be taken on any item listed on the Agenda.

THIS AGENDA AS WELL AS BOARD MEETING MINUTES CAN BE FOUND ON THE BOARD OF BEHAVIORAL SCIENCES WEBSITE AT www.bbs.ca.gov

NOTICE: The meeting facilities are accessible to persons with disabilities. Please make requests for accommodations to the attention of Christina Kitamura at the Board of Behavioral Sciences, 1625 N. Market Boulevard, Suite S-200, Sacramento, CA 95834, or by phone at 916-574-7835, no later than one week prior to the meeting. If you have any questions please contact the Board at (916) 574-7835.



State of California
State and Consumer
Services Agency
Arnold Schwarzenegger
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To: MFT Education Committee

Date: June 7, 2007

From: Christy Berger
Legislation Analyst

Telephone: (916) 574-7847

Subject: Discussion with Clients and Family Members Regarding Therapy Experiences

Consumers of therapy and their family members have been invited to this meeting to provide their input and to discuss their experiences with therapy. Their names were obtained from the California Mental Health Planning Council as part of their "expert pool" of consumers and family members.

One of the "core values" of the Mental Health Services Act (MHSA) is to "increase consumer and family member involvement in policy, program development, and employment in service delivery and behavioral health administration." The MHSA requires that California develop an education and training plan for future and current mental health professionals that includes consumers, in order to allow the integration of the consumer perspective into education and training programs.

Since the Committee is incorporating aspects of the MHSA into the educational requirements for Marriage and Family Therapists, information regarding the experiences of consumers and family members is crucial.

Consumers and family members scheduled to attend the committee meeting are as follows:

- **Marilyn Hillerman** of Elk Grove (Family Member)
- **Dave Schroeder** of North Highlands (Consumer and Family Member)
- **Sandra Sertyn** of Sacramento (Family Member)
- **Nancy Smith** of Lathrop (Family Member)
- **Warren Treacher** of Davis (Family Member)

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To: MFT Education Committee
From: Christy Berger
Legislation Analyst
Date: June 7, 2007
Telephone: (916) 574-7847
Subject: Discussion of Increasing the Minimum Unit Requirement for Qualifying Degrees

Attached is a list of schools that have one or more programs designed to lead to licensure as a Marriage and Family Therapist (MFT). This list is organized by the number of units required to graduate from each program, as determined by the school's website or catalog. The list uses semester units, which are used by most schools. Those schools that use quarter units are indicated, but have been converted into semester units for the purposes of comparison.

Averages calculated (based on the maximum where ranges were provided) were as follows:

Mean -- 53.9 units
Median -- 52 units

Of the 76 programs surveyed:

17 (18%) programs had a 48 unit degree
24 (32%) programs had a 49 –52 unit degree
13 (17%) programs had a 53 – 59 unit degree
22 (29%) programs had a 60 and above degree

The unit values used were maximums where ranges were offered.

Attachment
Schools with MFT Programs by Units Required

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Schools with MFT Programs by Number of Units Required

Units*	School Name	Location
48	Bethany University	Scotts Valley
48	CSU, Chico	Chico
48	CSU, Dominguez Hills	Carson
48	Pacific Oaks College	Pasadena
48	Pepperdine University	Malibu
48	San Jose State University	San Jose
48	St. Mary's College of California	Moraga
48	California Graduate Institute	Los Angeles and Irvine
48	Southern California University for Professional Studies	Santa Ana
48	Webster University	Irvine
48	Western Institute for Social Research	Berkeley
48 (72 qtr.)	CSU, East Bay	Hayward
48 (72 qtr.)	Pacifica Graduate Institute	Carpenteria
48 (72 qtr.)	Antioch University	Santa Barbara
48 (72 qtr.)	Western Seminary	Los Gatos
48 (72 qtr.)	World University of America	Ojai
48-51	Bethel Theological Seminary	San Diego
48-63	Phillips Graduate Institute	Encino
48.5	The Wright Institute	Berkeley
49 (73 qtr.)	Antioch University	Marina Del Rey
49	Golden Gate University	San Francisco
49	University of San Diego	San Diego
49	University of San Francisco	San Francisco
49	Argosy University	Point Richmond
49 (74 qtr.)	California State Polytechnic University	Pomona
49 (74 qtr.)	Institute of Transpersonal Psychology	Palo Alto
49 (74 qtr.)	Southern California Seminary	El Cajon
50 (74.5 qtr.)	Trinity College of Graduate Studies	Anaheim
50	Alliant International University	Sacramento
50	California Lutheran University	Thousand Oaks
50	Mount St. Mary's College	Los Angeles
50	Argosy University	Santa Ana
50-51 (75-77 qtr.)	Humboldt State University	Arcata
50-60	CSU, Fullerton	Fullerton
51 (76 qtr.)	Professional School of Psychology	Vacaville
51 (76 qtr.)	Ryokan College	Los Angeles
51	Alliant International University	Irvine and San Diego
51	CSU, Stanislaus	Turlock
51	University of Southern California	Los Angeles
51-60	San Francisco State University	San Francisco
52	Vanguard University of Southern California	Costa Mesa
52 (78 qtr.)	Loma Linda University	Loma Linda
52 (78 qtr.)	National University	San Diego
52 (78 qtr.)	Santa Clara University	Santa Clara
52-55 (78-82 qtr.)	CSU, San Bernardino	San Bernardino
53	Hope International University	Fullerton
53	Loyola Marymount University	Los Angeles
53-56	Saybrook Graduate School and Research Center	San Francisco
53-61 (79-92 qtr.)	John F. Kennedy University	Pleasant Hill
54	Chapman University	Orange
54	University of Phoenix	All 5 locations
54 (81 qtr.)	Church of God Theological Seminary	Oakland

*Quarter units converted to semester units by dividing by 1.5 and rounding to the nearest one.

June 4, 2007

Units*	School Name	Location
55	University of La Verne	La Verne
57	Holy Names University	Oakland
57	New College of California	San Francisco
57	HIS University	Corona
57 (86 qtr.)	Institute of Imaginal Studies	Petaluma
59 (88 qtr.)	Santa Barbara Graduate Institute	Santa Barbara
60	Azusa Pacific University	Azusa
60	California Baptist University	Riverside
60	California Institute of Integral Studies	San Francisco
60	CSU, Fresno	Fresno
60	CSU, Northridge	Northridge
60	Notre Dame de Namur	Belmont
60	Dominican University of California	San Rafael
60	Mennonite Brethren Biblical Seminary	Fresno
60	San Diego State University	San Diego
60	Sonoma State University	Rohnert Park
60 (90 qtr.)	California Polytechnic University	San Luis Obispo
60 (90 qtr.)	CSU, Bakersfield	Bakersfield
60-61	CSU, Sacramento	Sacramento
61 (91 qtr.)	San Diego University for Integrative Studies	San Diego
61	CSU, Long Beach	Long Beach
61	CSU, Los Angeles	Los Angeles
71 (106 qtr.)	Fuller Theological Seminary	Pasadena
76-78 (Ph.D. Only)	Biola University	La Mirada

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To: MFT Education Committee

Date: June 6, 2007

From: Paul Riches
Executive Officer

Telephone: (916) 574-7840

Subject: Revised Curriculum Draft

Attached to this memo is a "concept draft" of curriculum requirements for marriage and family therapists (MFT).

In summary, comments indicate that there is much of the current curriculum requirements that remains useful and meaningful to public practice, but that some added material is needed. However, the most significant changes focus on transmitting the culture and norms of public mental health work and principles of the Mental Health Services Act (including recovery, resiliency, consumer empowerment and participation, evidence based practice, etc.) that need to be infused throughout the curriculum to show how the core skills and knowledge imparted by the current curriculum apply. The committee has also heard repeated calls from educators for more flexibility in the curriculum requirements to allow innovation in curriculum design.

The attached concept draft expands on the draft presented at the last meeting based on comments received. It is intended a document to stimulate discussion and begin to bring the committee's deliberation to the point of suggesting concrete revisions.

Structurally, the most significant change is the addition of a 60-unit requirement for qualifying degrees. Current law requires a 48 unit qualifying degree. That change is proposed given the significantly expanded expectations of MFT graduates. As an element of the increase to 60 units, the draft adds three units and 75 contact hours in practicum to the requirements because many of the skills expected of graduates need to be learned and refined in practice experience. The other notable change is the addition of explicitly addressing the impact of socio-economic status on human behavior.

Remaining issues to be addressed by the committee are:

1. Revisiting the requirements relating to substance abuse and addiction based on current knowledge and understanding.
 2. Addressing the timelines for implementation of the proposed changes.
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**Concept Draft for MFT Curriculum
June 2007**

§4980.37. DEGREE PROGRAM

(a) Applicants shall possess a doctor's or master's degree conferred by a school, college or university accredited by the Western Association of Schools and Colleges, Commission on the Accreditation of Marriage and Family Therapy Education, or approved by the Bureau for Private Postsecondary and Vocational Education¹ in one of the following disciplines:

- (1) marriage, family, and child counseling,
- (2) marital and family therapy,
- (3) psychology,
- (4) clinical psychology,
- (5) counseling psychology,
- (6) counseling with an emphasis in marriage, family, and child counseling, or
- (7) counseling with an emphasis in marriage and family therapy.

(b) A qualifying doctor's or master's degree shall:

- (1) Integrate marriage and family therapy principles throughout its curriculum.
- (2) Integrate the principles and methods of service delivery in of-recovery model practice environments and resilience throughout its curriculum.
- (3) Allow for innovation and individuality in the education of marriage and family therapists.
- (4) Encourage students to develop those personal qualities that are intimately related to effective practice such as integrity, sensitivity, flexibility, insight, compassion, and personal presence.
- (5) Permit an emphasis or specialization that may address any one or more of the unique and complex array of human problems, symptoms, and needs of Californians served by marriage and family therapists.
- (6) Integrate the understanding of various cultures and the social and psychological implications of socio-economic position throughout its curriculum.
- (7) Encourage students to meet with various consumers and family members of mental health services so as to understand their experience of mental health treatment illness.

(c) In order to qualify for licensure, a doctor's or master's degree program shall contain no less than ~~48-60~~ semester or ~~72-90~~ quarter units of instruction that includes, but is not limited to:

- (1) Diagnosis, assessment, prognosis and treatment of mental disorders, including severe mental disorders, including psychological testing.
- (2) At least 12 semester or 18 quarter units in theories, principles, and methods of a variety of psychotherapeutic orientations directly related to marriage and family therapy, and marital and family systems approaches to treatment and how these theories can be applied therapeutically with individuals, couples, families, adults, children, and groups to improve, restore, or maintain healthy relationships.
- (3) Developmental issues from infancy to old age. This instruction shall include:

¹ This will be changed to reflect whatever is the final outcome regarding reform of the BPPVE and recent board actions to sponsor legislation recognizing regional accreditation agencies.

- (A) The effects of developmental issues on individuals, couples, and family relationships.
- (B) The psychological, psychotherapeutic, and health implications of developmental issues and their effects.
- (C) Aging and its biological, social, cognitive, and psychological aspects.
- (D) A variety of cultural understandings of human development.
- (E) The understanding of human behavior within the social context of socio-economic status and a representative variety of the various cultures found within California.

(4) The broad range of matters that may arise within marriage and family relationships and life events within a variety of California cultures including:

- (A) Child abuse assessment and reporting
- (B) Spousal or partner abuse assessment, detection, intervention strategies, and same gender abuse dynamics
- (C) Cultural factors relevant to abuse of partners and family members.
- (D) Childbirth
- (E) Child rearing, parenting and stepparenting,
- (F) Marriage
- (G) Divorce
- (H) Blended families
- (I) Long term care
- (J) End of life
- (K) Grief

Instruction shall include the psychological, psychotherapeutic, community, and health implications of these matters and life events.

(5) Cultural competency and sensitivity, including a familiarity with the racial, cultural, linguistic, and ethnic backgrounds of persons living in California.

(6) An understanding of the effects of socio-economic status on behavior, treatment and available resources.

(7) Human sexuality including the study of physiological-psychological and social-cultural variables associated with sexual identity, sexual behavior and sexual disorders.

(8) Provide specific instruction in substance abuse and addiction which shall include each of the following areas.

- (A) The definition of alcoholism and other chemical dependency, and evaluation of the affected person.
- (B) Medical aspects of alcoholism and other chemical dependency.
- (C) Current theories of the etiology of substance abuse.
- (D) The role of persons and systems that support or compound the abuse.
- (E) Major treatment approaches to alcoholism and chemical dependency.
- (F) Legal aspects of substance abuse.
- (G) Populations at risk with regard to substance abuse.
- (H) Community resources offering assessment, treatment and follow-up for the affected person and family.
- (I) The process of referring affected persons.
- (J) The prevention of substance abuse.

- (9) California law and professional ethics for marriage and family therapists. This course shall include, but not be limited to, the following areas of study:
- (A) Contemporary professional ethics and statutory, regulatory, and decisional laws that delineate the profession's scope of practice.
 - (B) The therapeutic, clinical, and practical considerations involved in the legal and ethical practice of marriage and family therapy, including family law.
 - (C) The current legal patterns and trends in the mental health profession.
 - (D) The psychotherapist/patient privilege, confidentiality, the patient dangerous to self or others, and the treatment of minors with and without parental consent.
 - (E) A recognition and exploration of the relationship between a practitioner's sense of self and human values and his or her professional behavior and ethics.

(10) Psychopharmacology.

(11) No less than ~~six~~ nine semester or ~~nine~~ thirteen quarter units of practicum in a supervised clinical placement that provides supervised fieldwork experience including a minimum of ~~450~~ 225 hours of face-to-face experience counseling individuals, couples, families, or groups. The practicum shall provide training in the following areas:

- (A) applied psychotherapeutic techniques.
- (B) assessment.
- (C) diagnosis.
- (D) prognosis.
- (E) treatment of individuals and premarital, couple, family, and child relationships, including:
 - (1) dysfunctions,
 - (2) healthy functioning,
 - (3) health promotion, and
 - (4) illness prevention.
- (F) Professional writing including documentation of services, treatment plans, and progress notes

Educational institutions are encouraged to design the practicum required by this paragraph to include marriage and family therapy experience in low-income and multicultural mental health settings.

(e) A degree qualifying for licensure shall include instruction in the following areas:

- (1) Case management
- (2) Systems of care for the severely mentally ill
- ~~(3) Professional writing including documentation of services, treatment plans, and progress notes~~
- ~~(4)-(3)~~ Public and private services and supports available for the mentally ill
- ~~(5)-(4)~~ Community resources for victims of abuse
- (5) Disaster/Trauma response
- (6) Advocacy for the mentally ill

The instruction required in this subdivision may be provided either in credit level coursework or through extension programs offered by the degree granting institution.

(f) The board has the authority to make the final determination as to whether a degree meets all requirements, including, but not limited to, course requirements, regardless of accreditation or approval.

(g) Each applicant shall submit to the board a certification from the educational institution stating that the institution's required curriculum for graduation and any associated coursework completed by the applicant satisfies the requirements of this section.

(h) The changes made to this section are intended to improve the educational qualifications for licensure in order to better prepare future licentiates for practice, and is not intended in any way to expand or restrict the scope of licensure for marriage and family therapists.

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To: MFT Education Committee

Date: June 7, 2007

From: Paul Riches
Executive Officer

Telephone: (916) 574-7840

Subject: Future Meeting Dates

The committee is scheduled to meet again on Friday, September 28 at a location to be determined. It is expected that the committee will conclude its work at that meeting. In addition to making final recommendations to the board regarding the content of the curriculum, the committee will make recommendations regarding timelines for implementing the proposed changes. Input from the schools is particularly important in developing the recommendations for implementation.

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To: MFT Education Committee

Date: June 6, 2007

From: Paul Riches
Executive Officer

Telephone: (916) 574-7840

Subject: Resources

Attached to this memo are a number of resources that have been valuable for staff in gaining some understanding of the concept of recovery in mental health. They are provided here simply as a resource to others.

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CHAPTER 4

GENERAL FINDINGS

During the strategic planning process, a series of major themes emerged. The themes constitute a set of general findings about the state of the workforce and provide a context for understanding the specific goals, objectives, and actions that are offered as recommendations in the latter sections of this report.

Widespread Concern about a Workforce Crisis

Across the nation there is a high degree of concern about the state of the current workforce and pessimism about its future. The varied problems and issues are outlined in detail in the Special Topics section of this report. Below is a sampling of issues designed to highlight some of the most troubling concerns.

- There is a critical shortage of individuals trained to meet the needs of children and youth, and their families. As just one example, the federal government has projected the need for 12,624 child and adolescent psychiatrists by 2020, which far exceeds the projected supply of 8,312. There currently are only 6,300 child and adolescent psychiatrists nationwide, with relatively few located in rural and low-income areas (American Academy of Child and Adolescent Psychiatry [AACAP] Task Force, 2001). There is an even more severe shortage of practitioners trained and credentialed to treat adolescents with substance use disorders, and only five states require adolescent-specific knowledge for licensure (Pollio, 2002). There is a significant shortage of behavioral health professionals who have been trained to work in the nation's schools. This particular shortage is critical because, as noted by the President's New Freedom Commission, the majority of children who would benefit from behavioral health interventions do not become engaged adequately with traditional community-based treatment settings, and schools offer unparalleled access as points of engagement with children to address their behavioral health needs. By and large, training programs that focus on prevention and treatment within this age group have not kept pace with current trends in the field. The trends have been shifting toward strengths-based and resiliency-oriented approaches, systems of care, and evidence-based

practices (Curie, Brounstein, & Davis, 2004; McLellan & Meyers, 2004; Meyers, Kaufman, & Goldman, 1999).

- There is a pronounced shortfall in the current workforce of providers with expertise in geriatrics. This deficit is expected to worsen. Nationwide, only 700 practicing psychologists view older adults as their principal population of focus, well short of the estimated 5,000 to 7,500 geropsychologists necessary to meet current needs (Jeste et al., 1999). Similarly, only 640 members of the American Psychiatric Nurses Association (2002) have a subspecialization in geriatrics. In 2001, there were only 81 geriatric psychiatry fellows in training in the nation, and 39% of the available fellowships went unfilled (Warshaw, Bragg, Shaull, & Lindsell, 2002). These figures indicate that simply adding training opportunities is not enough. In order to address the dramatic shortfall in trained providers with specialized competencies (many of whom have substantial student loans to repay), there needs to be a fundamental change in the way that services are organized and reimbursed.
- Each year, only 20% of the individuals in the United States who need treatment for substance use disorders receive it. This is due, in part, to severe difficulties in recruiting and retaining qualified staff in sufficient numbers (Gallon, Gabriel, & Knudsen, 2003; Hall & Hall, 2002; Northeast Addiction Technology Transfer Center, 2005). In the most compelling study of this issue, McLellan, Carise, and Kleber (2003) found a 50% turnover in frontline staff *and* directors of substance use disorder treatment agencies in a single year. Furthermore, 70% of frontline staff members in these agencies did not have access to basic information technology to support their daily work.
- The substance abuse prevention sector faces critical workforce issues, which center on the lack of clear educational and career pathways for workers. This hampers recruitment and contributes to turnover, as many skilled prevention workers leave the sector in the search for upward career mobility.
- In rural America, the workforce crisis is particularly acute. More than 85% of the 1,669 federally designed mental health professional shortage areas are rural (Bird, Dempsey, & Hartley, 2001). There are 3,075 counties in the country; 55% have no practicing psychiatrists, psychologists, or social workers, and all of these counties are rural. It has been extraordinarily difficult to recruit, train, and retain professionals in rural areas. Few training programs for providing behavioral health in rural areas exist.

- Figures from the 2000 U.S. Census indicated that 30% of the nation's population is drawn from the four major ethnic groups; Latinos, African Americans, Asian American/Pacific Islanders, and Native Americans. In contrast, the behavioral health workforce lacks such cultural diversity, particularly in mental health. For example, non-Hispanic Whites currently account for 75.7% of all psychiatrists, 94.7% of psychologists, 85.1% of social workers, 80% of counselors, 91.5% of marriage and family therapists, 69.8% of psychosocial rehabilitation practitioners, 95.1% of school psychologists, 83.8% of pastoral counselors, and 90.2% of female psychiatric nurses (Duffy et al., 2004). While cross-cultural training has the potential to improve quality of care and service use among people of color (Fortier & Bishop, 2003), the workforce at large cannot be characterized as culturally or linguistically competent.

High Levels of Dissatisfaction among Persons in Recovery and Families

Workforce issues are a personal matter for individuals with mental health problems and illnesses and substance use disorders. While the experiences of the people who receive care obviously vary greatly, the individuals whose voices were heard during the process of developing this plan expressed strong dissatisfaction with the workforce.

Many of the complaints carried an air of sympathy for members of the workforce. Individuals receiving care acknowledged the heavy workloads, large paperwork burden, comparatively low wages, lack of access to training in state-of-the-art practices, and absence of administrative and technological support that confront the staff. But they also expressed considerable anger for what many described as the stigmatizing attitudes within the workforce about persons with mental and addictive disorders. There is frank concern that many of the professionals and staff members in the field have negative attitudes toward the very persons they are to serve, and that these attitudes impede the ability of workers to be respectful of the people receiving care. At times, a more benevolent but still negative interpretation was offered. It centered on the notion that the workforce is uninformed about recovery-oriented approaches to care and unreceptive to shared decision-making with persons in recovery, children, youth, and family members by virtue of having been trained in a model that emphasizes traditional doctor-patient relationships in which patients are viewed as the passive recipients of the experts' services.

Perhaps of most concern is the perspective of many persons in recovery, children, youth, and family members that the emphasis on compassionate and caring therapeutic relationships has been significantly eroded in behavioral health care. The angriest voices argue that compassion and caring are not eroding because they weren't there to begin with in the mental health community. Advocates continue to report demeaning and dismissive attitudes on the part of treatment professionals as occurring altogether too often. The IOM (2006) has highlighted the central importance of "continuous healing relationships" in all

aspects of health care, and such a tradition has deep roots in the treatment of persons with mental illnesses and substance use disorders. In mental health, for example, training has historically centered on the development of empathic relationships and working alliances. Whether due to a shift in training approaches, the multiple burdens on staff, or the emphasis on evidence-based or manualized therapies, there is considerable concern that the basic human connections between the people providing and the people receiving care are being lost.

Employer Dissatisfaction with the Preservice Education of Professionals

Another group that has voiced strong concerns comprises managers within organizations that employ the workforce. Their constant lament is that recent graduates of professional training programs are unprepared for the realities of practice in real-world settings, or worse, have to unlearn an array of attitudes, assumptions, and practices developed during graduate training that hinder their ability to function. University-based training programs and professional schools, despite their academic base, are largely viewed as out of touch with the realities of contemporary practice and as failing to provide substantive training in evidence-based practices. These concerns exist regardless of the professional discipline. It is simply difficult to overstate the level of concern among workforce employers about the current relevance of professional education in the behavioral health disciplines.

Change Occurs with the Generations

There is general recognition in health care of the long delay between the emergence of evidence for the effectiveness of prevention or intervention strategies and their widespread adoption. This phenomenon exists in behavioral health and may be due, in part, to the fact that change in practice patterns is tied to the changing generations of practitioners within the field. Change occurs with the generations, which accounts for the 20-year lag that characterizes the transition from “science to services.”

Underlying this dynamic is the fact that educational systems in behavioral health, as in most of health care, emphasize the teaching of specific practices. The teaching is focused on content rather than on the process of continuous learning. Students learn certain skills and seem to practice them throughout their career, rather than “learning to learn” as a foundation for a lifelong process in which the evidence on effective interventions is continually re-examined, with personal practice patterns shifting in response to the changing evidence.

Multiple Silos and an Absence of Coordination

The recent report from the IOM (2006) particularly noted the myriad disciplines, differing levels of training, and variability across states in licensing and credentialing the diverse groups that constitute the behavioral health workforce. A labyrinth of organizations, associations, councils, and committees also shapes the training and oversight processes for various segments of the workforce. Diversity can be an asset, but the disciplinary “silos” that are firmly in place appear to impede interdisciplinary training and experience, despite the heavy emphasis on interdisciplinary, team-based practice in systems of care. Furthermore, there is little cooperative or coordinated effort among the disciplines on workforce efforts, such as the development and assessment of competencies, despite the fact that there are many shared competencies across the diverse sectors of the workforce.

Another version of the fragmentation in the field consists of the divide and tensions between the mental health and addiction sectors, with a similar gulf between the areas of behavioral health treatment and prevention. These rifts have major negative consequences. It is difficult to promote change in any large-scale measure throughout the nation’s behavioral health care system because of the multiple divisions and the tendency of each discipline or sector to work in isolation. But perhaps more tragic is that no discipline or sector has adequate resources to pursue on its own a robust agenda for quality improvement, including workforce development. The ultimate negative consequence of the legacy of these silos is that pioneering work by one discipline or sector remains largely unknown to the rest of the field; given the missed opportunities to collaborate and build on each other’s work, there is little synergy of effort.

A Narrow Focus on Urban White Adults

A comprehensive review of workforce issues and needs in the diverse sectors of the behavioral health field brings into stark relief the narrow focus that pervades the field and, in turn, its workforce. Prevention and intervention strategies have been developed and tested principally through research by individuals who are Caucasian residents of America’s metropolitan centers. The vast majority of intervention strategies have been designed principally for young and middle-age adults, and have excluded children and older Americans. Similarly, the participants in effectiveness and efficacy studies largely have been non-Hispanic, White adults residing in the nation’s urban and suburban cores. The vast majority of individuals who provide prevention and treatment services similarly are non-Hispanic Whites and are clustered in the major population centers.

A life-span approach is markedly missing throughout this field and manifests itself in workforce development, as relatively few individuals are trained to meet the needs of America’s children, youth, and

elders. The unique needs of the country's rapidly growing ethnically and racially diverse populations also receive sparse attention, with parallels in a behavioral health workforce that lacks cultural and linguistic diversity and cultural competence. Similarly ignored are the unique circumstances of Americans in rural and frontier areas, where traditional approaches to workforce development, centered on "programs and professionals," simply fail to address local needs.

A Scarcity of Data on the Workforce and its Development

While estimates vary, it appears that as much as 80% of behavioral health expenditures are in human resources. Given the core role of the workforce in prevention and treatment, there is a striking lack of data about the workforce and about workforce development practices. The scattered information that does exist has no uniformity, which hinders cross comparison or aggregation of the data to examine trends. Furthermore, the reliability of much of these data is open to question. There is little consensus about key workforce variables, and there are few benchmarks that organizations can use as a reference point in assessing the magnitude of their workforce problems or the success in addressing the problems.

As the Annapolis Coalition and advisors managing the planning process sought evidence on effective workforce development practices, it became abundantly clear that the workforce is seldom the focus of research. There certainly have been a range of scholarly articles and reviews on the workforce topic; most, however, contain no data or data that are simply descriptive in nature. Even on critical topics such as the retention of staff, there is little data drawn from carefully executed research or evaluation on which to identify effective practices.

A Propensity to do What is Affordable, Not What is Effective

Most behavioral health organizations feel under siege, given the multiple demands for improved access to and quality of treatment and prevention services amid worsening economics surrounding the provision of those services. In such an environment, the need to train and support the workforce is generally recognized, but not made a priority. A peculiar dynamic has emerged in many settings that involves token efforts to develop the workforce, even though managers recognize that the efforts are inadequate and unlikely to have significant effects. The most glaring example is the provision of, didactic, in-services or workshops. These constitute the most common approach to staff training and development, even though there is clear evidence that such sessions are ineffective in changing the practice of the workers who participate. In a parallel fashion, many organizations have introduced training in evidence-based practices to frontline staff without being able to educate or train supervisors and managers in the practices, and without being able to provide the ongoing training, consultation, and staff development that would be required to accomplish and sustain adoption of the practices within the organization.

The Field is Hungry for Workforce Tools

With broad recognition of a workforce crisis, there is a palpable demand in the field for practical models, strategies, and tools to address the myriad problems. Employers of the behavioral health workforce, by and large, are interested in moving rapidly to improve recruitment, training, and retention, but are finding relatively few interventions or models that are well described, portable, and easily adaptable to different settings.

Pockets of Workforce Innovation that are Difficult to Sustain or Disseminate

Across the nation, selected states and organizations are creatively addressing workforce problems. These initiatives can best be described as pockets of innovation, as systematic and substantive efforts to bolster the workforce remain the exception rather than the rule. Many of the workforce efforts detected during the planning process appeared to be sorely underfinanced because there are few sources of dedicated funding for workforce development. Thus, workforce initiatives are difficult to sustain in a single organization or jurisdiction, let alone to disseminate and replicate in other jurisdictions. Most innovations simply remain unknown to colleagues in the field who are grappling with similar issues.

The Workforce Crisis Extends Throughout Health and Human Services

While there are aspects of the workforce crisis in behavioral health care that are unique, the existence of such a crisis is common to multiple areas of health and human services. Recruiting and retaining capable frontline staff has been a crippling problem in the developmental disabilities field (Larson & Hewitt, 2005). The workforce crisis in the field of child welfare, where staff with minimal training is asked to help families burdened by multiple medical, social, and financial problems, has been described in graphic and sobering detail by the Annie E. Casey Foundation (2003). The recruitment and retention of nurses in all areas of health have received national attention and federal- and state-level intervention. Recent national reports have highlighted the growing crisis in recruiting individuals to pursue careers as pharmacists (DHHS, 2000) and in public health (Association of State and Territorial Health Officials [ASTHO], 2004). The national crisis of confidence regarding the safety and quality of health care (IOM, 2000, 2001) is largely responsible for the recent efforts in medicine, across all disciplines, to identify core competencies and demonstrate the competency of those within their ranks.

Hope for the Future

Despite the dire state of the workforce, there are a number of causes for optimism about the future. Many dedicated members of the workforce and committed leaders in the behavioral health field understand the critical need to seriously address the many issues outlined in this Action Plan. The workforce problems are now receiving federal, state, and local attention. The existing pockets of innovation are good starting points and building blocks for more comprehensive and systematic solutions to current workforce dilemmas. The field can and must move forward and tackle this challenge.

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CHAPTER 6

GOAL 1: Significantly expand the role of individuals in recovery, and their families when appropriate, to participate in, ultimately direct, or accept responsibility for their own care; provide care and supports to others; and educate the workforce.

One of the most profound changes in contemporary health care has been the emergence of the concept of patient-centered care. The IOM (2001), in its seminal report *Crossing the Quality Chasm: A New Health System for the 21st Century*, identified patient-centeredness as one of the six aims for health care improvement. The concept was defined as "...providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (IOM, 2001, p. 40). Ironic as it may seem, health care historically has not been patient-centered. Providers and the systems in which they work dominated decision-making processes; individual differences among the persons receiving care were largely ignored, and little information was provided to individuals and their families about illnesses and treatment options.

Individuals and their families are increasingly informed about health and health care. Recipients of services increasingly are bringing information to their providers, asking for information, and insisting on having a greater role in decisions about their care. While progress has been made on this front, the ideal of an individual and family fully informed and actively involved in decision making still occurs far too infrequently (IOM, 2001).

Evolving Roles in Mental Health and Addictions

Significant historical differences have existed between the mental health and addiction sectors regarding the roles of individuals and families. Treatment interventions for persons with substance use disorders carried a tradition of nonmedically driven approaches in which the client has been expected to assume significant responsibility for his or her recovery, and persons in recovery largely staffed treatment programs. In sharp contrast, the mental health field historically has centered on the medical model in its approach, emphasized the expertise and influence of a professional workforce, and considered

consumers and their families as recipients of the care or treatment selected by professionals. While these historical differences are important, there is evidence of convergence toward an approach in which the contributions of professionals and of persons in recovery and their families are simultaneously valued and emphasized. In the addictions sector, there is a growing emphasis on evidence-based practice, competencies, and the development of a professional workforce to deliver care, while also retaining and valuing the contribution of persons in recovery as members of the workforce. In mental health, a forceful consumer movement has been a counterbalance to the autonomy and independence of professionals; the consumer movement has emphasized consumer roles in treatment decisions as peer volunteers, as paid employees in the workforce, and as members of the governing boards of provider organizations and service systems. Simultaneously, families have made their voices heard as they have demanded information, influence in treatment decisions, and greater access to care, quality of care, and safety of services provided.

Senior advisors to the Annapolis Coalition grappled with the traditional and divergent ways in the behavioral health field of conceptualizing and describing the therapeutic relationship between persons in recovery and persons providing care. The advisors, hoping to move toward some common ground around the goal of improved care, made every effort to resolve, or at least address, the philosophical and language differences that often divide the field. Success in this effort was substantial, yet clearly only partial. The process revealed a common thread in all sectors and traditions, which is a core respect for the individual and family in need of care, and a desire to strengthen the notion of a partnership between those needing and those providing care. It is a partnership in which caregivers, whatever their training and professional status, have essential knowledge and skills to offer, and in which clients, consumers, or patients bring to the process their self-knowledge, values, and wisdom drawn from the lived experiences of mental and addictive disorders and efforts to achieve recovery.

The language and conceptual difficulties are compounded by the variability in the presentation, course, and severity of mental health and addictions conditions among individuals. For example, there are points in the experience of nearly all severe behavioral health conditions at which the capacity of the individual to fully participate in treatment decisions may be impaired. Thus, differing levels of intervention are required, and each must remain exquisitely sensitive to the dignity and personhood of the recovering individual.

The role of families also is complicated. Family members of children and young adults never lose their role as parent or sibling, and yet they are in a very real sense both primary caregivers and individuals in need of support to sustain their own health and well-being. For adults with mental health conditions, the

situation is even more complex because the family's role in treatment may be limited by the desires or needs of the client.

Persons in Recovery and their Families as Members of the Workforce

From the perspective of workforce planning and development, priority attention must be given to the fact that persons in recovery and their families have an enormous role in caring for themselves and each other. The amount of services provided by behavioral health professionals and other health and human service providers pales in comparison to the amount of self-care, peer support, and family caregiving that is rendered continuously. Individuals with mental health and addiction problems, along with their families, are a human resource that has been too often overlooked or underutilized. A core strategic goal must be to recognize persons in recovery and their families as part of the workforce and to develop their capacity to care for themselves and each other effectively, just as attempts are made to strengthen the professional workforce.

Goal 1 in this Action Plan is to greatly expand the role of persons in recovery and families as part of the workforce. Five major objectives have been identified to achieve this goal, each of which is discussed in the sections that follow. The first objective is to create fully informed individuals and family members by providing better educational supports. Shared decision-making is a second objective, to be accomplished by training individuals, families, and their providers in collaborative approaches to care. Two additional objectives focus on formal roles in the workforce for persons in recovery and family members through expanded peer- and family-support services and increased employment of these individuals as paid staff in prevention and treatment systems. A final objective, engaging persons in recovery and family members as educators of the workforce, is designed to shape the education of providers and, again, foster more collaborative relationships between the people receiving and providing care.

Objective 1: Provide information and education to individuals in care or recovery and their families to enable them to fully participate in or direct their own care and to assist and support each other.

There have been notable efforts to provide information and education to persons in recovery and family members. Examples in the area of substance use disorders treatment include the long-standing work of the Hazelden Foundation and the Johnson Institute. In mental health, the recent work of organizations such as the National Alliance on Mental Illness (NAMI), Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD), and the Depression and Bipolar Support Alliance (DBSA) to educate clients or consumers and family members is particularly noteworthy.

Despite these efforts, there is a general consensus that most individuals and family members with behavioral health needs lack adequate and timely information about illness and treatment options. Much of the information available is not considered user friendly. Furthermore, just as in professional education, there is a serious lag in making the findings or implications of recent studies available to those seeking help. Providing accurate and scientifically sound information to persons in recovery and family members is a core objective and an essential step in supporting their efforts to care for themselves and each other.

A requisite action step is to create mechanisms for developing or updating educational materials that are peer reviewed, scientifically sound, and tailored to individuals of diverse cultures, languages, and points across the life span. Parents also warrant special attention; they require unique information and education because of their evolving roles and needs as their children develop and transition to adulthood.

Several action steps are recommended to make educational materials accessible. They include using multiple media formats and creating a central clearinghouse from which individuals can directly access current information or link to sources of reliable educational materials. This action should be complemented by a searchable database of recent research findings that presents information in layman's language. Public and private health care payers should ensure that persons covered through health plans are provided with links to readily accessible information. State behavioral health agencies each should have an explicit system or structure for educating the public, including individuals receiving state-supported services.

Providers should be trained in communication skills with individuals and their family members, including the art of providing information. In large part, this training should be delivered by persons in recovery or family members, who are uniquely qualified to educate the workforce about the needs and perspectives of the individuals who will be receiving the information. All approaches to disseminating information must address issues of timing and need for repetition. A frequently heard complaint among persons in recovery and their families is that information is typically offered once, if at all, or in a cursory manner during a crisis, when neither the person in recovery nor a family member is likely to retain the information, however useful.

Objective 2: Develop shared decision-making skills among individuals receiving care and their families and service providers.

Education provides a foundation from which persons in recovery and their families are better prepared to exert more influence over their care. Evidence-based practice, as developed in general medicine, places a heavy emphasis on provider and patient collaboration in treatment decisions, informed by the best available and most relevant information for that individual (Guyatt & Rennie, 2002; Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). This concept of shared decision-making has been emerging as a model in multiple areas of health care (Charles & Demaio, 1993), including prevention (Sheridan, Harris, & Woolf, 2003), the treatment of persons with cancer (Cassileth, Zupkis, Sutton-Smith, & March, 1980), and diabetes care (Greenfield, Kaplan, Ware, Yano, & Frank, 1988).

The term *shared decision-making* has not been widely used in behavioral health (Hamann, Leucht, & Kissling, 2003), but it has roots in the field, embedded in efforts to assess client preferences, provide client-centered care, and implement self-directed care (Adams & Drake, 2006). The Annapolis Coalition recommends that efforts be expanded to further develop and widely disseminate this approach in the behavioral health field. This would entail adopting promising practices from other areas of health care and building on emerging models within the field, such as illness management and recovery (Mueser et al., 2002; Mueser et al., 2006) and person-centered (or family-focused and youth-guided) treatment planning (Adams & Grieder, 2004).

Increased adoption of these collaborative approaches will require training targeted not only to providers but also to persons in recovery and family members. Provider-focused trainings will target skills related to communication, building a therapeutic alliance, and eliciting and responding to questions and concerns of individuals and their families; client-focused interventions will facilitate the sharing of opinions and concerns (Adams & Drake, 2006). In addition to these skills-development approaches, the Coalition recommends attention to a range of documentation requirements, accreditation and licensing standards, and reimbursement practices that could be modified or adopted as action steps to support and reinforce shared decision-making practices.

Shared decision-making approaches are intimately related to issues regarding engagement in treatment (Adams & Drake, 2006). The substance use disorders community has focused successfully on the engagement issue by developing strategies such as motivational interviewing (Bernstein et al., 2005; DeJonge, Schippers, & Schaap, 2005; Hettema, Steele, & Miller, 2005). These strategies should be incorporated more broadly into provider training and skills development.

Objective 3: Significantly expand peer- and family-support services and routinely offer them in systems of care.

The role of peer supports and self-help has been at the foundation of substance use disorders treatment for decades. In mental health, formal peer- and family-support programs have a more recent history, yet there has been substantial growth in these approaches over the past decade. Fostering a strong and expanded role for persons in recovery and family members in formally helping their peers is a core workforce objective.

For the adult mental health community, this objective has special meaning; the emergence of peer supports as a Medicaid reimbursable service has become a major theme in system reform. There is an emerging body of evidence supporting peer services for persons with serious mental illnesses (Campbell & Leaver, 2003; Sabin & Daniels, 2003; Solomon & Draine, 2001). The evidence from implementing Medicaid reimbursable services in state systems such as Georgia and South Carolina adds support to the movement. It is recommended that all states pursue implementation of Medicaid reimbursable peer support. To foster this development, the federal Centers for Medicare and Medicaid Services (CMS) should work with its regional officers, states should develop relevant regulations for their Medicaid plans, and work must continue on identifying competencies and developing a curriculum for peer specialists.

On a parallel track, systems need to devise strategies to support the expanded use of volunteers, whenever possible. The 12-step and other mutual aid communities have values and traditions that mandate voluntary service, and many persons in recovery and family members are not interested in paid positions within systems of care. Their contributions cannot be slighted, or worse, thwarted by policies or practices that ensue from efforts to expand peer-support programs tied to Medicaid.

It is essential that family support initiatives, such as the Family to Family program developed by NAMI, be substantially expanded. Training in peer- and family-support models should be routinely available in all provider settings. Furthermore, these approaches to providing support must be adapted to the unique needs of individuals of color, non-English-speaking populations, and residents of rural communities. Finally, a more robust research and evaluation agenda should be mounted to ensure that emerging and promising practices in peer and family support receive adequate focus in the nation's effort to identify, develop, and fund evidence-based practices.

Though addressed elsewhere in this document, it is important to note that participants in the planning process called for all persons in recovery, family members, *and* providers to receive support. The

repeated message was that recovery can be stressful and demanding, regardless of one's role in the process. The benefits of peer support are not limited to individuals with a diagnosis or disorder.

Objective 4: Increase the employment of individuals in recovery and family members as paid staff in provider organizations.

The substance use disorders treatment community has far outstripped the rest of behavioral health in employing persons in recovery. However, all sectors of the behavioral health field have work to do to ensure that people in recovery are provided opportunities to enter the paid workforce, not only in positions identified as peer-support roles, but in standard or traditional workforce positions as well. A special challenge is to provide meaningful career ladders for people in recovery, so that they can not only enter but also remain in the field and continue to grow personally and professionally. Individuals in recovery and family members should hold supervisory and management positions within prevention and treatment organizations, in addition to the frontline, direct care positions for which they are so often recruited.

The realities of achieving increased employment of persons in recovery and family members are complex and will require creativity and flexibility in dealing with issues such as the education and licensure requirements for selected positions, as well as workforce-related provider accreditation standards. It will also require the creation of reimbursement policies that go beyond academic preparation and licensure as eligibility requirements for compensation. There is a strong need to recognize and pay for the services of individuals who bring life experience as a qualification and have demonstrated their competency in nontraditional ways.

To monitor and drive progress on this objective, all provider organizations, systems of care, and state behavioral health agencies should formally monitor the number and percentage of self-identified persons in recovery and family members that they directly employ or fund through contracts. Specific targets should be set on this objective within each organization and pursued through a comprehensive plan to recruit and orient peer and family employees, and most critically, to support individuals once they are engaged in these roles.

Objective 5: Formally engage persons in recovery and family members in substantive roles as educators for other members of the workforce in every provider training and education program.

One of the largest gaps in the field is the absence of individuals in recovery and their families as teachers of the traditional workforce about the experience of illness and treatment and the process of recovery.

These rich perspectives from lived experience are undervalued and are seldom provided in traditional academic preparation or continuing education. The conversation changes profoundly when people in recovery and their families are included as faculty in workshops or academic course work. Such inclusion, particularly in early phases of training, has the potential to foster a sense of partnership and collaboration, and to counter the paternalist attitudes and approaches that are taught in traditional academic curricula. This is less of an issue in substance use disorders training, given the historical engagement of persons in recovery as treatment providers. Yet, there is room to expand the role of these individuals as teachers.

A number of concrete strategies can further this objective. First, the educational accreditation bodies of the traditional behavioral health disciplines should endorse inclusion of individuals in recovery and family members on the faculties of their professional training programs and monitor the extent to which this actually occurs in a meaningful fashion. The leaders of state and county mental health and addiction systems can mandate that all trainings² paid for with state or county funds include presentations by members of the recovery community and their families. At the federal level, participation of persons in recovery and families could be required in the design, delivery, and evaluation of all federally sponsored training related to behavioral health. Similarly, organizations that accredit continuing education could require that selected course offerings be designed so as to include consumer and family educators.

Conclusion

Inherent in the concept of transforming the mental health system, as the New Freedom Commission on Mental Health called for in 2003, is a shift in power. Emerging approaches to care in behavioral health involve shifts in the locus of decision making and forming more equal partnerships between persons in recovery and family members, and providers. Many individuals who participated in the development of the Action Plan considered this strategic goal, focused as it is on an expanded role for persons in recovery and family members, to have the greatest potential to transform systems of care, especially within mental health. Persons in recovery and family members too often are unrecognized as members of the workforce. They currently make enormous contributions caring for themselves and each other, but they can have even greater impact if provided with information, skills in shared decision-making, opportunities to provide formal peer and family support, and a role in educating the traditional workforce. Given what appears to be an insurmountable gap between the demand for and supply of traditional providers, engaging individuals with the most at stake in roles that are more meaningful and effective

² There would be obvious exceptions for technical or organizational training matters or the use of content-specific instructors (e.g., epidemiologists, pharmacists, etc.).

provides the additional hope of reaching many individuals who have not connected with traditional systems of care.

Just as persons in recovery and family members are unrecognized members of the workforce, so too are communities. The role of communities in the workforce, a second potentially transformational strategic goal, is addressed in the following chapter.

Table 6.1: Objectives & Actions for Goal 1

GOAL 1: Significantly expand the role of individuals in recovery, and their families when appropriate, to participate in, ultimately direct, or accept responsibility for their own care; provide care and supports to others; and educate the workforce.

Objective 1: Provide information and education to individuals in care or recovery and their families to enable them to fully participate in or direct their own care and to assist and support each other.

Action 1: Identify and make available to people in care and their families a body of peer-reviewed, scientifically sound, culturally and linguistically relevant materials in a variety of formats (text, video) and languages, and make these materials accessible to people with different educational levels.

Action 2: Routinely provide families and other natural caregivers and supporters information about optimal ways to help and support loved ones with behavioral health conditions; this information is developed and provided by consumers, family members, educators, researchers, and providers working in partnership(s) and reflects the range of cultural and linguistic differences of the country.

Action 3: Routinely engage persons in recovery and family members in teaching providers how best to work with persons seeking recovery from the perspective of the lived experience of mental or substance use conditions.

Objective 2: Develop shared decision-making skills among individuals receiving care and their families and service providers.

Action 1: Expand the knowledge base about shared decision-making.

Action 2: Make person-centered (or family-focused or youth-guided) treatment planning the norm in behavioral health interventions.

Action 3: Make consumer, family, and provider education a part of every provider interaction – no matter how often the provider has seen the consumer or family.

Objective 3: Significantly expand peer- and family- support services and routinely offer them in systems of care.

Action 1: Implement certified peer specialist (CPS) services as Medicaid reimbursable in all states by 2010.

Action 2: Expand the use of volunteer and grant-funded peer-support programs where indicated.

Action 3: Expand family support services (such as the NAMI Family to Family program and similar programs) in all provider settings, and adapt these programs to meet the needs of diverse communities (based on race, class, sexual orientation, geographic isolation, and language).

Action 4: Continue to build the evidence base on peer-support practices.

Action 5: Create opportunities for providers to support each other emotionally. (The emotional demands of their jobs are intense, and support among providers would be an excellent way to build resilience.)

Objective 4: Increase the employment of individuals in recovery and family members as paid staff in provider organizations.

Action 1: Develop mandates and standardized reporting mechanisms for self-identified consumers and family members employed as providers in non-peer-support positions, as well as in peer-support positions.

Action 2: Advocate for CMS endorsement of the use of appropriately trained individuals in recovery or family members as providers under state Medicaid plans.

Objective 5: Formally engage persons in recovery and family members in substantive roles as educators for other members of the workforce in every provider training and education program.

Action 1: Propose that national oversight bodies for each of the major behavioral health disciplines endorse inclusion of individuals in recovery and family members on the faculties of their pre-professional training programs.

Action 2: Propose that national educational oversight organizations that accredit residencies and practica endorse the use of individuals in recovery and family members as preceptors or consultants to preceptors.

Action 3: Include individuals in recovery and family members in the design, oversight, delivery, and evaluation of all state-sponsored training.

Action 4: Include individuals in recovery and family members in the design, oversight, delivery, and evaluation of all federally sponsored training.

Action 5: Include a course led by consumers and family members regarding recovery from the consumer and family member perspective in all provider-sponsored continuing education programs.

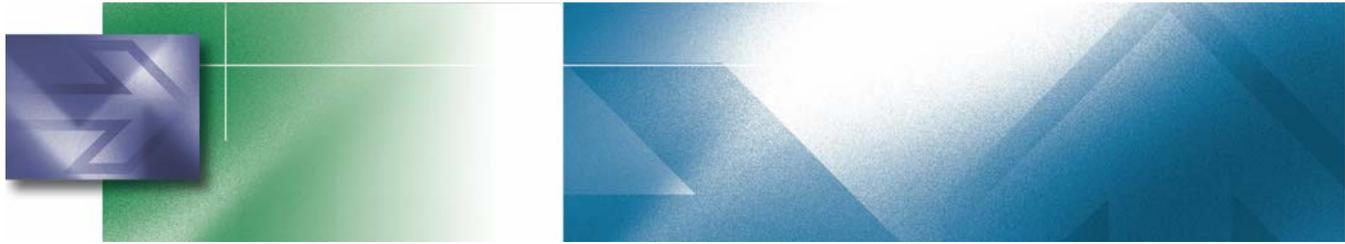
Action 6: Encourage providers, states, and organizations to use teams of consumers and providers to offer continuing education.

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CHAPTER 9

GOAL 4: Increase the relevance, effectiveness, and accessibility of training and education.

Throughout this planning process, all types of stakeholders expressed major concerns about the nature of training and education currently offered to the workforce. In virtually every setting in which the Coalition sought input for the Action Plan, three themes resounded: the content of current training and education offerings often is not relevant to contemporary practice; teaching methods are ineffective in changing the actual practice patterns of the workers being trained; and access to training and education is often quite limited, particularly in rural communities and for culturally diverse populations. The concerns applied to preservice professional training, the initial training offered to direct care paraprofessional staff, and the continuing education of all members of the workforce. The concerns were not specific to a particular sector of the field or discipline, but were described as generally applicable to the field as a whole. There also were many concerns about the absence of educational supports for persons in recovery, children, youth, and families. These issues have been addressed explicitly under Goal 1 (Chapter 6) and are not repeated below.

National Concerns about Health Professions Education

Concerns about the current state of education and training are not peculiar to behavioral health. Nationally, there has been widespread unease about the education of the general health care workforce. The IOM, in its seminal report *Crossing the Quality Chasm* (IOM, 2001), noted the dramatic changes in service delivery in the United States that require new skills among those working in delivery systems. The changes include the shift in emphasis from acute care to chronic care, the rapidly expanding evidence base, the increasing use of team-based and other complex service delivery structures, and more collaborative patient-clinician relationships. The report further noted that the basic approach to health care education has not been revamped since 1910 in response to the issuance of the Flexner Report on medical education (Flexner, 1910). The static nature of health care education is of major concern to medical school deans, three quarters of whom acknowledge that fundamental change in the current approach to medical education is required.

To stimulate needed reforms, the IOM subsequently convened a committee and a national, multidisciplinary summit on education. The final report from this process, titled *Health Professions Education: A Bridge to Quality* (IOM, 2003), offered a vision for workforce education to support 21st century health care systems:

All health professionals should be educated to deliver patient-centered care as members of an interdisciplinary team, emphasizing evidence-based practice, quality improvement approaches, and informatics. (p. 3).

The authors of the IOM report argued for a training focus on the five core competencies that are embedded in this vision. They suggested that change within educational systems be leveraged by working with the oversight organizations that accredit, certify, and license training programs, service programs, and individual practitioners.

Issues Surrounding Behavioral Health Education & Training

Graduate education has been the cornerstone of professional workforce development in mental health and, increasingly, in the addictions sector. There is a strong foundation to graduate education, derived from nearly a century of educational experience. However, there is a widely held perception that graduate training has not kept pace with recent changes in the field, producing a “training gap” (Borus, 1994; Brooks & Riley, 1996; Feldman & Goldman, 1997; Hoge, 2002; Hoge, Jacobs & Belitsky, 2000; Hoge, Jacobs, Belitsky, & Migdole, 2002; Lewis & Blotcky, 1993; Meyer & McLaughlin, 1998; Morris & Hanley, 2001; Raskin & Blome, 1998; Sabin, 1991; Sabin & Borus, 1992; Strom-Gottfried, 1997; Stuart, 2001).

Despite the fact that most graduate training occurs in academic settings, it is ironic that this training often is inadequately grounded in the scientific evidence base regarding prevention and treatment. Evidence-based practice is the conscientious, explicit, and judicious use of the best evidence gained from systematic research for the purpose of making informed decisions about the care of individuals (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). It blends a practitioner's clinical expertise with the best available research evidence. It is also a method of self-directed, career-long learning in which the clinician continually seeks the best possible health outcomes and implements effective interventions based on the most current research evidence. Such evidence reflects verifiable, replicable facts and relationships that have been exposed to stringent scientific criteria. This research has less potential for bias than other bases for practice, in particular, the traditional “that’s how we’ve always done it” basis for practice.

It is important to remember, however, that not all clinical practice is based on science. Many aspects will not or cannot be adequately tested empirically. Furthermore, clinical acumen or intuition is important, particularly with respect to certain clinical situations in which scientific inquiry may be unable to give clear guidance on the variables related to clinical decisions. In these cases, the judgment developed from experience is even more essential. Finally, new ways of thinking take the field beyond evidence-based practice. It has been suggested that there is evidence-supported, evidence-informed, and evidence-suggested practice, as well as evidence-based practice.

The explosion of knowledge in the field makes it difficult for educational programs to remain current. The gap in knowledge and practice is exacerbated by the slow evolution of curricula in academia and the reluctance in many professional programs to train students in evidence-based or empirically validated treatments (Crits-Christoph, Chambless, Frank, Brody, & Karp, 1995). For example, a recent survey by Weissman and colleagues found that 67% of doctoral-level clinical psychology programs and 62% of social work programs did not require didactic and clinical supervision in any evidence-based psychotherapy (Weissman et al., in press). Similarly, practice guidelines, which draw on expert opinion to translate the evidence base into practical recommendations regarding treatment options, appear not to be used or taught widely in course work, supervision, and clinical placements (Yager, Zarin, Pincus & McIntyre, 1997).

Graduate programs have been slow to respond to numerous critical trends in practice, such as shared decision-making with persons in recovery, youth, and families; prevention, rehabilitation, and resilience- and recovery-oriented approaches to care; peer support; outreach; home-based services; systems of care, managed care; and patient safety. Training continues to be conducted in disciplinary silos, despite the fact that there is an emphasis in the field on interdisciplinary team-based practice, a substantive literature on inter-professional education, and historical attempts to promote interprofessional collaboration (American Psychological Association Office of Rural Health, 1995; Casto & Julia, 1994; Richards, 1996; Zlotnik et al., 1999). Perhaps most distressing is that among graduate programs focused principally on mental health, few are providing adequate training on substance use and co-occurring disorders, despite the overwhelming evidence of the prevalence of these conditions and the frequency with which individuals with such conditions seek help from mental health practitioners (Harwood, Kowalski, & Ameen, 2004).

As a consequence of the slow response of academia to the changing health care environment, the leaders of provider organizations that employ the workforce almost universally view new graduates as ill prepared for critical aspects of practice (Blumenthal, Gokhale Campbell, & Weissman, 2001; Shueman &

Shore, 1997). This makes the transition from training to practice particularly difficult for the new graduate and the employer (Gabbard, 1992), with an estimated 2 years of post training experience required to develop the requisite knowledge and skills (Blumenthal & Their, 1996).

There are many dedicated faculty in academic settings, but it is important to note that they are seldom rewarded for excellence in teaching and frequently are not even compensated for their educational activities. Many faculty report feeling constrained by the discipline-based training accreditation standards, which are slow to evolve and tend to be highly prescriptive in the areas of training content and required training experiences. Faculty efforts at reform are further hampered because training is often embedded in complex and highly bureaucratic university and health system settings, which also are slow to change. Support and development of faculty and educators remain critical areas of need if workforce development in the behavioral health field is to advance. The work on interdisciplinary faculty development in addictions through Project Mainstream, administered by the Association for Medical Education and Research in Substance Abuse (AMERSA at <http://www.amersa.org>) and supported by the Health Research and Services Administration (HRSA) and CSAT, is one exceptional model that should be studied and emulated by other sectors of the field (Haack & Adger, 2002).

Beyond the many issues surrounding graduate education and faculty development are other daunting training problems in behavioral health. Large portions of the direct care workforce are not graduate-level prepared, and yet these workers receive little substantive orientation or training about behavioral health problems and their treatment. Of further concern is that continuing education for all segments of the workforce tends to rely on single-session, didactic approaches which have proven ineffective in changing workforce practice patterns. Finally, the positive effects of training too often are thwarted when the environment in which the trainee works fails to support or perhaps even hinders the use of newly learned skills. Each of these critical issues is addressed in the context of a series of objectives and actions designed to strengthen workforce training and education.

Objective 1: Identify core competencies and focused competencies for behavioral health practice.

Competency identification, development, and assessment are getting increasing attention in all areas of health care, including behavioral health. This trend is driven by the compelling notion that, for a field to advance, there must be more precision in specifying the optimal attitudes, knowledge, and skills of the workforce. Once those competencies have been identified, the objective is to build them into the workforce and to demonstrate, using various assessment strategies, that the competencies have been acquired by individual health care providers.

In May of 2004, the Annapolis Coalition convened an expert panel on competencies as a national consensus conference (Hoge, Morris, & Paris, 2005). Experts who were developing competencies in 13 sectors of the behavioral health field met to report on their work and to learn from each other (Hoge, Paris et al., 2005). It became clear that many initiatives were underway to identify competencies and to develop comprehensive competency models and assessment strategies. It was also clear, however, that the initiatives largely were occurring in isolation, without benefit of the knowledge of competencies emerging in other disciplines or sectors of the field. For example, an extensive planning process on competency identification in one discipline reportedly occurred without any discussion of competencies being developed related to recovery- and resilience-oriented practice.

Recommendations from the consensus conference included a call for the establishment of a Competency Collaborative that would link multiple groups and organizations developing behavioral health competencies. Each group would retain independence in its work, but substantial benefits and efficiencies would accrue from the collaboration with other groups. As outlined in the conference recommendations, members of the proposed collaborative could be linked electronically and through periodic meetings to accomplish the following tasks:

- Share information regarding ongoing efforts to develop and employ competency models and to assess competence;
- assemble key resources on competency development and assessment and make these readily accessible to individual and organizational members of the collaborative;
- identify common, core, or cross-cutting competencies and competency domains;
- consider cooperative endeavors to develop and implement core competency models and assessment strategies or to jointly acquire technical assistance;
- review the relevance of competencies identified by one sector of the field (e.g., substance use disorders) for other groups and organizations that are developing competency models;
- identify areas where new competencies are needed, such as those related to patient advocacy, working in interdisciplinary teams, and informatics;
- cross-walk existing and emerging competency models to promote further development of competencies for treating individuals with co-occurring mental illnesses and substance use disorders;
- identify and disseminate case examples of successful efforts to identify and assess competencies; and
- communicate collectively and formally with professional associations, state departments of health, accrediting organizations, and other relevant bodies to inform them of available

competency models, and promote the adoption of these competencies in training, certification, and licensing processes.

(p. 660; Hoge, Morris, Daniels, et al., 2005)

One of the greatest frustrations among the experts who are developing competencies is the slow adoption of this work in training programs. The proposed Competency Collaborative could serve a critical dissemination function as its members worked together to leverage more rapid adoption of competencies and competency assessment. The collaborative also could provide faculty development in the integration of these competencies in curricula and clinical training programs. Finally, the collaborative could develop consensus standards for evaluating competency models and competency assessment procedures both on rigor and relevance to contemporary practice.

The substance use disorders treatment field has pioneered work on core competencies for addiction counseling through the development of Technical Assistance Publication (TAP) Series 21 (DHHS, 1998). This work has been extraordinarily well received, translated into multiple languages, and adopted as a focus of training and certification in numerous countries around the world. In contrast, a widely recognized set of core competencies for mental health practice simply does not exist. While many of the mental health professions are developing their own competencies, there are many high-school-, associate's-, or bachelor's-degreed members of the workforce for whom a well-developed competency model is not available and for whom competency-based training is seldom provided.

The Annapolis Coalition strongly recommends that a set of core competencies for mental health practice be developed. Senior advisors to the Coalition on substance use disorders recommended that this effort use the TAP 21 addiction counseling competencies as a base of departure. The work could be further informed by competencies sponsored by the Center for Mental Health Services (CMHS) for practice in managed care environments (e.g., Coursey et al., 2000a; Coursey et al., 2000b; <http://www.uphs.upenn.edu/cmhpsr/cmhs>) and by the training models developed by organizations such as the Center for Psychiatric Rehabilitation at Boston University (<http://www.bu.edu/cpr>). The core competencies should include basic skills related to the assessment and treatment of substance use disorders and co-occurring mental and addictive disorders.

Some efforts have been made to develop specialty competencies related to the care of children and adolescents, older persons, and other populations and specialty sectors (Hoge, Paris, et al., 2005). The locus of continued activity on competency development in these areas must be identified and adequate funding must be provided to support the continued work. In addition, concerted, systematic attention is needed to ensure that competencies are developed in such specific and critical practices as: person-

centered planning; culturally competent care; development of therapeutic alliances; shared decision-making; prevention, routine use of evidence-based practices; recovery- and resiliency-oriented care; rehabilitation; interdisciplinary and team-based practice; advocacy, use of informatics; and continuous quality improvement.

Objective 2: Develop and implement competency-based curricula.

An obvious corollary to the development of the competencies is to design and implement curricula that are competency based. One area of urgent need is to develop a competency-based, portable curriculum for entry-level, direct care staff in settings where individuals with mental illnesses and co-occurring mental and addictive disorders receive services. Despite the fact that these staff members are often the primary caregivers in many publicly funded programs, it appears that, across the nation, they receive little substantive training. To the extent that states and provider organizations are attempting to educate this critical segment of the workforce, they appear to be cobbling together homegrown curricula and relying on brief didactic orientation programs that are highly unlikely to build competency in core skill areas.

The Annapolis Coalition recommends that a panel of experts be convened to guide the development of competency-based curriculum for this segment of the workforce. The curriculum should be field-tested, finalized, and made broadly available to states and service organizations at low cost or no cost. While core competencies are more developed in the addiction sector of the field (DHHS, 1998), existing curricula based on those competencies similarly should be identified, reviewed, strengthened if necessary, and broadly disseminated.

The locus of competency-based curriculum development in all specialty sectors of the field needs to be identified, and efforts to do so should be supported and advanced. The field lacks a set of consensus standards for evaluating the quality of curricula, and the proposed Competency Collaborative would be capable of developing such standards, in consultation with other groups and organizations. Most critically, education and training program administrators must speed the process of curriculum reform by reviewing and updating their curricula biannually. To create transparency in this process, the Coalition recommends that all education and training program administrators evaluate the relevance and effectiveness of their curricula and make these assessments available to prospective and current students, persons in recovery, youth, family members, advocates, and the general public.

Objective 3: Adopt evidence-based training methods that have been demonstrated as effective through research.

It is common to discuss the evidence base for prevention and treatment interventions, but the field has paid less attention to the evidence base for teaching methods. There is a solid evidence base in medicine regarding effective and ineffective teaching and skill development approaches (Davis et al., 1999). The core finding in this literature is that didactic, single-session, noninteractive teaching approaches may increase knowledge, but are ineffective in building skills among trainees (Mazmanian & Davis, 2002). Unfortunately, it is the didactic, single-session approach that predominates in continuing education and is quite prominent in preservice education as well. Thus, enormous amounts of training time and resources likely are being squandered. The data on this issue are so consistent that Davis and his colleagues (1999) concluded that continuing education credit should probably not be offered for most continuing education events.

There is a growing body of evidence on effective teaching practices that produce behavior changes among learners (Stuart, Tondora, & Hoge, 2004). To be effective in building skills, it is necessary to combine multiple teaching strategies as there is no single “magic bullet” (Oxman, Thomson O’Brien, Davis, & Haynes, 1995). Strategies that have proven effective are: interactive approaches; sequenced, longitudinal learning experiences; outreach visits, known as academic detailing; auditing of practice with feedback to the learner; reminders; the use of opinion leaders to influence practice; and patient-mediated interventions, such as providing information on treatment options to persons in recovery, which in turn influences the practice patterns of their providers (Borgiel et al., 1999; Davis et al., 1999; Soumerai, 1998; Thomson O’Brien et al., 2003).

The evidence on effective teaching strategies is evolving rapidly and it is imperative that this knowledge base have an impact on current training practices. This will require focused faculty development initiatives. To achieve this objective within behavioral health, the Annapolis Coalition recommends that an expert, multidisciplinary panel of educators be convened to review, summarize, and disseminate the evidence on effective teaching approaches. The panel, with assistance from the proposed National Technical Assistance Structure, should also develop an evaluation tool for use by training and education organizations to conduct self-assessments of their teaching practices. The results of these evaluations should be made available to the public, just as the self-evaluations of curricula are. Because educational practices are largely driven by accreditation standards and processes (IOM, 2003), it is imperative that these standards be modified to require the use of evidence-based teaching approaches in both preservice and continuing education.

Enormous amounts of training resources in behavioral health are invested in conferences and meetings, supported by state and federal resources or financed as fee-based continuing education events. Given the research findings on effective teaching and learning strategies, there is little reason to believe that the conference model leads individual participants to change their practice patterns or other professional behaviors. Furthermore, the noneducational objectives and outcomes of these large meetings often seem unclear.

As a first step in addressing the issue of adapting evidence-based training methods that research has shown to be effective, the Annapolis Coalition recommends that the proposed panel in effective education develop and disseminate technical assistance on alternative conference and meeting models. The organizers of the meetings are responsible for adopting more effective approaches to such gatherings. The funders of such meetings, including federal and state agencies and professional associations, should require the use of effective teaching models and demonstrated outcomes as a condition of financial support.

Objective 4: Use technology to increase access to and the effectiveness of training and education.

Clearly, major advances in the use of technology to support teaching and learning have occurred. A virtual explosion in the use of computer-assisted and Web-based instruction has provided greater access to curricula. Less evident is the effectiveness of these methods in teaching clinical skills. Critical questions remain about the key elements that must accompany technology-assisted instruction, such as supervised experience and mentoring, for these electronic methods of educational delivery to be effective for clinicians.

Given the promise of technology as a vehicle of workforce training and development, the Annapolis Coalition recommends that the evidence-based and best practices in this arena be summarized and broadly disseminated to the field. Widespread implementation of these best practices will require funding of demonstration programs as organizations adopt and adapt new technologies to behavioral health. As educators self-assess their use of effective teaching practices, so too should they evaluate whether their technology-assisted teaching approaches are supported by research evidence.

Objective 5: Launch a national initiative to ensure that every member of the behavioral health workforce develops basic competencies in the assessment and treatment of substance use disorders and co-occurring mental and addictive disorders.

Nearly 22 million persons ages 12 and older, totaling 9.4% of the U.S. population, are dependent on or abuse alcohol or illicit drugs. Only 1 person in 10 with a drug use disorder and 1 person in 20 with an alcohol use disorder receive treatment for the condition (Wright, 2004). Furthermore, the prevalence of persons with co-occurring mental and addictive disorders has been on the rise. For example, one study found that 61% of individuals with a severe mental illness had a substance abuse or dependence problem (Jaffee, Comtois, Calsyn & Saxon, 1998).

Individuals with addictive and co-occurring mental and addictive disorders frequently seek help from members of the workforce who are trained as mental health practitioners. Research suggests that, depending on the practice setting, between 20% and 75% of persons seeking services from mental health practitioners have co-occurring disorders (Menezes et al., 1996). One review found that half of all individuals presenting with psychiatric emergencies had a substance abuse problem (McNamara, Schumacher, Milby, Wallace, & Usdan, 2001).

Unfortunately, few mental health professionals are adequately trained to address the needs of persons with substance use disorders or problems. CSAT, in collaboration with six professional associations, created the Practitioner Services Network to study this issue among association members (Harwood, Kowalski, & Ameen, 2004). The findings revealed that in private-practice settings 15% to 25% of clients presented with substance abuse problems, while in treatment facilities, the percentages ranged from 20% to 40%. Despite the prevalence of addiction problems among individuals being served, no more than half of the mental health practitioners surveyed through the Practitioner Services Network had any formal coursework or internship in addiction treatment.

The need to train professionals in the prevention, recognition, assessment, and referral to or basic treatment of persons with substance use disorders is glaring, yet little progress appears to be occurring on this agenda. As an example, a survey of 10 doctoral psychology programs by Aanavi, Taube, Ja, and Duran (1999) found that none required coursework on substance use disorders and that half offered only a single elective course on the topic. In another study, three quarters of social workers surveyed in New England indicated that they had either a moderate, significant, or maximum need for additional training in addictions (Hall, Amodeo, Shaffer, & Vander Bilt, 2000).

The obstacles to educating the mental health workforce in basic addiction-related competencies are complex. They relate to the structures and processes surrounding curriculum development, the accreditation of training and provider programs, and the certification and licensing procedures for providers. To explore and address the many obstacles, the Annapolis Coalition recommends the creation of a Commission on the Adoption of Competencies related to the treatment of substance use disorders and co-occurring mental and addictive disorders. The Commission would bring together the key organizations that govern curricula, accreditation, certification, and licensure to systematically identify and implement strategies to overcome each of the barriers that historically have hindered major progress on this agenda. The Commission would issue an annual report to the nation on the progress made on the agenda. Beyond addressing the urgent need to expand training in addictions, this process would shed light on the dynamics of change necessary to curriculum development, accreditation, certification, and licensure. It would inform future efforts to speed the translation of sciences to services in workforce development activities.

Objective 6: Educate prospective students about best practices in training and education to inform their selection of a training program or training provider.

Students are at a disadvantage as they pursue training because there are currently no tools to assist them in evaluating the quality of competing preservice and continuing education programs. The Annapolis Coalition recommends the creation, field-testing, and broad dissemination to prospective students of a guide that outlines best practices in training and education programs. The objective is to help prospective students choose training programs that have the greatest likelihood of effectively preparing them to enter the workforce with the skills required in the contemporary health care environment. A student “shopping guide” was developed and successfully implemented in primary care medicine by the Partnerships for Quality Education (<http://www.pqe.org>), which is a consortium of academic programs focused on preparing young doctors for community-based practice in a managed care environment. Helping students to become informed “purchasers” of training and education has the potential to leverage change and relevance more rapidly within behavioral health training systems.

Objective 7: Identify and implement strategies to support and sustain the use of newly acquired skills in practice settings.

There is evidence that an effectively trained provider will fail to use newly acquired skills if he or she returns to a work environment where the new skills are not understood and actively supported. Building skills and changing practice involves a combination of training and environmental change. Without attention to the work environment, training efforts will be undermined. As Geary Rummier, an expert in

human performance, has so cogently stated, “When you pit a bad system against a good performer, the system almost always wins” (Rummler, 2004).

There is a growing body of knowledge and evidence related to sustaining newly acquired skills, drawn from efforts to implement evidence-based practices (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). The Coalition recommends that experts on the environmental changes required to support new practices be convened to distill and subsequently disseminate this knowledge through the provision of technical assistance to states and organizations that employ the workforce.

Conclusion

Increasing the relevance, effectiveness, and accessibility of training and education are urgent priorities for the field of behavioral health. Achieving reform in current approaches to training and education will be an essential step in improving quality and transforming systems of care.

Continued work on competency identification and assessment will be a foundation for this work, with collaboration among the many groups and organizations that are tackling this issue for specific populations or sectors within the field. Curricula that are competency-based and delivered via instructional techniques that are evidence based are also key elements of needed reform, with greater emphasis on the use of technology to facilitate access to educational materials.

Perhaps most important, it is essential to unpack and address the roadblocks that prevent the timely updating of curricula, training programs, accreditation standards, and certification and licensure processes. These are the key elements and drivers of the education and training system. It is imperative that they become more relevant to prevention and treatment in current health care systems.

[Table 9.1: Objectives & Actions for Goal 4](#)

GOAL 4: Increase the relevance, effectiveness, and accessibility of training and education.
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Objective 1: Identify core competencies and focused competencies for behavioral health practice.

Action 1: Establish a Competency Collaborative that links organizations developing behavioral health competencies and provides technical assistance.

Action 2: Develop a model set of core mental health competencies.

Action 3: Identify and further develop specialty competencies, relevant to specific areas of behavioral health practice.

Action 4: Identify and further develop competencies in critical practices that include (a) person-centered planning, (b) culturally competent care, (c) development of therapeutic alliances, (d) shared decision-making, (e) evidence-based practice, (e) recovery- and resilience-oriented care, (f) rehabilitation, (g) interdisciplinary and team-based practice, (h) advocacy, (i) use of informatics, and (j) continuous quality improvement.

Objective 2: Develop and implement competency-based curricula.

Action 1: Develop model, portable curricula for entry-level, direct care staff based on the core competencies.

Action 2: Develop a set of consensus standards for evaluating curricula on relevance and effectiveness.

Action 3: Identify or further develop competency-based specialized curricula, relevant to specific areas of behavioral health practice.

Action 4: Require training and education organizations routinely to review and update their curricula and conduct self-evaluations using the consensus standards.

Objective 3: Adopt evidence-based training methods that have been demonstrated as effective through research.

Action 1: Identify effective teaching methods through a systematic review of available research.

Action 2: Employ evidence-based teaching methods in training and education organizations.

Action 3: Require (through accreditation standards for preservice and continuing education) the use of evidence-based teaching methods.

Action 4: Identify and adopt conference and meeting models that have demonstrated impact on participant learning and behavior.

Objective 4: Use technology to increase access to and the effectiveness of training and education

Action 1: Provide technical assistance to training and education organizations in best practices in the use of technology for learning.

Action 2: Employ best practices in the use of technology-assisted instruction.

Action 3: Fund demonstration initiatives in technology-assisted instruction.

Objective 5: Launch a national initiative to ensure that every member of the behavioral health workforce develops basic competencies in the assessment and treatment of substance use disorders and co-occurring mental and addictive disorders.

Action 1: Incorporate addiction and co-occurring competencies into all competency models, preservice and continuing education curricula, training accreditation and program accreditation standards, and certification and licensure requirements.

Action 2: Implement or expand training and staff development on the assessment and treatment of substance use disorders and co-occurring mental and addictive disorders throughout preservice and continuing education.

Objective 6: Educate prospective students about best practices in training and education to inform their selection of a training program or training provider.

Action 1: Develop and disseminate a *Guide to Selecting Relevant and Effective Training* designed for prospective students.

Objective 7: Identify and implement strategies to support and sustain the use of newly acquired skills in practice settings.

Action 1: Identify strategies proven to be effective in supporting and sustaining newly acquired skills and behavior change within organizations.

Action 2: Adopt organizational interventions to support and sustain newly acquired skills and measure sustained behavior change within the workforce.

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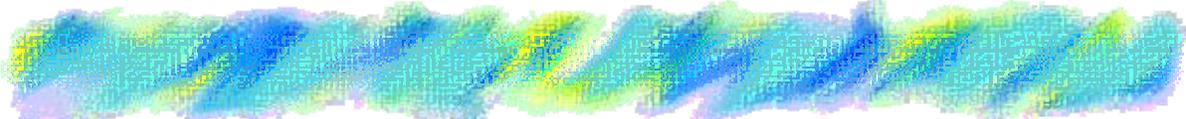
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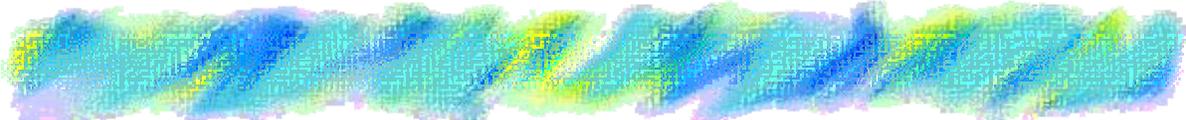
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Practice Guidelines for Recovery-Oriented Behavioral Health Care



Connecticut Department of
Mental Health and Addiction Services



“No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his[/her] own person, free from all restraint or interference of others, unless by clear and unquestioned authority of law.”

— United States Supreme Court
(Union Pacific Railway Co. v. Botsford)

Prepared for the Connecticut Department of Mental Health and Addiction Services by the Yale University Program for Recovery and Community Health (Tondora & Davidson, 2006).

Forward by Commissioner Thomas A. Kirk, Jr., Ph.D.

The document that you are about to read is an extraordinary one in its origins, its content, and its value as another step toward achieving and maintaining a recovery-oriented health care service system in Connecticut.

In my view, if not *the* most important, the following document is one of the most significant products to result within the last five years from the public/private partnership composed of persons in recovery, families, staff and leadership of DMHAS, prevention specialists, private nonprofit service providers, the academic community, and other advocates and stakeholders. This collective group has focused on assessing and improving the quality of services available for persons with mental illness and/or substance use disorders in the State of Connecticut.

Consider a few of its origins. Listening to the suggestions and continuing guidance of those who need or use our services is one of the most basic and essential characteristics of a recovery-oriented service system. Thus, beginning in 1999 we asked Advocacy Unlimited, Inc. and the Connecticut Community for Addiction Recovery, Inc. to work together to develop a set of **Recovery Core Values** that could serve as guideposts for DMHAS as it began the journey of restructuring its service system. The result was 27 principles divided into four categories: **Direction, Participation, Programming and Funding/Operations**. Go to www.dmhas.state.ct.us, click on major Initiatives, then “Recovery Initiative” for further information about the Recovery Core Values.

Well before 1999, there had been “champions” of recovery in any number of state and private service sectors who understood the meaning of “recovery” and the importance of it in the lives and care of the people receiving services. They now had the opportunity to speak in a louder voice and educate the rest of us. We all stand on the shoulders of those who came before us.

DMHAS later hosted a few statewide Recovery Conferences, established a Recovery Institute and Centers of Excellence, and conducted a series of consensus-building retreats for executive directors, medical and clinical leadership, and several other stakeholder groups within the mental health and addiction service communities and elicited their views about the concept of recovery, what it would mean for their activities, and what gaps needed to be addressed and barriers removed for us to achieve a recovery-oriented system.

All of the above, and other work, led to the signing in September 2002 of **Commissioner’s Policy Statement No. 83 on “Promoting a Recovery-Oriented Service System.”** This landmark policy designated the concept of recovery as the overarching goal, guiding principle, and operational framework for the system of care supported by the DMHAS. It incorporated the Recovery Core Values. It stated that:

“We shall firmly embed the language, spirit, and culture of recovery throughout the system of services, in our interactions with one another and with those persons and families who trust us with their care.”

In addition, this policy envisioned and mandated services characterized by:

“...a high degree of accessibility, effectiveness in engaging and retaining persons in care

...effects shall be sustained rather than solely crisis-oriented or short-lived

...age and gender appropriate, culturally competent, and attend to trauma and other factors known to impact on one’s recovery

...whenever possible, shall be provided within the person’s home community, using the person’s natural supports.”

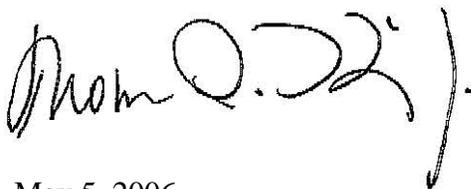
But how do you actually do a recovery-oriented service system? This key question remained after all of the above work and many current activities—too numerous to mention. Absent answers to this question, one may think “all this recovery stuff is conceptual ... it has no real meaning or practical reality. The focus will not really change our system.”

The following document answers this question by identifying eight domains of a recovery-oriented service system ranging from degree of participation of persons in recovery in the recovery planning and system development process to “Identifying and Addressing Barriers to Recovery.” It then lists a dozen or so concrete, practical and well-researched action steps or guidelines in each domain. It answers questions like: “**You will know when you are placing primacy on the participation of people in recovery when...**”

The document gives examples, identifies potential barriers, and uses the words of people in recovery to explain what each domain means and what they can expect in that domain. It includes a glossary and distinguishes a **Deficit-based Perspective** from a **Recovery-oriented, Asset-based Perspective**. As service providers review their Agency Recovery Assessment Plans and as DMHAS fiscal, service, and quality staff go about their business, they now will have a roadmap to inform policy, develop outcomes and funding strategies, and a framework to monitor our fidelity with the guidelines of a recovery-oriented health care system. Persons in recovery and other recipients of services will know what to expect, what they need to be educated about, and what they have a right to demand in their interactions with the system.

It is said that successful initiatives have a thousand fathers and mothers and failed initiatives are orphans. I believe our journey to a recovery-oriented and transformed service system has many parents. I hope this document will help those who either cannot understand or who have not yet embraced a recovery-oriented service system to become another parent of this journey.

I would welcome any comments about the above or your opinion of this document at Thomas.Kirk@po.state.ct.us.

A handwritten signature in black ink, appearing to read "Thomas Kirk", with a large, stylized flourish extending from the end of the signature.

May 5, 2006

Table of Contents

Executive Summary

Introduction

Defining Our Terms

Recovery

From Recovery to Recovery-Oriented Care

Practice Guidelines

A. Primacy of Participation

B. Promoting Access and Engagement

C. Ensuring Continuity of Care

D. Employing Strengths-Based Assessment

E. Offering Individualized Recovery Planning

F. Functioning as a Recovery Guide

G. Community Mapping, Development, and Inclusion

H. Identifying and Addressing Barriers to Recovery

Recommended Resources for Further Reading

Appendix

Glossary of Recovery-Oriented Language

Examples of Strengths-Based Conceptualizations

Executive Summary

The notion of recovery has become the focus of a considerable amount of dialogue and debate between and among various constituencies within the mental health and addiction communities. Following a brief introduction to the topic, in which we clarify various sources of confusion about the term, these practice guidelines begin to operationalize the various components of DMHAS' vision of a recovery-oriented system of behavioral health care. This vision was first put forth in Commissioner's Policy #83, "Promoting a Recovery-Oriented Service System," and has since been embodied in various DMHAS education, training, and program development initiatives. These guidelines represent the first systematic effort to bring recovery into the concrete everyday practice of DMHAS-funded providers.

Defining our Terms

One major source of the confusion surrounding use of the term in recovery in behavioral health derives from a lack of clarity about the respective roles of behavioral health practitioners and those of people with behavioral health disorders themselves. For the purposes of this document, we offer the following two definitions which we have found to distinguish usefully between the process of recovery (in which the person him or herself is engaged) and the provision of recovery-oriented care (in which the practitioner is engaged).

***Recovery** refers to the ways in which a person with a mental illness and/or addiction **experiences** and **manages** his or her disorder in the process of reclaiming his or her life in the community.*

***Recovery-oriented care** is what psychiatric and addiction treatment and rehabilitation practitioners **offer** in support of the person's recovery.*

Practice Guidelines

A. Primacy of Participation

An essential characteristic of recovery-oriented behavioral health care is the primacy it places on the participation of people in recovery and their loved ones in all aspects and phases of the care delivery process. Participation ranges from the initial framing of questions or problems to be addressed and design of the capacity and needs assessments to be conducted, to the delivery, evaluation, and monitoring of care, to the design and development of new services, interventions, and supports.

Practice guidelines to be included in this domain:

- A.1.** People in recovery are routinely invited to share their stories with current service recipients and/or to provide training to staff.
- A.2.** People in recovery comprise a significant proportion of representatives to an agency's board of directors, advisory board, or other steering committees and work groups.
- A.3.** Agencies reimburse people for the time they spend providing input into services, providing peer support and mentoring, and/or providing educational and training sessions for clients or staff.
- A.4.** Each person served is provided with an initial orientation to agency practices.
- A.5.** Initial orientation is supplemented by the routine availability of information and agency updates to people in recovery and their loved ones.
- A.6.** Policies are established and maintained that allow people in recovery maximum opportunity for choice and control in their own care.
- A.7.** Measures of satisfaction are collected routinely and in a timely fashion from people in recovery and their loved ones.
- A.8.** Formal grievance procedures are established and made readily available to people in recovery and their loved ones to address their dissatisfaction with services.
- A.9.** Administration enforces ethical practice (e.g., "first, do no harm") through proactive human resource oversight.
- A.10.** Assertive efforts are made to recruit people in recovery for a variety of staff positions for which they are qualified.
- A.11.** Active recruitment of people in recovery for existing staff positions is coupled with ongoing support for the development of a range of peer-operated services that function independent of, but in collaboration with, professional agencies.
- A.12.** Self-disclosure by employed persons in recovery is respected as a personal decision and is not prohibited by agency policy or practice.
- A.13.** Staff encourage individuals to claim their rights and to make meaningful contributions to their own care and to the system as a whole.
- A.14.** The agency offers to host local, regional, state, and/or national events and advocacy activities for people in recovery and their loved ones.

B. Promoting Access and Engagement

For every one person who seeks and/or receives behavioral health care for a diagnosable psychiatric disorder or addiction there are from two (in mental health) to six (in addiction) individuals, with similar conditions, who will neither gain access to nor receive such care. Recovery-oriented practitioners promote access to care by facilitating swift and uncomplicated entry and by removing barriers to receiving care. Engagement involves making contact with the person rather than with the diagnosis or disability, building trust over time, attending to the person's stated goals and needs and, directly or indirectly, providing a range of services in addition to clinical care.

Practice guidelines to be included in this domain:

- B.1.** The service system has the capacity to go where the potential client is, rather than always insisting that the client come to the service.
- B.2.** People can access a wide range of services from many different points.
- B.3.** There is not a strict separation between clinical and case management functions.
- B.4.** Assessment of motivation is based on a stages of change model, and interventions incorporate motivational enhancement strategies which assist providers in meeting each person where he or she is.
- B.5.** Staff look for signs of organizational barriers or other obstacles to care before concluding that a client is non-compliant or unmotivated.
- B.6.** Agencies have "zero reject" policies that do not exclude people from care based on symptomatology, substance use, or unwillingness to participate in prerequisite clinical or program activities.
- B.7.** Agencies have an "open case" policy which dictates that a person's refusal of services, despite intensive and long-term engagement efforts, does not require that he or she be dropped from the "outreach" list.
- B.8.** The system builds on a commitment to and practice of motivational enhancement, with reimbursement for pre-treatment and recovery management supports.
- B.9.** Outpatient addiction treatment clinicians are paired with outreach workers to capitalize on the moment of crisis that can lead people to accept treatment, and to gain access to their appropriate level of care.
- B.10.** Mental health and addiction practitioners, including people in recovery, are placed in critical locales to assist in the early stages of engagement.
- B.11.** The agency employs staff with first hand experience of recovery who have a special ability to make contact with and engage people into care.

- B.12.** Housing and support options are available for people who are not yet interested in, or ready for, detoxification, but who may begin to engage in their own recovery if housing and support are available to them.
- B.13.** The availability of sober housing is expanded to make it possible for people to go immediately from residential or intensive outpatient treatment programs into housing that supports their recovery.

C. Ensuring Continuity of Care

Recovery is seldom achieved from a single episode of care, so practitioners, as well as people in recovery, families, and policy makers, need to recognize that there are no quick fixes in behavioral health. Similar to other chronic illnesses, previous treatment of a person's condition also should not be taken to be indicative of a poor prognosis, non-compliance, or the person's not trying hard enough to recover. Relapses in substance use and exacerbations of psychiatric symptoms are to be viewed as further evidence of the severity of the person's condition rather than as causes for discharge. All of these principles suggest that treatment, rehabilitation, and support are not to be offered through serial episodes of disconnected care offered by different providers, but through a carefully crafted system that ensures continuity of the person's most significant healing relationships and supports over time and across episodes and agencies.

Practice guidelines to be included in this domain:

- C.1.** The central concern of engagement shifts from: "How do we get the client into treatment?" to: "How do we nest the process of recovery within the person's natural environment?"
- C.2.** Services are designed to be welcoming to all individuals and there is a low threshold (i.e., minimal requirements) for entry into care.
- C.3.** Eligibility and reimbursement strategies for outreach and engagement strategies are established and refined by administrative leadership.
- C.4.** People have a flexible array of options from which to choose and options are not limited to what "programs" are available.
- C.5.** Individuals are not expected or required to progress through a pre-determined continuum of care in a linear or sequential manner.
- C.6.** In a Recovery Management Model, an individual's stage of change is considered at all points in time, with the focus of care on enhancing existing strengths and recovery capital.

- C.7.** Goals and objectives in the recovery plan are not defined by staff based on clinically-valued outcomes (e.g., reducing symptoms, increasing adherence), but rather are defined by the person with a focus on building recovery capital and pursuing a life in the community.
- C.8.** The focus of care shifts from preventing relapse to promoting recovery.
- C.9.** Valued outcomes are influenced by a commitment to ensuring continuity of care and generating long-term effects in the lives of people in recovery.
- C.10.** The range of valued expertise is expanded beyond specialized clinical and rehabilitative professionals and technical experts to include the contributions of multiple individuals and services. These individuals may include peers in paid or volunteer positions, mutual aid groups, indigenous healers, faith community leaders, primary care providers, and other natural supports.
- C.11.** Individuals are seen as capable of illness self-management and interventions support this as a valued goal of recovery-oriented services.
- C.12.** New technologies (e.g., tele-medicine and web-based applications and self-help resources) are incorporated as service options to enhance illness self-management treatment relationships.
- C.13.** Access is enhanced to housing, employment, and other supports that make recovery sustainable.
- C.14.** Policy formulation and legislative advocacy at the administrative level is coupled with on-going efforts to work collaboratively with a variety of state systems to ensure continuity of care.
- C.15.** To facilitate sustained recovery and community inclusion, advocacy efforts are extended beyond institutional policies and procedures to the larger community, including stigma-busting, community education, and community resource development activities.

D. Employing Strengths-Based Assessment

Focusing solely on deficits in the absence of a thoughtful analysis of strengths disregards the most critical resources an individual has on which to build in his or her efforts to adapt to stressful situations, confront environmental challenges, improve his or her quality of life, and advance in his or her recovery. Strengths-based approaches allow providers to balance critical needs that must be met with the resources and strengths that people possess to assist them in this process.

Practice guidelines to be included in this domain:

- D.1.** A discussion of strengths is a central focus of every assessment, care plan, and case summary.
- D.2.** Initial assessments recognize the power of simple, yet powerful, questions such as “What happened? And what do you think would be helpful? And what are your goals in life?”
- D.3.** Staff interpret perceived deficits within a strengths and resilience framework, as this will allow the individual to identify less with the limitations of their disorder.
- D.4.** While strengths of the individual are a focus of the assessment, thoughtful consideration also is given to potential strengths and resources within the individual’s family, natural support network, service system, and community at large.
- D.5.** The diversity of strengths that can serve as resources for the person and his or her recovery planning team is respected.
- D.6.** In addition to the assessment of individual capacities, it is beneficial to explore other areas not traditionally considered “strengths,” e.g., the individual’s most significant or most valued accomplishments, ways of relaxing and having fun, ways of calming down when upset, personal heroes, educational achievements, etc.
- D.7.** Assessments explore the whole of people’s lives while ensuring emphasis is given to the individual’s expressed and pressing priorities.
- D.8.** Assessments ask people what has worked for them in the past and incorporate these ideas in the recovery plan.
- D.9.** Guidance for completing the assessment may be derived from interviewing strategies used within solution-focused approaches to care.
- D.10.** Illness self-management strategies and daily wellness approaches such as WRAP are respected as highly effective, person-directed, recovery tools, and are fully explored in the assessment process.
- D.11.** Cause-and-effect explanations are offered with caution, as such thinking can lead to simplistic resolutions that fail to address the person’s situation. In addition, simplistic solutions may inappropriately assign blame for the problem to the individual, with blame being described as “the first cousin” of deficit-based models of practice.
- D.12.** Assessments are developed through in-depth discussion with the person as well as attempts to solicit collateral information regarding strengths from the person’s family and natural supports.
- D.13.** Efforts are made to record the individual’s responses verbatim rather than translating the information into professional language.

- D.14.** Staff are mindful of the power of language and carefully avoid the subtle messages that professional language has historically conveyed to people with psychiatric disorders, addictions, and their loved ones.
- D.15.** Practitioners avoid using diagnostic labels as a means of describing an individual, as such labels often yield minimal information regarding the person’s experience or manifestation of the illness or addiction.
- D.16.** Language used is neither stigmatizing nor objectifying. “Person first” language is used to acknowledge that the disability is not as important as the person’s individuality and humanity.
- D.17.** Exceptions to person-first and empowering language that are preferred by some persons in recovery are respected.

E. Offering Individualized Recovery Planning

All treatment and rehabilitative services and supports to be provided shall be based on an individualized, multi-disciplinary recovery plan developed in partnership with the person receiving these services and any others that he or she identifies as supportive of this process. While based on a model of collaboration, significant effort is taken to ensure that individuals’ rights to self-determination are respected and that all individuals are afforded maximum opportunity to exercise choice in the full range of treatment and life decisions. The individualized recovery plan will satisfy the criteria of treatment, service, or care plans required by other bodies (e.g., CMS) and will include a comprehensive and culturally sensitive assessment of the person’s hopes, assets, strengths, interests, and goals and will reflect a holistic understanding of his or her behavioral health conditions, general medical concerns, and desires to build or maintain a meaningful life in the community

Practice guidelines to be included in this domain:

- E.1. Core principles of “person-centered” planning are followed in the process of building individualized recovery plans. For example:**
 - E.1.1.** Consistent with the “nothing about us, without us” dictum, staff actively partner with the individual in all planning meetings and/or case conferences regarding his or her recovery services and supports.
 - E.1.2.** The individual has reasonable control as to the location and time of planning meetings, as well as to who is involved.
 - E.1.3.** The language of the plan is understandable to all participants, including the focus person and his or her non-professional, natural supports. Where technical or professional terminology is necessary, this is explained to all participants in the planning process.

- E.1.4.** When individuals are engaged in rehabilitation services (e.g., housing social, or educational/employment areas), rehabilitation practitioners are involved in all planning meetings (at the discretion of the individual) and are given copies of the resulting plan.
- E.1.5.** Within the planning process, a diverse, flexible range of options must be available so that people can access and choose those supports that will best assist them in their recovery.
- E.1.6.** Goals are based on the individual's unique interests, preferences, and strengths, and objectives and interventions are clearly related to the attainment of these stated goals.
- E.1.7.** Planning focuses on the identification of concrete next steps, along with specific timelines, that will allow the person to draw upon existing strengths to move toward recovery and his or her vision for the future.
- E.1.8.** Assessments begin with the assumption that individuals are the experts on their own recovery, and that they have learned much in the process of living with and working through their struggles.
- E.1.9.** Information on rights and responsibilities of receiving services is provided at all recovery planning meetings.
- E.1.10.** The individual has the ability to select or change his or her service providers within relevant guidelines and is made aware of the procedures for doing so.
- E.1.11.** In the spirit of true partnership and transparency, all parties must have access to the same information if people are to embrace and effectively carry out responsibilities associated with the recovery plan.
- E.1.12.** The team reconvenes as necessary to address life goals, accomplishments, and barriers.

- E.2. A wide range of interventions and contributors to the planning and care process are recognized and respected. For example:**
- E.2.1.** Practitioners acknowledge the value of the person's existing relationships and connections.
- E.2.2.** The plan identifies a wide range of both professional supports and alternative strategies to support the person's recovery, particularly those which have been helpful to others with similar struggles.
- E.2.3.** Individuals are not required to attain, or maintain, clinical stability or abstinence before they are supported by the planning team in pursuing such goals as employment.

- E.2.4.** Goals and objectives are driven by a person’s current values and needs and not solely by commonly desired clinical/professional outcomes.
- E.3. Community inclusion is valued as a commonly identified and desired outcome. For example:**
 - E.3.1.** The focus of planning and care is on how to create pathways to meaningful and successful community life and not just on how to maintain clinical stability or abstinence.
 - E.3.2.** Recovery plans respect the fact that services and practitioners should not remain central to a person’s life over time, and exit criteria from formal services are clearly defined.
 - E.3.3.** Recovery plans consider not only how the individual can access and receive needed supports from the behavioral health system and the community, but how the individual can, in turn, give back to others.
 - E.3.4.** Practitioners are mindful of the limited resources available for specialized services and focus on community solutions and resources first by asking “Am I about to recommend or replicate a service or support that is already available in the broader community?”
- E.4. The planning process honors the “dignity of risk” and “right to fail” as evidenced by the following:**
 - E.4.1.** Prior to appealing to coercive measures, practitioners relentlessly try different ways of engaging and persuading individuals in ways which respect their ability to make choices on their own behalf.
 - E.4.2.** Unless determined to require conservatorship by a judge, individuals are presumed competent and entitled to make their own decisions.
 - E.4.3.** Practitioners are encouraged to offer their expertise and suggestions respectfully within the context of a collaborative relationship, outlining for the person the range of options and their possible consequences.
 - E.4.5.** In keeping with this stance, practitioners encourage individuals to write their own crisis and contingency plans.
- E.5. Administrative leadership demonstrate a commitment to both outcomes and process evaluation. For example:**
 - E.5.1.** Outcomes evaluation is a continuous process involving expectations for successful outcomes in a broad range of life domains.
 - E.5.2.** There is a flexible application of process tools, such as fidelity scales, to promote quality service delivery.

F. Functioning as a Recovery Guide

The sentiment that “we’re not cases, and you’re not our managers” has been accepted increasingly as a fundamental challenge to the ways in which behavioral health care is conceptualized within a recovery-oriented system. Rather than replacing any of the skills or clinical and rehabilitative expertise that practitioners have obtained through their training and experience, the recovery guide model offers a useful framework in which these interventions and strategies can be framed as tools that the person can use in his or her own recovery.

Practice guidelines to be included in this domain:

- F.1.** The primary vehicle for the delivery of most behavioral health interventions is the relationship between the practitioner and the person in recovery. The care provided must be grounded in an appreciation of the possibility of improvement in the person’s condition, offering people hope and/or faith that recovery is “possible for me.”
- F.2.** Providers assess where each person is in relation to the various stages of change with respect to the various dimensions of his or her recovery.
- F.3.** Care is based on the assumption that as a person recovers from his or her condition, the addiction or psychiatric disorder then becomes less of a defining characteristic and more simply one part of a multi-dimensional sense of identity that also contains strengths and competencies.
- F.4.** Interventions are aimed at assisting people in gaining autonomy, power, and connections with others.
- F.5.** Opportunities and supports are provided for the person to enhance his or her own sense of personal and social agency.
- F.6.** Individuals are allowed the right to make mistakes, and this is valued as an opportunity for them to learn.
- F.7.** People are allowed to express their feelings, including anger and dissatisfaction, without having these reactions attributed to the illness.
- F.8.** Care is not only attentive to cultural differences across race, ethnicity, and other distinctions of difference (e.g., sexual orientation), but incorporates this sensitivity at the level of the individual.
- F.9.** Rather than dwelling on the person’s distant past or worrying about the person’s long-term future, practitioners focus on preparing people for the next one or two steps of the recovery process by anticipating what lies immediately ahead, by focusing on the challenges of the present situation, and by identifying and helping the person avoid or move around potential obstacles in the road ahead.

- F.10.** Interventions are oriented toward increasing the person’s recovery capital as well as decreasing his or her distress and dysfunction.
- F.11.** Practitioners are willing to offer practical assistance in the community contexts in which their clients live, work, learn, and play.
- F.12.** Care is not only provided in the community but is also oriented toward increasing the quality of a person’s involvement in community life.
- F.13.** Efforts are made to identify sources of incongruence between the person and his or her environment and to increase person-environment fit.
- F.14.** In order to counteract the often hidden effects of stigma, practitioners explicitly draw upon their own personal experiences when considering the critical nature of various social roles in the lives of all individuals, continuing to view people in recovery squarely within the context of their daily lives.
- F.15.** Rather than devaluing professional knowledge, the “recovery guide” approach moves behavioral health much closer to other medical specialties in which it is the health care specialist’s role to assess the person, diagnose his or her condition, educate the person about the costs and benefits of the most effective interventions available to treat his or her condition, and then provide the appropriate interventions.
- F.16.** Recovery is viewed as a fundamentally social process, involving supportive relationships with family, friends, peers, community members, and practitioners

G. Community Mapping and Development

Given its focus on life context, one tool required for effective recovery planning and the provision of recovery-oriented care is adequate knowledge of the person’s local community, including its opportunities, resources, and potential barriers. Community mapping and development are participatory processes that involves persons in mapping the resources and capacities of a community’s individuals, its informal associations, and its structured institutions, as a means of identifying existing, but untapped or overlooked, resources and other potentially hospitable places in which the contributions of people with disabilities and/or addiction will be welcomed and valued.

Practice guidelines to be included in this domain:

- G.1.** People in recovery are viewed primarily as citizens and not as clients and are recognized for the gifts, strengths, skills, interests, and resources they have to contribute to community life.

- G.2.** Community leaders representing a range of community associations and institutions work together with people in recovery to carry out the process of community development.
- G.3.** Opportunities for employment, education, recreation, social and civic involvement, and religious participation are regularly identified and are compiled in asset maps, capacity inventories, and community guides.
- G.4.** Asset maps and capacity inventories created collaboratively by actively involved community stakeholders reflect a wide range of *natural* gifts, strengths, skills, knowledge, values, interests, and resources available to a community through its individuals, associations, and institutions.
- G.5.** Value is placed on the less formal aspects of associational life that take place in neighborhood gatherings, block watch meetings, salons, coffee clatches, barbershops, book groups, etc.
- G.6.** Institutions do not duplicate services that are widely available in the community through individuals and associations.
- G.7.** Community development is driven by a creative, capacity-focused vision identified and shared by community stakeholders.
- G.8.** The relational process of gathering information about community assets and capacities through personal interviews and sharing of stories is recognized as being as important as the information that is collected.

H. Identifying and Addressing Barriers to Recovery

There currently are elements and characteristics of the service delivery system and the broader community that unwittingly contribute to the creation and perpetuation of chronicity and dependency in individuals with behavioral health disorders. There also are several aspects of behavioral health disorders and their place within contemporary society that complicate the person's efforts toward recovery. The competent behavioral health care practitioner will have tools and strategies for identifying and addressing these barriers to recovery.

Practice guidelines to be included in this domain:

- H.1. There is a commitment at the local level to embrace the values and principles of recovery-oriented care and to move away from the dominant illness-based paradigm. Systemic changes that reflect this paradigm shift include the following:**
 - H.1.1.** Stakeholders understand the need for recovery-oriented system change as a civil rights issue which aims to restore certain elementary freedoms to American citizens with psychiatric disorders and/or addictions.

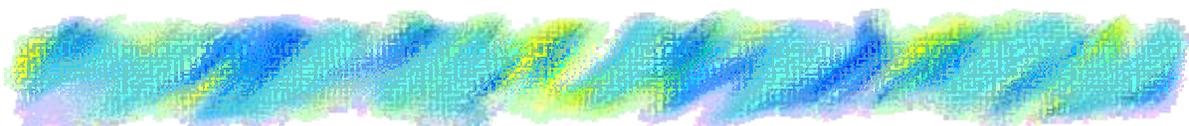
- H.1.2.** Stakeholders work together to move away from the criteria of “medical necessity” toward “human need,” from managing illness to promoting recovery, from deficit-oriented to strengths-based, and from symptom relief to personally-defined quality of life.
- H.1.3.** The possibility of recovery, and responsibility for delivering recovery-oriented care, are embraced by stakeholders at all levels of the system.
- H.2. Systemic structures and practices which impede the adoption of recovery-oriented practices are identified and addressed. Representative change strategies in this area include the following:**
 - H.2.1.** Sequential movement through a pre-existing continuum of care is no longer required, as it is inconsistent with a civil rights perspective and contradicts current knowledge suggesting that recovery is neither a linear process nor a static end product or result.
 - H.2.2.** Agencies need to have coordinating structures to attend to both the prioritization and integration of the range of new initiatives, policies, and procedures they are attempting to implement at any given time.
 - H.2.3.** Performance and outcome indicators need to reflect the fact that the desired goal of recovery-oriented care is to promote growth, independence, and wellness; goals which sometimes involve the taking of reasonable risks that may result in interim setbacks.
 - H.2.4.** Continual quality assurance and independent audits are conducted by people in recovery and families trained in recovery-oriented care.
 - H.2.5.** Initial placement and service design are driven as much by the person’s perception of what services and supports would be most helpful as by the staff’s assessments of what the individual seeking services needs.
 - H.2.6.** Recovery plans respect the fact that services and practitioners should not remain central to a person’s life over time.
 - H.2.7.** To integrate employment within the larger system, the task of assisting people in entering employment and education is made inherent to the responsibilities of the entire practitioner network, including those not specifically charged with supported employment or education tasks.
- H.3. Implementation of recovery-oriented care needs to be facilitated, rather than impeded, by funding, reimbursement, and accrediting structures. Change strategies to address this issue include:**
 - H.3.1.** Even though Medicaid is funded by federal dollars, it remains primarily a state-administered program, and considerable flexibility exists in using these dollars to support innovative, community-based, supports.

- H.3.2.** Within existing funding structures, training and technical assistance can be provided to practitioners attempting to implement recovery-oriented practices to assist them in learning how to translate the wishes of people in recovery into reimbursable service goals and to describe their interventions in a manner that will generate payment.
- H.3.3.** Rather than being an add-on to existing services, transformation to recovery-oriented care begins with discovering ways to be creative and flexible within the constraints of existing resources.
- H.3.4.** Self-directed funding opportunities should be considered both on a collective basis and through individualized budget programs.
- H.4. **Training and staff development is prioritized as an essential function to increase individual practitioners’ competencies in providing recovery-oriented care. Necessary change strategies to address this issue include the following:****
- H.4.1.** As consensus emerges regarding the knowledge and skills needed to implement recovery-oriented care, this information must lead to the development of competency models, and these models must be disseminated broadly as guidance for training programs and licensing bodies which prepare and accredit providers of behavioral health care.
- H.4.2.** Once established, competency models should be incorporated in all human resource activities as a means of promoting accountability and quality improvement.
- H.4.3.** An analysis of staff’s current competencies and self-perceived training needs should guide the development of on-going skill-building activities at the agency level.
- H.4.4.** Competency-based training must be coupled with on-going mentorship, enhanced supervision, recovery-oriented case conferences, and opportunities for peer consultation.
- H.4.5.** Clinical directors and agency leaders should be involved in ongoing training initiatives so that there is consistency between proposed recovery-oriented practices and the system’s administrative structures.
- H.4.6.** Recovery-oriented care does *not* imply that there is no longer any role for the practitioner to play. Rather, the provider’s role has changed from that of all-knowing, all-doing caretaker to that of coach, architect, cheerleader, facilitator, mentor, or shepherd—roles that are not always consistent with one’s clinical training or experiences.
- H.4.7.** Training initiatives need to support people in recovery and families to develop their own capacity to self-direct their care and life decisions.

- H.5. Forces at the societal level which undermine recovery and community inclusion are identified and addressed. Necessary change strategies to address this issue include the following:**
- H.5.1.** Behavioral health practitioners have significant expertise to address the lack of basic resources and opportunities in the broader community, and are prepared to offer supportive guidance and feedback at both the individual and community level.
- H.5.2.** Community collaborations and education must be coupled with efforts on the part of behavioral health practitioners to recognize instances of discrimination, to understand relevant disability legislation, and to effectively utilize state and local resources.
- H.5.3.** Agencies are cautioned to avoid the establishment of ‘one stop shopping’ service programs which may inadvertently contribute to the perpetuation of discriminatory and unethical practices on the part of community members. We must continue to work with community partners to uphold their obligation to respect people with behavioral health disorders as citizens who have the right to be treated according to the principles of law that apply to all other individuals
- H.5.4.** Professionals and service recipients should be mindful of the limited resources available for specialized services and should focus on community solutions and resources first by asking “Am I about to recommend or replicate a service or support that is already available in the broader community?”
- H.6. Certain internal barriers unique to behavioral health disorders are identified and addressed. Necessary change strategies to address these barriers include the following:**
- H.6.1.** Staff appreciate the fact that, based on a complex interaction of the person’s conditions and his or her past experiences in the behavioral health care system, people with behavioral health disorders may be reluctant to assume some of the rights and responsibilities promoted in recovery-oriented systems. They may initially express reluctance, fears, mistrust, and even disinterest when afforded the right to take control of their treatment and life decisions. Exploring and addressing the many factors influencing such responses is an important component of care.
- H.6.2.** Research indicates that many individuals with behavioral health disorders also have histories of trauma. Failure to attend to such histories may seriously undermine the treatment and rehabilitation enterprises, and further complicate the person’s own efforts toward recovery.

H.6.3. Certain symptoms of illnesses may also pose direct impediments to the recovery process. In certain conditions, the elimination or reduction of symptoms may also come with great ambivalence, e.g., while episodes of mania can be destructive, they may include a heightened sense of creativity, self importance, and productivity that are difficult to give up. Being able to identify and address these and other sequelae requires knowledge and skill on the part of the clinical practitioner.

In each of the following sections, practitioners are given examples of what they are likely to hear from people in recovery when these guidelines have been implemented successfully. In addition, there is a list of recommended resources for further reading on transformation to recovery-oriented care, as well as a glossary of recovery-oriented language and examples of strengths-based conceptualizations that are proposed as alternatives to current deficit-based ones.



Introduction

The notion of recovery has become the focus of a considerable amount of dialogue and debate between and among various constituencies within the mental health and addiction communities. Prior to attempting to operationalize the various components of DMHAS' vision of a recovery-oriented system of care, we thought it important to clarify these confusions, some of which are due to the fact that the notion of recovery is in transition, moving gradually from a well-established vision among people with addictions or mental illnesses to exerting more influence on the practice of behavioral health care providers.



For example, being “in recovery” has long been the guiding vision and goal of self-help¹ within the addiction community. Primarily a force within self-help, however, this notion has not played as much of a role historically within the addiction service provider community, where concepts of treatment and relapse prevention have been more central. Having a fifty-year history of peaceful, if benign, co-existence, these two complementary approaches have recently entered into a period of partnership in which there is now considerable potential for them to build dynamically on each others’ strengths to promote a unified and coherent vision of recovery among people with addictions.

Despite being a long-standing core value in addiction, the notion of “recovery” has emerged as a dominant force within mental health just within the last decade. Most recently, it has taken center stage through its prominent role in both the Surgeon General’s *Report on Mental Health*² and the President’s New Freedom Commission on Mental Health. In its influential *Final Report*, the Commission strongly recommended “fundamentally reforming” all of mental health care to be based on the goal of recovery³. In both of these reports, however—as well as in clinical and rehabilitative practice—there is considerable ambiguity and a tangible lack of clarity about what precisely is meant by recovery in mental health. As in addiction, much work remains to be done in mental health in developing a coherent and unified vision of recovery that can prove to be acceptable (as well as useful) to all involved parties.

¹ Derived from Alcoholics Anonymous, these so-called “12-step” groups have expanded to include many other addictions and life conditions, and have consistently been shown to help promote and maintain abstinence.

² Department of Health and Human Services. (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: Substance Abuse and Mental Health Services Administration.

³ Department of Health and Human Services. (2003). *Achieving the promise: Transforming mental health care in America*. Rockville, MD: Substance Abuse and Mental Health Services Administration, p. 4

Given its multiple and complicated parentage and the diverse constituencies involved, it is not surprising that it has been difficult to reach consensus on any one definition, or even on any one list of essential aspects, of the concept of recovery in behavioral health. For the sake of clarity—as well as to facilitate future discussions as these concepts continue to evolve—we propose the following distinction as a prelude to articulating the Guidelines that will be used to guide the development, monitoring, and evaluation of clinical and rehabilitative services and supports offered within a recovery-oriented system of behavioral health care. Rather than mutually exclusive, these two concepts are intended to be somewhat overlapping and complementary, with the eventual goal of being brought together into a unified vision that can be promoted equally by people in recovery, their loved ones, behavioral health care providers, and the community at large.



Defining our Terms

One major source of the confusion surrounding use of the term in recovery in behavioral health derives from a lack of clarity about the respective roles of behavioral health practitioners and those of people with behavioral health disorders themselves. For the purposes of this document, we offer the following two definitions which we have found to distinguish usefully between the process of recovery (in which the person him or herself is engaged) and the provision of recovery-oriented care (in which the practitioner is engaged).

- **Recovery** refers to the ways in which a person with a mental illness and/or addiction **experiences** and **manages** his or her disorder in the process of reclaiming his or her life in the community.
- **Recovery-oriented care** is what psychiatric and addiction treatment and rehabilitation practitioners **offer** in support of the person's own recovery efforts.

Recovery

Given that the notion of recovery derives from the self-help and self-advocacy communities in both addictions and mental health, the first definition of recovery refers to *what people who have these conditions do to manage their mental illness and/or addiction and to claim or reclaim their lives in the community*. In addition to managing the condition, this sense of recovery therefore also involves *what people do to overcome the effects of being perceived as an addict or a mental patient*—including rejection from society, alienation from one’s loved ones, poverty, substandard housing or homelessness, social isolation, unemployment, loss of valued social roles and identity, and loss of sense of self and purpose in life—in order to regain some degree of control over their own lives.

As experiences of being discriminated against are viewed as traumatic and irreversible, advocates also argue that a return to a pre-existing state of health (as another alternative definition of recovery) is not only impossible, but also would diminish the gains the person has had to make to overcome the disorder and its effects. Overcoming the scars of stigma requires the development and use of new muscles, often leaving people feeling stronger than prior to the onset of their illness.

Beginning with a common foundation, recovery in addiction and in mental health can then be seen to divide into two distinct, but at times parallel and at other times overlapping, paths. Before turning to the characteristics of recovery-oriented care, we provide a brief overview of the similarities and differences between these two paths to recovery. Given the high rate at which addiction and mental illness co-occur in the same person, we understand that any given individual may be involved in either, or both, of these paths at the same time. For the sake of clarity, it still may be useful to highlight a few of the salient differences between them prior to turning to their implications for care.



Addiction Recovery. Derived from the self-help community, people who are achieving or maintaining abstinence from drug or alcohol use following a period of addiction have described themselves as being “in” this form of recovery for over half a century. Being “in recovery” in this sense is meant to signify that the person is no longer actively using substances but, due to the long-term nature of addiction, continues to be vulnerable to relapses and therefore has to remain vigilant in

protecting his or her sobriety. In this tradition—in which continued vulnerability to relapse is seen as inherent to addiction—recovery does not connote cure, nor does it entail remission of the signs, symptoms, or other deficits of a disorder as is common to recovery in other medical illnesses. Unlike in most physical illnesses, people may consider themselves to be in recovery while continuing to be affected by their addiction.

People who are achieving or maintaining abstinence . . . have described themselves as being . . . in recovery for over half a century.

Based on this definition, it is possible that many people who have used substances to an extent that would have met current diagnostic criteria for an addiction at one point earlier in their lives, but who are no longer actively using or having to focus on protecting their sobriety, would not consider themselves to be “in recovery.” While for some people it may apply to the remainder of their lives, being in recovery from addiction appears to pertain more specifically to the period following active use in which the person is consciously and actively involved in remaining abstinent and in which there continues to be a sense of vulnerability to relapse. In this sense, recovery in addiction is not only hard-won but often has to be protected and reinforced through persistent vigilance and adherence to the self-help and other principles that made it possible in the first place.

In addition to being in recovery from the addiction, this process involves addressing the effects and side effects of the addiction as well. The self-help tradition recognizes that living life with an addiction generates many negative effects on one’s life beyond the addiction *per se*, including detrimental effects on one’s relationships, on one’s ability to learn or work, and on one’s self-esteem, identity, and confidence.

Recovery involves the person’s efforts to abstain from substance use while resuming increasing responsibility for his or her overall life.

With the toxic effects of addiction spreading to the person’s life as a whole, this sense of being in recovery involves the person’s efforts to abstain from substance use while also resuming increasing responsibility for his or her life. It thus often involves returning to school or work, making amends to others who have been hurt, repairing damaged relationships, and, in general, learning how to live a clean and sober life.

It also is true that for many people, achieving recovery may be the first time they have known how to live without their addiction, tracing its origins back to their earlier lives even prior to actual substance use. For these people, a clean and sober life is not so much restored by abstinence as it is created for the first time; a gain which they credit to their recovery above and beyond sobriety. It is not unusual in

such cases for people in recovery to believe they are now a better person for having gone through the addiction and recovery process than if they had never become addicted in the first place.



Mental Health Recovery. It was this same sense of being “in recovery” that was first introduced into the mental health community approximately thirty years ago through the self-help/consumer movement. In the process of its introduction into mental health, this sense of recovery took on a few characteristics specific to the history of the perception and treatment of mental illness in society. Being associated initially with being liberated from mental hospitals (many, if not all, of the first self-advocates were former inpatients), the mental health self-help community viewed itself first and foremost as a civil rights movement rather than as part of any treatment or rehabilitative enterprise.

For people with mental illnesses, prior to denoting anything like a cure or improvement in their psychiatric condition, recovery meant having one’s civil rights restored as a full and contributing member of society. It meant no longer being defined entirely by one’s mental illness (i.e., as a mental patient) and having, as a result, one’s major life decisions—as well as one’s day-to-day life activities—determined by others. In addition to advocating for the radical reform of involuntary commitment laws and inpatient care, advocates have since been active in identifying ways in which community services also have unwittingly perpetuated many of the discriminatory practices historically seen in institutional settings.

. . . prior to denoting anything like a cure or improvement in [one’s] psychiatric condition, recovery meant having one’s civil rights restored as a full and contributing member of society.

Within mental health, then, two related but distinct uses of the term recovery have emerged. While not inconsistent with use of the term within addiction, the first of these two senses acquires a different emphasis as an advocacy issue. This sense of recovery is proposed as a fundamental challenge to the “mentalism” which advocates see as continuing to permeate health and human services and to influence the ways in which people with psychiatric disabilities are treated both inside and outside of

mental health⁴. Similar to other forms of prejudice, a set of attitudes and that have the effect of of the general population to

... recovery [poses] a fundamental challenge to ... "mentalism"

racism, sexism, and mentalism involves associated behaviors confining a segment second-class citizen

ship. In this case, the discrimination is based on the belief that people with mental illness are more like children than adults, unable to make their own decisions, to function independently, or to take care of themselves. They thereby require the care and direction of well-intended others in order to meet their basic needs—whether this care and direction be provided, as earlier, in hospital settings or, as is now more common, through community services.

Within this historical context, recovery has come to be a powerful rallying cry and tool in the advocacy movement's efforts to counteract mentalism and its legacy in the lives of people with mental illnesses. It has been fueled both by the personal conviction of people in recovery and by over thirty years of clinical research findings which consistently have demonstrated a broad heterogeneity in outcome over time and across domains of functioning in serious mental illness. Research has shown that mental illness not only comes and goes over time and varies significantly in severity and duration, but that even when a person is actively experiencing psychosis, it most often affects only some of the person's abilities, leaving other abilities intact.

Rather than subsuming the entirety of the person, mental illnesses are better understood—even in their most severe form—as disabilities that co-exist with other areas of competence within the context of the person's life.

Rather than subsuming the entirety of the person, mental illnesses are better understood—even in their most severe form—as disabilities that co-exist with other areas of competence within the context of the person's life.⁵ Just as we would not assume that someone with a visual, auditory, or mobility impairment was unable to take care of him or herself because he or she could not see, hear, or ambulate unassisted, we need not assume that a person's mental illness renders him or her unable or

⁴ Chamberlin, J. (1984). Speaking for ourselves: An overview of the Ex-Psychiatric Inmates' Movement. *Psychosocial Rehabilitation Journal*, 2, 56-63.

⁵ Beginning with the World Health Organization's International Pilot Study of Schizophrenia launched in 1967, there have been a series of long-term, longitudinal studies conducted around the world that have produced a consistent picture of a broad heterogeneity in outcome for severe psychiatric disorders. With respect to schizophrenia, this line of research has documented partial to full recovery in between 45-65% of each sample. In this context, recovery has been defined narrowly as amelioration of symptoms and other deficits associated with the disorder and a return to a pre-existing healthy state. We now know that up to two thirds of people achieve even this narrowly-defined form of recovery from psychosis, with many others able to function independently despite continued symptoms. For more on this research, see Davidson, L., Harding, C.M. & Spaniol, L. (2005). *Recovery from severe mental illnesses: Research evidence and implications for practice*. Boston, MA: Center for Psychiatric Rehabilitation of Boston University.

incompetent to be in control of his or her life. As other people with disabilities may require Braille signs, visual indicators of doorbells or ringing telephones, or wheelchairs, people with mental illness may require similar social and environmental supports in order to function optimally in community settings. While we have just begun to learn to identify and offer such supports, this represents a very promising, and important, area for future growth and development.

It is at this juncture that the civil rights movement in mental health meets up with the sense of recovery used in addiction in order to promote an alternative vision of mental health recovery. This second sense of recovery involves viewing psychiatric disorder as only one aspect of a person who otherwise has assets, interests, aspirations, and the desire and ability to continue to be in control of his or her own life. Paralleling in some ways addiction recovery, this sense of recovery involves the person's assuming increasing control over his or her illness while reclaiming responsibility for his or her life; a life that previously had been subsumed by the disorder.

Recovery involves viewing psychiatric disorder as only one aspect of a person who otherwise has assets, strengths, interests, aspirations, and the desire and ability to continue to be in control of his or her own life.

In other respects, however, this sense of recovery differs from recovery in addiction. For example, being in recovery from an addiction invariably involves some degree of abstinence; it requires a change in the person's condition from being controlled by the addiction to the addiction being under at least some degree of the person's control. While vulnerability to relapse remains a core element of addiction recovery, a person who continues to use cannot be viewed as in recovery; i.e., active substance use in the context of a lack of awareness of the addiction, or in the lack of any progress made toward decreasing use, precludes recovery.

The same cannot be said, however, for mental illness. In this respect, mental health recovery borrows from the disability rights movement in arguing that recovery remains possible even while a person's condition may not change. A person with paraplegia does not have to regain his or her mobility in order to have a satisfying life in the community. Being in recovery similarly cannot require a cure or remission of one's psychiatric disorder or a return to a pre-existing state of health. Rather, it involves a redefinition of one's illness as only one aspect of a multi-dimensional person who is capable of identifying, choosing, and pursuing personally meaningful aspirations despite continuing to suffer the effects and side effects of the illness.

With recovery in both addiction and mental health now defined, it becomes more evident why we have said that recovery is *what the person does*. Addiction treatment providers are well aware that they have not been able to make a person stop using drugs or alcohol. In this sense, addiction recovery has always been in the hands of the person with the addiction. What may be different about recovery-oriented care in the addiction field are the number of things practitioners can now do over time to increase a person's desire to choose abstinence through the use of motivational enhancement strategies. In mental health, however, the idea that recovery is what the person with the mental illness does is a less commonly accepted notion. With the assumption that mental illness incapacitates the person in his or her entirety, more of the focus has been on what practitioners can do to and for the person to alleviate his or her symptoms and suffering and enhance his or her functioning.

It is important to note that defining recovery in mental health as pertaining to what the person with the mental illness does in no way diminishes the importance of professional competence or the role of mental health care practitioners. What it does, instead, is to shift the responsibility for deriving maximum benefit from health care services from the educated and caring people who provide them to the person him or herself who needs to use them. Rather than

This definition of . . . recovery in no way diminishes the importance of professional competence or the role of . . . health care practitioners.

devaluing professional knowledge and experience, this approach moves psychiatry much closer to other medical specialties in which it is the health care specialist's role to assess the person, diagnose his or her condition, educate the person about the costs and benefits of the most effective interventions available to treat his or her condition, and then provide the appropriate interventions. No matter how expert or experienced the practitioner, it is then ideally left up to the person and his or her loved ones to make decisions about his or her own care. It is not the practitioner's role or responsibility to make such health care decisions *for* the person.⁶ The idea of recovery extends this conventional model of care to behavioral health as well.

⁶ Emergency medicine provides another exception in cases in which the issue of informed consent/permission to treat is suspended temporarily in order to perform life-saving measures. Such situations certainly occur in behavioral health as well, in which practitioners must take action to protect an individual or the public in the event of emergency or crisis situations as narrowly defined by statutory laws (e.g., suicidality, homicidality, and grave disability). In these cases, practitioners have solid legal ground on which to stand in making decisions for the person (i.e., against his or her will). As in medicine, however, this transfer of authority can only be a temporary measure, in effect only for as long as an acute episode takes to resolve. In all other cases, the decision of a judge is required in the state of Connecticut in order to terminate or otherwise place limits on a person's autonomy through the appointment of a conservator of person or other means.

From Recovery to Recovery-Oriented Care

In suggesting how behavioral health might come to resemble more closely other forms of medical care, we have arrived at the point where recovery—i.e., what the person with a behavioral health condition does—comes into contact with recovery-oriented care—i.e., what practitioners of mental health and substance abuse treatment and rehabilitation offer in support of the person’s recovery. As we have suggested above, our focus on the process of recovery as the unique journey of each individual should not be taken to suggest that there is no longer an integral role for services and supports.

This is no more true in behavioral health than in other forms of medicine. When we suggest that someone who has been in an accident follow a graduated plan of convalescence and exercise in order to regain his or her physical functioning, for example, we do not thereby diminish the importance of the orthopedist’s role in assessing the impact of the trauma, setting the broken bones, and prescribing an exercise plan, which may then need to be implemented with the assistance of a physical therapist and the support of the person’s family.

We know that while broken bones may heal of their own accord—with or without detriment to the person’s functioning—they are more likely to heal completely with timely and effective care. Similarly, while the person might eventually regain his or her functioning following an accident without a graduated exercise plan or physical therapy, he or she is more likely to do so in an expedient and uncomplicated fashion, and is less likely to suffer unexpected setbacks, with the guidance of competent and experienced experts. Based on these considerations, we reject both assertions, either that: 1) the person will not benefit from professional intervention or 2) the orthopedist is responsible for the person’s recovery. Although it is unquestionably each person’s own recovery, this recovery can be substantially supported and facilitated by the assistance of competent and experienced practitioners. The fact that we find it necessary to make this point, perhaps repeatedly, derives mostly from the history of stigma, discrimination, and prejudice against people with behavioral health conditions rather than from any wish to devalue or diminish the role of behavioral health practitioners.

What, then, is the most appropriate role for the behavioral health care provider in relation to recovery? Similar to the example provided above, what the person in recovery is most in need of is information about the nature of his or her difficulties, education about the range of effective interventions available to overcome or compensate for these difficulties, access to opportunities to utilize these interventions in regaining functioning, and the supports required in order to be successful in doing so.

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Drawing from the orthopedic analogy, the person will need to exercise and resume use of those faculties most directly affected by his or her trauma. In the case of behavioral health conditions, these faculties include the person's cognitive, social, and emotional life as well as his or her sense of self, personal and social identity, and belonging within his or her community. If a person with a broken leg does not try to walk again, he or she will not regain the use of the leg that was broken. If a person with a psychiatric or substance use disorder does not try to reclaim responsibility for his or her life, he or she will be unable to regain his or her functioning. This fact poses a fundamental challenge to the provision of recovery-oriented care.

Like the proverbial horse that cannot be made to drink, recovery-oriented practitioners can create or enhance access for people in recovery to a variety of educational, vocational, social, recreational, and affiliational activities in the community. They cannot, however, make the decisions *for* the person as to which, if any, of these activities he or she will participate in and find enjoyable or meaningful. The challenge confronting recovery-oriented practitioners may not, in this way, be unique to behavioral health. Cardiologists, for example, cannot make their patients stick to a heart-healthy diet any more than oncologists can keep some of their patients from smoking. What complicates the picture in the case of behavioral health is the perception that the person's decision-making capacity is itself among the faculties most directly affected by the illness.

As both psychiatric and substance use disorders are currently viewed primarily to be diseases of the brain, such a concern is understandable. In and of itself, however, this concern cannot be taken to lead inevitably to the conclusion that other, well-intentioned, people must therefore step in and make decisions for the person. In certain, limited, circumstances practitioners are legally authorized, if not also obligated, to do so. These circumstances include imminent risk of harm to the person and/or others (i.e., homicidality, suicidality, grave disability). In most other circumstances, however, practitioners are left in the difficult position of having to honor—if not actively support—the person's decisions, even in cases in which the practitioner is persuaded that it is the illness, rather than the person's best judgment, which is driving the decision-making process.

In the absence of conservatorship, guardianship, or other legal mechanisms, practitioners can educate, inform, discuss, debate, and attempt to persuade the person to embrace some options rather than others. If the person is ever to regain his or her functioning, however, in the end she or he will have to be accorded, in Pat Deegan's terms, the "dignity of risk" and the "right to failure."⁷ As is true in most components of recovery-oriented care, it requires concerted effort and reflection—and perhaps supervision—as well as compassion, for behavioral health practitioners to continue to view and treat the person as sitting in the driver's seat of his or her own life. Given the damage that these disorders can do to the person's self-esteem and confidence, though, it is difficult to imagine how recovery can be achieved through other means.

As suggested in the definition above, recovery-oriented care takes as its primary aim offering people with psychiatric and/or addictive disorders a range of effective and culturally-responsive interventions from which they may choose those services and supports which they find useful in promoting or protecting their own recovery. As further defined in Commissioner's Policy #83 on Recovery:

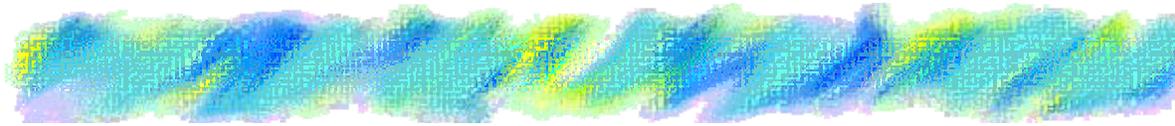
A recovery-oriented system of care identifies and builds upon each person's assets, strengths, and areas of health and competence to support the person in achieving a sense of mastery over mental illness and/or addiction while regaining his or her life and a meaningful, constructive sense of membership in the broader community.

While the goal of recovery-oriented care may appear, in this way, to be relatively clear and straightforward, the ways in which care can be used to promote recovery are neither so clear nor so straightforward—neither, unfortunately, are the ways in which care, as currently configured, may impede or undermine recovery. The following guidelines are offered as a beginning roadmap of this territory, bringing together what we think we know at this point about how care can best promote and sustain recovery, and how care may need to be transformed to no longer impede it. These guidelines are drawn from over two years of conversations with practitioners, people in recovery, families, and program managers, and are informed by the current professional literature on recovery and recovery-oriented practice.

These guidelines focus primarily on the concrete work of practitioners and provider agencies so as to provide practical and useful direction to individuals and collectives that are committed to implementing recovery-oriented care. We recog-

⁷Deegan, P.E. (1992). The Independent Living Movement and people with psychiatric disabilities: Taking back control over our own lives. *Psychosocial Rehabilitation Journal*, 15, 3-19.

nize, however, that many of the practices described will require a broader commitment of agency leadership to significant and on-going administrative restructuring. We offer these guidelines as only one piece of a much larger whole, but as an important step forward in the overall process of system transformation. Equally important steps were taken in the past through the development of practice standards for culturally competent care⁸ (which therefore are not duplicated here), and future efforts are planned to address the crucial roles of prevention and early intervention and the need for ongoing evaluation and monitoring of the outcomes of care.



⁸ State of Connecticut Department of Mental Health and Addiction Services Office of Multicultural Affairs. (2001). *Multicultural behavioral healthcare: Best practice standards and implementation guidelines*. Hartford, CT: State of Connecticut Department of Mental Health and Addiction Services

Practice Guidelines for Recovery-Oriented Behavioral Health Care

- A. Primacy of Participation
- B. Promoting Access and Engagement
- C. Ensuring Continuity of Care
- D. Employing Strengths-Based Assessment
- E. Offering Individualized Recovery Planning
- F. Functioning as a Recovery Guide
- G. Community Mapping, Development, and Inclusion
- H. Identifying and Addressing Barriers to Recovery

A. The Primacy of Participation

An essential characteristic of recovery-oriented behavioral health care is the primacy it places on the participation of people in recovery and their loved ones in all aspects and phases of the care delivery process. Beginning with the Federal Rehabilitation Act of 1973 and reaffirmed in 1990 in Public Law 99-660, federal and state governments have mandated the involvement of people with behavioral health disorders in all components of designing and implementing systems of community-based behavioral health care. This mandate has been confirmed consistently in numerous federal and state statutes and regulations issued since, and forms the foundation of CT DMHAS's Recovery and System Transformation Initiative.

For the involvement of people in recovery and their families to be meaningful and substantive, it must go well beyond asking them to sign off on provider-driven treatment plans or to endorse the adoption or replication of practitioner-driven models of care. Recovery-oriented care requires that people in recovery be involved in all aspects and phases of the care delivery process, from the initial framing of questions or problems to be addressed and design of the capacity and needs assessments to be conducted, to the delivery, evaluation, and ongoing monitoring of care, to the design and development of new services, interventions, and supports.

As recovery is what the person with the behavioral health condition *does*, rather than something that can be done *to* or *for* the person by a care provider, people in recovery, by definition, are understood to be the foremost experts on their own needs and preferences for assistance in managing their condition and reconstructing their lives. As a result, recovery-oriented care consistently elicits and is substantially informed by the input and involvement of people in recovery across all levels, from recovery planning led by individual clients (see Section E, Individualized Recovery Planning), to program development and evaluation, to policy formulation.

**You will know that you are placing primacy
on the participation of people in recovery when:**

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| <p>A.1. People in recovery are routinely invited to share their stories with current service recipients and/or to provide training to staff.</p> <p>A.2. People in recovery comprise a significant proportion of representatives to an agency's board of directors, advisory board, or other steering committees and work groups. Persons in recovery are provided orientation to their committee role by the chair, and actively contribute to the group process. Their involvement in these groups is reflected in meeting minutes and in decision-making processes.</p> |
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- A.3.** The input of people in recovery is valued, as embodied in the fact that the agency reimburses people for the time they spend participating in service planning, implementation, or evaluation activities, providing peer support and mentoring, and/or providing educational and training sessions for clients or staff. Where system involvement is a mutually negotiated volunteer activity, people in recovery are reimbursed for out of pocket expenses that may be associated with their participation.
- A.4.** Each person served is provided with an initial orientation to agency practices regarding client rights, complaint procedures, treatment options, advance directives, access to their records, advocacy organizations (e.g., PAMI, Human Rights Commission), rehabilitation and community resources, and spiritual/chaplaincy services. Contact information on program staff and agency leaders is made available. Provision of orientation is documented in the person's record.
- A.5.** Initial orientation is supplemented by the routine availability of information and agency updates to people in recovery and their loved ones. This information is provided in a variety of formats (e.g., information tables, service directories, educational programs, newsletters, web postings, etc.) to enable people in recovery and their loved ones to make informed choices about treatments, rehabilitation, and supports and to provide meaningful input about program and agency performance. Feedback is regularly solicited from people in recovery and their loved ones regarding their informational needs.
- A.6.** Policies are established and maintained that allow people in recovery maximum opportunity for choice and control in their own care. For example, people in recovery are able to a) access their records with minimal barriers, b) incorporate psychiatric advance directives in their recovery and crisis plans, c) secure the services of local or state advocacy services as necessary, d) request transfer to an alternative provider within agency guidelines, and e) participate actively in agency planning activities. These policies and procedures are highlighted on agency admission and are routinely publicized throughout the agency through newsletters, educational postings, Consumer Empowerment Councils, etc. This process is particularly crucial within services such as "money management" where the line between providing a service and infringing on people's rights can easily be blurred in the absence of clear programmatic guidelines and safeguards.

A.7. Measures of satisfaction with services and supports are collected

routinely and in a timely fashion from people in recovery and their loved ones. These data are used in strategic planning and quality improvement initiatives to evaluate and make meaningful changes in programs, policies, procedures, and interventions. Feedback mechanisms are in place to inform people in recovery and their loved ones of changes and actions taken based on their input.

- A.8.** Formal grievance procedures are established and made readily available to people in recovery and their loved ones to address their dissatisfactions with services. People in recovery and their loved ones are fully informed about these procedures on a regular basis, and the frequency and focus of grievances are tracked to inform agency or program quality improvement processes.
- A.9.** Administration enforces ethical practice through proactive human resource oversight. This oversight prohibits the use of coercive practices, and holds all staff accountable for affording people in recovery maximum control over their own treatment and rehabilitation.
- A.10.** Assertive efforts are made to recruit people in recovery for a variety of staff positions for which they are qualified. These include positions for which their personal experience of disability and recovery make them uniquely qualified (e.g., peer support), as well as positions for which they are qualified by virtue of licensure (e.g., nursing, psychiatry) or other training or work experience (clerical, administrative, medical records, etc.). Assertive efforts include establishing mentoring programs for employees in recovery so they can advance in their skills and attain the necessary credentialing that will allow them to occupy a more diverse range of agency positions.
- A.11.** Active recruitment of people in recovery for existing staff positions is coupled with ongoing support for the development of a range of peer-operated services that function independent of, but in collaboration with, the professional agency. This will help to ensure that the recovery community's role is supported, while avoiding co-opting by transforming it into an adjunct service provider. As one example, recovery community centers operated by people in recovery should be available in all areas. Such recovery centers are neither treatment centers nor social clubs. They are places where people who are interested in learning about recovery can meet with other non-professionals to get support, learn about recovery and treatment resources, and simply find people to talk to. Agencies can demonstrate their support for peer-operated services by offering material and supervisory support to

emerging programs. For example, technical assistance or mentoring regarding business management, attainment of 501(c)3 status, human resource practices, etc., can greatly facilitate the establishment and long-term viability of emerging peer-operated services. Care should be taken to ensure capacity-building and enhanced independence in the peer-operated program over time. As with all community support programs, peer-operated services should be well integrated with the agency at large in terms of committee membership and with recovery planning at the individual level.

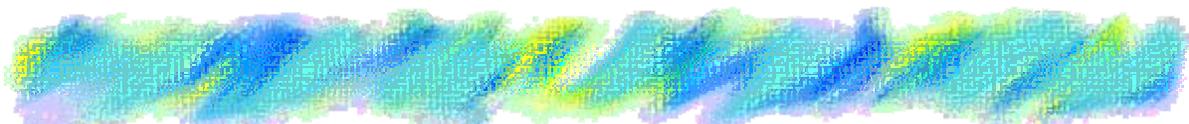
- A.12.** Self-disclosure by employed persons in recovery is respected as a personal decision and is not prohibited by agency policy or practice. Supervision is available to discuss the complex issues which can arise with self-disclosure.

- A.13.** Staff appreciate that many people in recovery may not, at first, share the understanding that they are the foremost experts on the management of their own condition. Persons who have come to depend upon services and professionals to alleviate their distress may neither believe themselves capable of being the expert nor recognize that they are entitled to occupy this role. Therefore, staff encourage individuals to claim their rights and to make meaningful contributions to their own care and to the system as a whole. For example, individuals are encouraged to become involved in local and state advocacy as a means of developing their confidence and skills in self-determination and collective action, agency efforts to enhance the participation of service users are widely publicized to the recovery community, and general education is offered regarding the necessity of active service-user involvement to achieve recovery outcomes. While people are to be encouraged to become involved at all levels of the system, not everyone will want to participate beyond the primary level of involvement, i.e., their personal recovery plan. As in other areas of self-determination, this too is respected as a valid choice.

- A.14.** The agency offers to host local, regional, and/or state events and advocacy activities for people in recovery and their loved ones, e.g., meetings of 12-step fellowships, Connecticut Community for Addiction Recovery, Advocacy Unlimited, and Focus on Recovery-United.

**What you will hear from people in recovery
when you are placing primacy on their participation:**

- *You know, at first I thought, “What do I know or what could I possibly say at this meeting?” But then, I could tell that what I had to say made a difference. People were really listening to me. I finally got a place at the table!*
- *I knew I was in recovery when I could help somebody else that was in the same awful place I used to be. But I think about where I am today: healthy, and drug free, and being a real Grandma. And getting back in the work field as a peer provider makes me feel good; makes me understand that I can do this. I can really do this. And if I could do this, anybody can do this. Folks get hope when they look at me.*
- *I don’t have to hide who I am—even the part of me that isn’t well. Because it’s that part of me and all the things I’ve experienced as a client here -- good and bad -- that gives me ideas for how things could change.*
- *I just didn’t think my program was a good fit for me. I was sticking it out, but lots of other folks stopped showing up. But then, somebody came in and we had a great talk about what was working and what wasn’t in the program. And some changes actually got made. Things are a lot better now. The group is packed every week!*



B. Promoting Access and Engagement

A core principle of the deinstitutionalization movement of the 1950s and beyond was that persons with psychiatric disabilities should receive mental health services in the least restrictive setting possible within their home communities. Community mental health centers and clinics were developed in large part in response to this principle. Unfortunately, many persons with psychiatric disabilities did not receive care due to a variety of factors such as: inadequate funding for community-based services, administrative and bureaucratic barriers that discouraged people from seeking care, expectations of motivation for treatment that did not take into account internal (to the clinic) or external (in the person's environment) barriers to care, a lack of knowledge of ways to engage people living in the community into mental health treatment, clients' avoidance of the mental health system because of previous negative experiences, and persons' inability to meet the requirements of treatment (e.g. appointment times, etc.) due to the exigencies of their lives of poverty and/or homelessness, or due to their psychiatric symptoms. Thus, many people who were eligible for services did not receive them, and suffered impoverished lives without adequate treatment, social support, or material resources in the community.

For these, and additional, reasons, the recent U.S. Surgeon General's *Report on Mental Health*⁹ suggested that for every one person who seeks and receives specialty mental health care for a diagnosable psychiatric disorder, there remain two individuals, with similar conditions, who will neither gain access to nor receive such care. This report was followed by a supplement on culture, race, and ethnicity, which further identified lack of access to care as an even more formidable obstacle to recovery among people of color¹⁰.

While this situation may seem dire, the proportion of people who access and receive care to those who are in need of such care is even worse in the case of addiction, with approximately 1 out of 7 people with an addiction actually receiving active behavioral health treatment. These facts clearly warrant the attention of the behavioral health system, including a greater focus on efforts to enhance access and engage people in care.

Access to care involves facilitating swift and uncomplicated entry into care, and can be increased through a variety of means. These include: 1) conducting outreach to persons who may not otherwise receive information about services or who may avoid institutional settings where services are provided; 2) establishing numerous points of entry into a wide range of treatment, rehabilitative, social, and

⁹Department of Health and Human Services. (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: Substance Abuse and Mental Health Services Administration.

¹⁰Department of Health and Human Services. (2001). *Mental health: Culture, race, and ethnicity*. Rockville, MD: Substance Abuse and Mental Health Services Administration.

other support services. For example, a public health nurse working with a homeless outreach team facilitates a person's entry into behavioral health care, a clinician might help the person gain access to vocational services and entitlement income support, and, with the client's permission, all of these service providers meet with or talk to each other regularly to coordinate their work with the person; and 3) ensuring that information about services is made readily available and understandable to people through public education and information, liaison with other agencies, links to self-help groups, and other venues.

Access to care also involves removing barriers to receiving care, including bureaucratic red tape, intimidating or unwelcoming physical environments and program procedures, schedule conflicts, and modes of service provision that conflict with the life situations and demands of persons with psychiatric disabilities or addiction. It also means that access to care goes far beyond mere eligibility to receive services. Finally, access to care involves moving away from traditional philosophies of treatment—including hitting bottom (e.g., “Addicts can’t be helped until they hit bottom and have lost everything”) and incrementalism (e.g., “We can’t house people with addictions until they’ve been in recovery for 6 months”)—and toward stages of change approaches, recognizing that addressing basic needs, employment, and housing can enhance motivation for treatment and recovery.

Engagement into services is closely tied to access to care. Engagement involves making contact with the person rather than with the diagnosis or disability, building trust over time, attending to the person's stated needs and, directly or indirectly, providing a range of services in addition to clinical care. The process of engagement benefits from new understandings of motivational enhancement, which sees people standing at various points on a continuum from pre-readiness for treatment to being in recovery, rather than being either motivated or unmotivated.

Engagement involves sensitivity to the thin line between persuasion and coercion and attention to the power differential between the service provider and the client or potential client, and the ways in which these factors can undermine personal choice. Finally, methods of ensuring access and engagement are integrated within and are part of providing good clinical and rehabilitative care, not adjuncts or qualifications to them.

**You will know that you are
promoting access and engagement when:**

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| <p>B.1. The service system has the capacity to go where the potential client is, rather than always insisting that the client come to the service. Services and structures (e.g., hours of operation and locations of services) are designed around client needs, characteristics, and preferences.</p> |
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- B.2.** The team provides, or can help the person gain swift access to, a wide range of services. People can access these services from many different points. In a “no wrong door” approach to providing an array of services, individuals can also self-refer to a range of service options (e.g., specialized rehabilitation supports) without the need for referral from a primary clinical provider. In addition, individuals can access DMHAS-funded rehabilitation programs without being mandated to participate in clinical care. However, self referrals will be subject to admission and oversight and need approval by a licensed entity to satisfy reimbursement and accreditation needs.
- B.3.** There is not a strict separation between clinical and case management functions, though there may be differences in expertise and training of the people providing these services. Services and supports address presenting clinical issues, but are also responsive to pressing social, housing, employment, and spiritual needs. For example, employment is valued as an important element of recovery. Skill building and finding employment are competencies included in all staff job descriptions, including clinical providers, with only the most difficult-to-place clients being referred to specialized programs.
- B.4.** The assessment of motivation is based on a stages of change model, and services and supports incorporate motivational enhancement strategies which assist providers in meeting each person at his or her own level. Training in these strategies is required for all staff who work with people with addictions in order to help move people toward recovery.
- B.5.** Staff and agencies look for signs of organizational barriers or other obstacles to care before concluding that a client is non-compliant with treatment or unmotivated for care, e.g., meeting the needs of women with children for daycare.
- B.6.** Agencies have “zero reject” policies that do not exclude people from care based on symptomatology, substance use, or unwillingness to participate in prerequisite clinical or program activities. For example, vocational rehabilitation agencies do not employ screening procedures based on arbitrary “work readiness” criteria, as such criteria have limited predictive validity regarding employment outcomes. In addition, such procedures suggest that individuals must attain, and maintain, clinical stability or abstinence before they can pursue a life in the community, when, in fact, employment and other meaningful activities are often a path through which people become stable in the first place.

- B.7.** Staff have an “open case” policy which dictates that a person’s refusal of services, even despite intensive and long-term outreach and engagement, does not require that he or she be dropped from the “outreach” list. This person may still accept services at another time. Committee structures and supervision are in place to evaluate the fine line between assertive outreach versus potential harassment or coercion. In addition, the agency establishes guidelines regarding what defines an “active” versus an “outreach” client, and considers how such definitions impact program enrollment, documentation standards, 30 day drop out lists, case load definitions, and reimbursement strategies.
- B.8.** From an administrative perspective, the system builds on a commitment to and practice of motivational enhancement, with reimbursement for pre-treatment and recovery management supports. This includes flexibility in outpatient care, including low-intensity care for those who do not presently benefit from high-intensity treatment.
- B.9.** Outpatient substance abuse treatment clinicians are paired with outreach workers to capitalize on the moment of crisis that can lead people to accept treatment, and to gain access to their appropriate level of care.
- B.10.** Mental health professionals, addictions specialists, and people in recovery are placed in critical locales to assist in the early stages of engagement, e.g., in shelters, in courts, in hospital emergency rooms, and in community health centers. The agency develops and establishes the necessary memoranda of agreement and protocols to facilitate this co-location of services.
- B.11.** The team or agency employs staff with first person experience of recovery who have a special ability to make contact with and engage people into services and treatment.
- B.12.** Housing and support options are available for those who are not interested in, or ready for, detoxification, but who may begin to engage in their own recovery if housing and support are available to them. Provider ambivalence regarding harm reduction approaches and the issue of public support for persons who are actively using must be addressed in regard to this point.
- B.13.** The availability of sober housing is expanded to make it possible for people to go immediately from residential or intensive outpatient treatment programs into housing that supports their recovery.

What you will hear from people in recovery when you are promoting access and engagement:

- *I didn't want nothing to do with them at first. But, folks from the Center just kept showing up . . . they didn't drop me or let me get off on the wrong track... they didn't give up, they just stuck by me. It was like a velvet bulldozer.*
- *I hated going to their building. Everybody looked at me as I was walking up the block like "Oh, I wonder if he's a patient there – crazy and on dope." So, I just never went. But, they came to me on my own turn and my own terms. Today, I think my case manager is the reason I'm still alive.*
- *I got help with the kinds of things that were most important to me – like getting my daughter back, and putting food on the table for her. Since they were willing to help me with that stuff, I figured "Hey, maybe I should listen to what they are telling me and try out that program they keep talking about." Today I've been clean for 9 months...*
- *Nobody wanted anything to do with me before. It was always "Come back and see us when you get serious about your recovery... when you've got some clean urines." But, then, this program tried to help me out with getting this job I had wanted for a really long time. Now, I am working part time and I've finally got a reason to be sober every day.*
- *They knew when to take "no" for an answer. They didn't stay on my back all the time, but I knew they were always there for me if I needed them. Now I don't say "no" so often.*



C. Ensuring Continuity of Care

Recovery in both addiction and in mental health, in the sense in which we are using it in this document, refers to a prolonged or long-term process. It does not refer, that is, to an acute phenomenon such as recovery from the flu or from a broken bone. This is not to say that substance use or mental illness cannot also be acute in nature. Many people do, in fact, experience one episode of mental illness or a short-lived period of substance use and do not develop prolonged conditions to begin with.

For such people experiencing only one acute and delimited episode of either substance use or mental illness, however, the notion of recovery is unlikely to have much relevance. Such individuals are unlikely to consider themselves, or to refer to themselves, for example, as being “in recovery” from psychiatric or substance use disorders. In the face of the significant stigma and discrimination which continue to accrue to psychiatric and substance use disorders in the general public, these persons seldom disclose their psychiatric or addiction history or define themselves in terms of this isolated episode of illness, preferring to return quietly to the normal lives they led previously. Without giving much thought to the repercussions of their condition for their social role or sense of identity, such individuals are unlikely to describe themselves as being “in recovery” from anything.

For those individuals for whom being in recovery is a meaningful goal, the nature of their struggle with mental illness and/or addiction is likely to be sustained. In such cases—which, it should be acknowledged, comprise a significant segment of Connecticut citizens receiving care from DMHAS—an acute model of care is not the most useful or appropriate. Particularly in terms of system design, prolonged conditions call for longitudinal models that emphasize continuity of care over time and across programs. Consistent with the principles undergirding the “new recovery movement” in addictions, the long-term nature of addiction and mental illness suggests a number of parameters for developing new models of care that go beyond loosely linked acute episodes¹¹.

These models are based on the belief that full recovery is seldom achieved from a single episode of treatment, and that providers, as well as clients, families, and policy makers, should not be disappointed or discouraged by the fact that there are no quick fixes. Similar to (other) chronic medical illnesses, previous treatment of a person’s condition also should not be taken to be indicative of a poor prognosis, of non-compliance, or of the person’s not trying hard enough to recover. Relapses in substance use and exacerbations of psychiatric symptoms are to be viewed as further evidence of the severity of the person’s condition rather than as causes for discharge (e.g., we do not discharge a person from the care of a cardiologist for having a

¹¹White, W. (2001). The new recovery advocacy movement: A call to service. *Counselor*, 2(6), 64-67.

second or third heart attack). All of these principles suggest that treatment, rehabilitation, and support are not to be offered through serial episodes of disconnected care offered by different providers, but through a carefully crafted system of care that ensures continuity of the person's most significant healing relationships and supports over time and across episodes, programs, and agencies.

**You will know that you are
ensuring continuity of care when:**

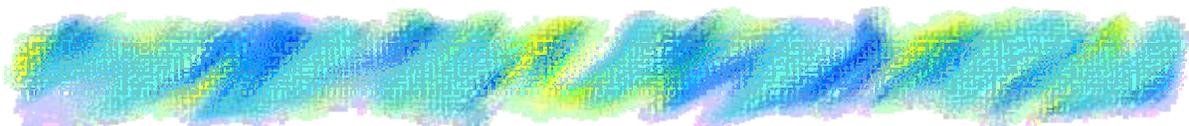
- C.1.** The central concern of engagement shifts from: “How do we get the client into treatment?” to: “How do we nest the process of recovery within the person’s natural environment?” For example, people have often asked for meeting places and activities to be available on weekends, especially for those individuals who are in the early stages of their recovery.
- C.2.** Services are designed to be welcoming to all individuals and there is a low threshold (i.e., minimal requirements) for entry into care. There also is an emphasis on outreach and pre-treatment recovery support services that can ensure that individuals are not unnecessarily excluded from care. If a person is denied care, they receive written explanations as to why and are connected to appropriate alternatives including appointment and transportation.
- C.3.** Eligibility and reimbursement strategies for this group of individuals (i.e., outreach and pre-engagement) are established and refined as necessary over time by administrative leadership.
- C.4.** People have a flexible array of options from which to choose, and options are not limited to what “programs” are available. These options allow for a high degree of individualization and a greater emphasis on the physical/social ecology (i.e., context) of recovery.
- C.5.** Individuals are not expected or required to progress through a continuum of care in a linear or sequential manner. For example, individuals are not required to enroll in a group home as a condition of hospital discharge when this is determined solely by professionals to be the most appropriate level of care. Rather, within the context of a responsive continuum of care, individuals work in collaboration with their recovery team to select those services from within the array that meet their particular needs and preferences at a given point in time.

- C.6.** In a Recovery Management Model, an individual's stage of change is considered at all points in time and the focus of care is on enhancing existing strengths and recovery capital. The assessment of problems and needs is consistently coupled with an assessment of resources and strengths both in initial and in on-going recovery planning. This is best achieved by including the person's family/kinship network and/or any natural supports she or he believes would be supportive of recovery.
- C.7.** Goals and objectives in the recovery plan are not defined by practitioners based on clinically-valued outcomes (e.g., reducing symptoms, increasing adherence), but rather are defined by the person with a focus on building recovery capital and pursuing a life in the community.
- C.8.** The overall focus of care shifts from preventing relapse to promoting recovery. Services are not primarily oriented toward crisis or problem resolution, e.g., detoxification and stabilization. There is a full array of recovery support services, including proactive, preventive supports and post-crisis, community-based resources such as adequate safe housing, recovery community centers operated by people in recovery, sustained recovery coaching, monitoring with feedback, and early re-intervention if necessary. The concept of "aftercare" is irrelevant as all care is conceptualized as continuing care and there is a commitment to provide ongoing, flexible supports as necessary.
- C.9.** Valued outcomes are influenced by the system's commitment to ensuring continuity of care. For example, less emphasis is placed on a professional review of the short-term outcomes of single episodes of care (e.g., readmission or incarceration rates) and more emphasis is placed on the long-term effects of service combinations and sequences on those outcomes valued by the person such as quality of life domains including satisfaction with housing, relationships, and employment.
- C.10.** The range of valued expertise is expanded beyond specialized clinical and rehabilitative professionals and technical experts to include the contributions of multiple individuals and services. These individuals may include peers in paid or volunteer positions, mutual aid groups, indigenous healers, faith community leaders, primary care providers, and other natural supports. Valuing and incorporating such community resources in ongoing care planning is viewed as essential to decreasing dependence on formal behavioral health care and assisting the person to develop a more natural recovery network. In this spirit, the community, rather than the clinic, agency, or program, is viewed as the ultimate context for sustained recovery.

- C.11.** Individuals are seen as capable of illness self-management and interventions support this as a valued goal of recovery-oriented services. People are actively involved in all aspects of their care including policy development, assessment, goal setting, and evaluation. These different forms of involvement build capacity for independent community living and are powerful antidotes to the passivity and dependence that may have resulted from years of being a recipient of professionally-prescribed and delivered care. In the process of decreasing the power differential that traditionally has characterized relationships between clients and providers, care is conceptualized within a partnership or consultant framework in which services—while available over the long-term—may be time-limited and accessed by the person when and as she or he deems necessary.
- C.12.** New technologies (e.g., tele-medicine and web-based applications and self-help resources) are incorporated as service options to enhance illness self-management collaborative treatment relationships.
- C.13.** Access to housing, employment, and other supports that make recovery sustainable is enhanced. This includes changing policies and laws that restrict people’s access to employment and home ownership, such having a criminal record for non-violent, one-time, drug-dealing offenses or offenses related to psychiatric disability.
- C.14.** Policy formulation and legislative advocacy at the administrative level is coupled with on-going efforts to work collaboratively with a variety of state systems to ensure continuity of care, e.g., with the Department of Corrections to put into place plans for re-entry, with resources such as Oxford Houses and rental assistance for people with substance use disorders coming out of jails and prisons.
- C.15.** In order to facilitate sustained recovery and community inclusion, advocacy efforts are extended beyond institutional policies and procedures to the larger community, including stigma-busting, community education, and community resource development activities.

What you will hear from people in recovery when you are ensuring continuity of care:

- *They were there for me – no strings attached. I didn't walk through the door and get a whole bunch of expectations dumped on me.*
- *People respected that I was doing the best I could. It was two steps forward one step back for a long time, but overall, I was moving in the right direction for the first time in as long as I could remember. But they stuck with me for the long haul. Now, I've been clean for 18 months, and someone still calls me everyday to check in—even if its just to day “Hi, How ya' doin'?”*
- *I didn't get kicked out of the program because I had a dirty urine—it used to be that happened every week. This time, I had been clean for two months. My case manager reminded of how good it was in those two months and I wanted to get back there.*
- *It used to be I was terrified of leaving detox. I'd go back to the same crappy environment and be back out on the streets in a matter of days. But, I got into some sober housing and it changed my life.*
- *They knew I needed to work on my recovery AND my life at the same time. That meant getting a part-time job, paying off my debts, working on my marriage, and learning how to enjoy myself again and to do it all drug-free.*



D. Employing Strengths-Based Assessment

As described above, traditional behavioral health services have been based on a narrow and acute medical model that perceives mental illnesses and addictions as diseases that can be treated and cured. While this approach works effectively for many people, for many others it primarily serves to add additional weight to their already heavy burdens. In this case, providers have had an unfortunate tendency to overlook the remaining and co-existing areas of health, assets, strengths, and competencies that the person continues to have at his or her disposal—what remains “right” with people—by focusing on the assessment and treatment of their deficits, aberrations, and symptoms—what is “wrong” with people. Emphasizing the negative in this way has led to a tremendous sense of hopelessness and despair among both clients and the behavioral health practitioners who serve them.

In addition, whether one has a psychiatric disability or an addiction, focusing solely on deficits in the absence of a thoughtful analysis of strengths disregards the most critical resources an individual has on which to build in his or her efforts to adapt to stressful situations, confront environmental challenges, improve his or her quality of life, and advance in his or her unique recovery journey. As the process of improvement depends, in the end, on the resources, reserves, efforts, and assets of and around the individual, family, or community, a recovery orientation thus encourages providers to view the glass as half full rather than half empty¹².

Following principles that have been articulated at length by Rapp and others¹³, strengths-based approaches allow professionals to balance critical needs that must be met with the resources and strengths that individuals and families possess to assist them in this process. This perspective encourages providers to recognize that no matter how disabled, every person continues to have strengths and capabilities as well as the capacity to continue to learn and develop. The failure of an individual to display competencies or strengths is therefore not necessarily attributed to deficits within the person, but may rather, or in addition, be due to the failure of the service system and broader community to adequately elicit information in this area or to create the opportunities and supports needed for these strengths to be displayed.

While system and assessment procedures have made strides in recent years regarding inquiry into the area of individual resources and capacities, simply *asking* an individual what strengths they possess or what things they think they are “good at” may not be sufficient to solicit the information that is critical to the recovery planning process. For example, many people who have prolonged conditions will at first report

¹²Saleebey, D. (2001). The diagnostics strengths manual. *Social Work, 46*, (2), 183-187.

¹³Rapp, C.A. (1998). *The Strengths Model: Case management with people suffering from Severe and Persistent Mental Illness*. New York: Oxford University Press.

that they have no strengths. Such a response should not be taken at face value, but rather to represent the years of difficulties and failures they may have endured and the degree of demoralization which has resulted. Over time, it is not uncommon for such individuals to lose touch with the healthier and more positive aspects of themselves and become unable to see beyond the “patient” or “addict” role.

When facing such circumstances, providers need to conceptualize one of their first steps as assisting this person to get back in touch with his or her previous interests, talents, and gifts. The guidelines below are intended to assist providers in conducting a comprehensive, strengths-based assessment that can help people to rediscover themselves as capable persons with a history, a future, and with strengths and interests beyond their symptoms, deficits, or functional impairments.

You will know that you are providing strengths-based assessment when:

- D.1.** A discussion of strengths is a central focus of every assessment, care plan, and case summary. Assessments begin with the assumption that individuals are the experts on their own recovery, and that they have learned much in the process of living with and working through their struggles. This strengths-based assessment is conducted as a collaborative process and all assessments in written form are shared with the individual.
- D.2.** Initial assessments recognize the power of simple, yet powerful, questions such as “What happened? And what do you think would be helpful? And what are your goals in life?” Self-assessment tools rating level of satisfaction in various life areas can be useful ways to identify diverse goal areas around which supports can then be designed.
- D.3.** Practitioners attempt to interpret perceived deficits within a strengths and resilience framework, as this will allow the individual to identify less with the limitations of their disorder. For example, an individual who takes their medication irregularly may automatically be perceived as “non-compliant,” “lacking insight,” or “requiring monitoring to take meds as prescribed.” This same individual, however, could also be seen as “making use of alternative coping strategies such as exercise and relaxation to reduce reliance on medications” or could be praised for “working collaboratively to develop a contingency plan for when medications are to be used on an ‘as-needed’ basis.”

- D.4.** While strengths of the individual are a focus of the assessment procedure, thoughtful consideration also is given to potential strengths and resources within the individual's family, natural support network, service system, and community at large. This is consistent with the view that recovery is not a solitary process but rather a journey toward interdependence within one's community of choice.
- D.5.** The diversity of strengths that can serve as resources for the person and his or her recovery planning team is respected. Saleeby, for example, has recommended conceptualizing strengths broadly to include the following dimensions: skills (e.g., gardening, caring for children, speaking Spanish, doing budgets); talents (e.g., playing the bagpipes, cooking); personal virtues and traits (e.g., insight, patience, sense of humor, self-discipline); interpersonal skills (e.g., comforting the sick, giving advice, mediating conflicts); interpersonal and environmental resources (e.g., extended family, good neighbors); cultural knowledge and lore (e.g., healing ceremonies and rituals, stories of cultural perseverance); family stories and narratives (e.g., migration and settlement, falls from grace and redemption); knowledge gained from struggling with adversity (e.g., how one came to survive past events, how one maintains hope and faith); knowledge gained from occupational or parental roles (e.g., caring for others, planning events); spirituality and faith (e.g., a system of meaning to rely on, a declaration of purpose beyond self); and hopes and dreams (e.g., personal goals and vision, positive expectations about a better future)¹⁴.
- D.6.** In addition to the assessment of individual capacities, it is beneficial to explore other areas not traditionally considered "strengths," e.g., the individual's most significant or most valued accomplishments, ways of relaxing and having fun, ways of calming down when upset, preferred living environment, educational achievements, personal heroes, most meaningful compliment ever received, etc.
- D.7.** Assessment explores the whole of people's lives while ensuring emphasis is given to the individual's expressed and pressing priorities. For example, people experiencing problems with mental illness or addiction often place less emphasis on symptom reduction and abstinence than on desired improvements in other areas of life such as work, financial security, safe housing, or relationships. For this reason, it is beneficial to explore in detail each individuals' needs and resources in these areas.

¹⁴Saleeby, D. (2001). The diagnostics strengths manual. *Social Work, 46*(2), 183-187.

- D.8.** Strengths-based assessments ask people what has worked for them in the past and incorporate these ideas in the recovery plan. People are more likely to use strategies that they have personally identified or developed rather than those that have been prescribed for them by others.
- D.9.** Guidance for completing a strengths-based assessment may be derived from certain interviewing strategies employed within solution-focused approaches to treatment. For example, DeJong and Miller recommend the following types of inquiry: exploring for exceptions (occasions when the problem could have occurred but did not), imagining a future when the problem has been solved and exploring, in detail, how life would then be different; assessing coping strategies, i.e., asking how an individual is able to cope despite the presence of such problems; and using scaling questions (where the individual rates his or her current experience of the problem) to elucidate what might be subtle signs of progress¹⁵.
- D.10.** Illness self-management strategies and daily wellness approaches such as WRAP¹⁶ are respected as highly effective, person-directed, recovery tools, and are fully explored in the strengths-based assessment process.
- D.11.** Cause-and-effect explanations are offered with caution in strengths-based assessment as such thinking can lead to simplistic resolutions that fail to address the person's situation. In addition, simplistic solutions may inappropriately assign blame for the problem to the individual, with blame being described as "the first cousin" of deficit-based models of practice¹⁷. For example, to conclude that an individual did not pay his or her rent as a direct consequence of his or her "non-compliance" with medications could lead to an intrusive intervention to exert control over the individual's finances or medication. Strengths-based assessments respect that problem situations are usually the result of complex, multi-dimensional influences, and explore with the person in more detail the various factors that led to his or her decisions and behavior (e.g., expressing displeasure with a negligent landlord).

¹⁵DeJong, G. & Miller, S. (1995) How to interview for client strengths, *Social Work*, (40), 729-736.

¹⁶Copeland, M. (2002). *The depression workbook: A guide for living with depression and manic depression. Wellness Recovery Action Plan*. Oakland, CA: New Harbinger Publications.

¹⁷Cowger, C.D. (1994). Assessing client strengths: Clinical assessment for client empowerment. *Social Work* 39(3), 262-268.

- D.12.** Strengths-based assessments are developed through in-depth discussion with the individual as well as attempts to solicit collateral information regarding strengths from the individual’s family and natural supports. Since obtaining all of the necessary information requires time and a trusting relationship with the person, a strengths-based assessment may need to be completed (or expanded upon) after the initial contact as treatment and rehabilitation unfold. While each situation may vary, the assessment is written up as soon as possible in order to help guide the work and interventions of the Recovery Planning Team. Modular approaches to service delivery, billing, and reimbursement are considered by local and state administrative leadership, e.g., certain information is gathered in the first 24 hours with additional areas being assessed by the end of one week, one month, etc.
- D.13.** Efforts are made to record the individual’s responses verbatim rather than translating the information into professional language. This helps to ensure that the assessment remains narrative-based and person-centered. If technical language must be used, it is translated appropriately and presented in a person-first, non-offensive manner, e.g., avoiding the language of “dysfunction, disorder.”
- D.14.** Practitioners are mindful of the power of language and carefully avoid the subtle messages that professional language has historically conveyed to people with psychiatric diagnoses, addictions, and their loved ones. Language is used that is empowering, avoiding the eliciting of pity or sympathy, as this can cast people with disabilities in a passive, “victim” role and reinforce negative stereotypes. For example, just as we have learned to refer to “people who use wheelchairs” as opposed to “the wheelchair bound” we should refer to “individuals who use medication as a recovery tool” as opposed to people who are “dependent on medication for clinical stability.” In particular, words such as “hope” and “recovery” are used frequently in documentation and delivery of services.
- D.15.** Practitioners avoid using diagnostic labels as “catch-all” means of describing an individual (e.g., “she’s a borderline”), as such labels yield minimal information regarding the person’s actual experience or manifestation of their illness or addiction. Alternatively, a person’s needs are not well captured by a label, but by an accurate description of his or her functional strengths and limitations. While diagnostic profiles may be required for other purposes (e.g., decisions regarding medication, justification of level of care), asset-based assessment places limited value on diagnosis per se. In addition, acknowledging

limitations and areas of need are not viewed as accepting one's fate as a mentally ill person or an addict. Rather, identifying and accepting one's current limitations is seen as a constructive step in the process of recovery. Gaining a sense of perspective on both strengths and weaknesses is critical in this process as it allows the person to identify, pursue, and achieve life goals despite the lingering presence of disability.

D.16. Language used is neither stigmatizing nor objectifying. At all times “person first” language is used to acknowledge that the disability is not as important as the person's individuality and humanity, e.g., “a person with schizophrenia” versus “a schizophrenic” or a “person with an addiction” versus “an addict.” Employing person-first language does not mean that a person's disability is hidden or seen as irrelevant; however, it also is not to be the sole focus of any description about that person. To make it the sole focus is depersonalizing, and is no longer considered an acceptable practice.

D.17. Exceptions to person-first and empowering language that are preferred by some persons in recovery are respected. For instance, the personal preferences of some individuals with substance use disorders, particularly those who work the 12-Steps as a primary tool of their recovery, may at times be inconsistent with person-first language. Within the 12-Step Fellowship, early steps in the recovery process involve admitting one's powerlessness over a substance and acknowledging how one's life has become unmanageable. It is also common for such individuals to introduce themselves as: “My name is X and I am an alcoholic.” This preference is respected as a part of the person's unique recovery process, and it is understood that it would be contrary to recovery principles to pressure the person to identify as “a person with alcoholism” in the name of person-first language or principles. Use of person-first language is in the service of the person's recovery; it is not a super-ordinate principle to which the person must conform. While the majority of people with disabilities prefer to be referred to in first-person language, when in doubt ask the person what he or she prefers.

What you will hear from people in recovery when you are employing strengths-based assessment:

- *I used to think my life was over, but my illness isn't a death sentence. Its just one small part of who I am. Sometimes I forget about those other parts – the healthy parts of me. But my counselor always reminds me. You really need someone like that in your life.*

- *Being in recovery means that I know I have certain limitations and things I can't do. But rather than letting these limitations be an occasion for despair and giving up, I have learned that in knowing what I can't do, I also open up the possibilities of all I can do.*¹⁸
- *I thought I was so alone in my problems. I may not feel as though I have much strength right now, but I realize I can draw strength from all the people around me... my friends, my neighbors, my pastor, and my counselors here at the Center.*
- *When they asked me about what I was good at and what sorts of things in my life made me happy, at first I didn't know who they were talking to. Nobody ever asked me those kinds of questions before. Just sitting through that interview, I felt better than before I had walked through the door!*
- *No one here treats me like a label. Just because I have schizophrenia, that doesn't tell you a whole lot. My roommate does too, but we couldn't be more different. Folks here take the time to get to know lots of things about me, not just the things that go along with my diagnosis.*



¹⁸Deegan, P.E. (1993). Recovering our sense of value after being labeled mentally ill. *Journal of Psychosocial Nursing*, 31(4), 7-11.

E. Offering Individualized Recovery Planning

In accordance with the Connecticut General Statutes, as well as Federal and JCAHO guidelines regarding the need for individualized care, all treatment and rehabilitative services and supports to be provided shall be based on an individualized, multidisciplinary recovery plan developed in collaboration with the person receiving these services and any others that he or she identifies as supportive of this process. While based on a model of collaboration and partnership, significant effort will be taken to ensure that individuals' rights to self-determination are respected and that all individuals are afforded maximum opportunity to exercise choice in the full range of treatment and life decisions. The individualized recovery plan will satisfy the criteria of treatment, service, or care plans required by other bodies (e.g., CMS) and will include a comprehensive and culturally sensitive assessment of the person's hopes, assets, strengths, interests, and goals in addition to a holistic understanding of his or her behavioral health conditions and other medical concerns within the context of his or her ongoing life.

Typical examples of such life context issues include employment, education, housing, spirituality, social and sexual relationships, and involvement in meaningful and pleasurable activities. In order to ensure competence in these respective areas, including competence in addressing the person's cultural background and affiliations, the multi-disciplinary team will not be limited to physician/psychiatrists, nurses, psychologists, and social workers, but may also include rehabilitative and peer staff, and wherever possible, relevant community representatives and/or others identified by the person.

Building on the strengths-based assessment process, individualized recovery planning both encourages and expects the person to draw upon his or her strengths to participate actively in the recovery process. It is imperative throughout this process that providers maintain a belief in the individual's potential for growth and development, up to, and including, the ability to exit successfully from services. Providers also solicit the person's own hopes, dreams, and aspirations, encouraging individuals to pursue their preferred goals even if doing so presents potential risks or challenges.

For example, many people identify returning to work as a primary recovery goal. It is not uncommon for practitioners to advise against this step based on an assumption that an individual either is not "work ready" or that employment will be detrimental to his or her recovery (e.g., by endangering his or her disability benefits). While such advice is based on good intentions, it sends a powerful message to the individual and can reinforce self-doubts and feelings of inadequacy. Rather than discouraging the person from pursuing this goal, the practitioner can have a frank discussion with the person about his or her concerns while simultaneously

highlighting the strengths that the individual can draw upon to take the first step toward achieving this goal.

In this vein, individualized recovery planning explicitly acknowledges that recovery entails the person's taking risks to try new things, and is enhanced by the person having opportunities to learn from his or her own mistakes and their natural consequences. This represents an important source of progress in the person's efforts to rebuild his or her life in the community that—similar to exercising one's muscles—cannot proceed without an exertion of the person's own faculties.

You will know that you are offering Individualized Recovery Planning when:

E.1. Core principles of “person-centered” planning are followed in the process of building individualized recovery plans. For example:

E.1.1. Consistent with the “nothing about us, without us” dictum, providers actively partner with the individual in all planning meetings and/or case conferences regarding his or her recovery services and supports.

E.1.2. The individual has reasonable control as to the location and time of planning meetings, as well as to who is involved, including conserved persons who wish to have an advocate or peer support worker present. Planning meetings are conducted and services are delivered at a time that does not conflict with other activities that support recovery such as employment. The individual can extend invitations to any person she or he believes will be supportive of his or her efforts toward recovery. Invitations extended are documented in the recovery plan. If necessary, the person (and family as relevant) are provided with support before the meeting so that they can be prepared and participate as equals¹⁹.

E.1.3. The language of the plan is understandable to all participants, including the focus person and his or her non-professional, natural supports. Where technical or professional terminology is necessary, this is explained to all participants in the planning process.

¹⁹Osher, D. & Keenan, S. (2001). From professional bureaucracy to partner with families. *Reaching Today's Youth*, 5(3), 9–15.

- E.1.4.** When individuals are engaged in rehabilitation services, the rehab practitioners are involved in all planning meetings (at the discretion of the individual) and are given copies of the resulting plan.
- E.1.5.** Within the planning process, a diverse, flexible range of options must be available so that people can access and choose those supports that will best assist them in their recovery. These choices and service options are clearly explained to the individual, and documentation reflects the options considered.
- E.1.6.** Goals are based on the individual's unique interests, preferences, and strengths, and objectives, and interventions are clearly related to the attainment of these stated goals. In the case of children and youth, the unique goals of the family are also considered, with the youth increasingly driving the process as he or she approaches the age of maturity. In cases in which preferred supports do not exist, the recovery team works collaboratively with the individual to develop the support or to secure an acceptable alternative.
- E.1.7.** Planning focuses on the identification of concrete next steps, along with specific timelines, that will allow the person to draw upon existing areas of strength to move toward recovery and his or her vision for the future. Individuals, including non-paid, natural supports who are part of the planning process, commit to assist the individual in taking those next steps. The person takes responsibility for his or her part in making the plan work. Effective recovery plans help people rise to this challenge regardless of their disability status.
- E.1.8.** A discussion of strengths is a central focus of all recovery plans (See Section #D). Assessments begin with the assumption that individuals are the experts on their own recovery, and that they have learned much in the process of living with and working through their struggles.
- E.1.9.** Information on rights and responsibilities of receiving services is provided at all recovery planning meetings. This information should include a copy of the mechanisms through which the individual can provide feedback to the practitioner and/or agency, e.g., protocol for filing a complaint or compliments regarding the provision of services.
- E.1.10.** The individual has the ability to select or change his or her service providers within eligible guidelines and is made aware of the procedures for doing so.

E.1.11. In the spirit of true partnership and transparency, all parties must have access to the same information if people are to embrace and effectively carry out responsibilities associated with the recovery plan²⁰. Clients are automatically offered a copy of their written plans, assessments, and progress notes. Knowing ahead of time that a copy will be shared is a simple but powerful strategy that can dramatically impact both the language of the plan and the content of its goals and objectives.

E.1.12. The team reconvenes as necessary to address life goals, accomplishments, and barriers. Planning is characterized by celebrations of successes, and meetings can occur beyond regular, established parameters (e.g., 6-month reviews) and crises (e.g., “all-treaters” meetings to address hospitalization or relapse).

E.2. A wide range of interventions and contributors to the planning and care process are recognized and respected. For example:

E.2.1. Practitioners acknowledge the value of the person’s existing relationships and connections. If it is the person’s preference, significant effort is made to include these “natural supports” and unpaid participants as they often have critical input and support to offer to the team. Interventions should complement, not interfere with, what people are already doing to keep themselves well, e.g., drawing support from friends and loved ones²¹.

E.2.2. The plan identifies a wide range of both professional supports and alternative strategies to support the person’s recovery, particularly those which have been helpful to others with similar struggles. Information about medications and other treatments are combined with information about self-help, peer support, exercise, nutrition, daily maintenance activities, spiritual practices and affiliations, homeopathic and naturopathic remedies, etc.

E.2.3. Individuals are not required to attain, or maintain, clinical stability or abstinence before they are supported by the planning team in pursuing such goals as employment. For example, in some systems access and

²⁰Osher, T., & Osher, D. (2001). The paradigm shift to true collaboration with families. *The Journal of Child and Family Studies*, 10(3), 47-60.

²¹Osher, D. and Webb, L. (1994). *Adult Literacy, Learning Disabilities, and Social Context: Conceptual Foundations for a Learner-Centered Approach*. Washington, DC, U.S. Department of Education.

referral to vocational rehabilitation programs may be controlled by a clinical practitioner, and people are often required to demonstrate “work readiness” or “symptomatic stability” as a prerequisite to entry. In addition to an abundant literature which has shown that screening procedures and criteria have limited predictive validity, this structure also neglects that fact that activities such as working are often the path through which people become clinically stable in the first place.

- E.2.4.** Goals and objectives are driven by the person’s current values and needs and not solely by commonly desired clinical/professional outcomes, e.g., recovery is a process that may or may not begin with the individual understanding or appreciating the value of abstinence or of taking medications.

E.3. Community inclusion is valued as a commonly identified and desired outcome. For example:

- E.3.1.** The focus of planning and care is on how to create pathways to meaningful and successful community life and not just on how to maintain clinical stability or abstinence. Person-centered plans document areas as physical health, family and social relationships, employment/education, spirituality, housing, social relations, recreation, community service and civic participation, etc., unless such areas are designated by the person as not-of-interest. For example, traditional planning has often neglected the spiritual and sexual aspects of peoples’ lives. Achieving interdependence with natural community supports is a valued goal for many people in recovery who express a strong preference to live in typical housing, to have friendships and intimate relationships with a wide range of people, to work in regular employment settings, and to participate in school, worship, recreation, and other pursuits alongside other community members²². Such preferences often speak to the need to reduce time spent in segregated settings designed solely to support people labeled with a behavioral health disorder.

- E.3.2.** Recovery plans respect the fact that services and practitioners should not remain central to a person’s life over time, and exit criteria from formal services are clearly defined. Given the unpredictability of illness, and life more generally, however, readmission also remains uncomplicated, with avenues clearly defined for people on discharge.

²²Reidy, D. (1992). Shattering illusions of difference. *Resources*, 4(2), 3-6.

E.3.3. Recovery plans consider not only how the individual can access and receive needed supports from the behavioral health system and the community, but how the individual can, in turn, give back to others. People have identified this type of reciprocity in relationships as being critical to building recovery capital and to the recovery process as a whole. Therefore, individuals should be encouraged to explore how they can make meaningful contributions in the system or in the community, e.g., through advocacy, employment, or volunteering.

E.3.4. A focus on community is consistent not only with person-centered care principles but with the need for fiscal efficiency. Practitioners and people in recovery should be mindful of the limited resources available for specialized services and should focus on community solutions and resources first by asking “Am I about to recommend or replicate a service or support that is already available in the broader community?” At times this has direct implications for the development of service interventions within recovery plans, e.g., creating on-site health and fitness opportunities such as exercise classes without first exploring to what extent that same opportunity might be available in the broader community through public recreational departments, YMCAs, etc. If natural alternatives are available in the community, individuals should be informed of these opportunities and to the extent to which what is offered is culturally responsive and accessible, they should be supported in pursuing activities of choice in integrated settings.

E.4. The planning process honors the “dignity of risk” and “right to fail” as evidenced by the following:

E.4.1. Prior to appealing to coercive measures, practitioners try different ways of engaging and persuading individuals in ways which respect their ability to make choices on their own behalf.

E.4.2. Unless determined to require conservatorship by a judge, individuals are presumed competent and entitled to make their own decisions. As part of their recovery, they are encouraged and supported by practitioners to take risks and try new things. Only in cases involving imminent risk of harm to self or others is a practitioner authorized to override the decisions of the individual. Person-centered care does not take away a practitioner’s obligation to take action to protect the person or the public in the event of emergent or crisis situations, but limits the authority of practitioners to specifically delimited circumstances involving imminent risk as defined by relevant statutes.

E.4.3. In all other cases, practitioners are encouraged to offer their expertise and suggestions respectfully within the context of a collaborative relationship, clearly outlining for the person his or her range of options and possible consequences. Practitioners support the dignity of risk and sit with their own discomfort as the person tries out new choices and experiences that are necessary for recovery.

E.4.5. In keeping with this stance, practitioners encourage individuals to write their own crisis and contingency plans (such as psychiatric advanced directives or the crisis plans of the WRAP model). Ideally, such plans are directed by the individual but developed in collaboration with the entire team so as to share responsibility and resources in preventing or addressing crises²³. Such plans provide detailed instructions regarding preferred interventions and responses in the event of crisis, and maximize an individual's ability to retain some degree of autonomy and self-determination at a time when he or she is most likely to have these rights taken away. This plan is kept in an accessible location and can be made available for staff providing emergency care.

E.5. Administrative leadership demonstrate a commitment to both outcomes and process evaluation. For example:

E.5.1. Outcomes evaluation in a provider-driven paradigm is typically limited to change in specific agency functions (e.g., length of hospital stays) as well as by the need to protect the image of the agency (e.g., consumer satisfaction)²⁴. In a consumer or family-driven paradigm, in contrast,

evaluation is a continuous process and expectations for successful outcomes in a broad range of quality of life dimensions (e.g., in areas such as employment, social relationships, community membership, etc.) are high. The maintenance of clinical stability alone is not accepted as a treatment outcome as the experience of recovery is about much more than the absence of symptoms or distress.

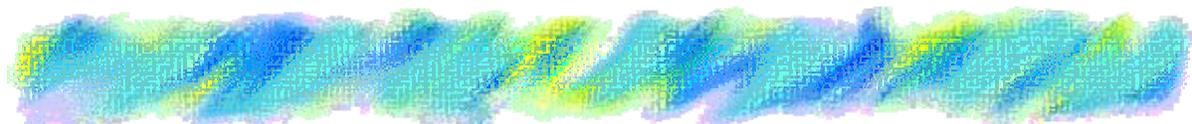
²³Kendziora, K. T., Bruns, E., Osher, D., Pacchiano, D., & Mejia, B. (2001). *Wraparound: Stories from the Field*. Washington, DC: Center for Effective Collaboration and Practice, American Institutes for Research.

²⁴Osher, T. & Osher, D. (2001). The paradigm shift to true collaboration with families. *The Journal of Child and Family Studies*, 10(3), 47-60.

E.5.2. There is a flexible application of process tools, such as the Assessment of Person-Centered Planning Facilitation Integrity Questionnaire²⁵, to promote quality service delivery. Assuming attention is paid to the larger organizational culture, process tools can be helpful in defining the practice and then monitoring its effective implementation²⁶.

What you will hear from people in recovery when you are offering individualized recovery planning:

- *It's amazing what you can do when you set your mind to it ... especially when you're no longer supposed to have one!*
- *It made such a huge difference to have my pastor there with me at my planning meeting. He may not be my father, but he is the closest thing I've got. He knows me better than anyone else in the world and he had some great ideas for me.*
- *I had been working on my recovery for years. Finally, it felt like I was also working on my LIFE!*
- *Not everybody thought it was a good idea for me to try to get my daughter back. But they realized that without her, I didn't have a reason to be well. So, we figured out a plan for what to do if I couldn't handle the stress, and my whole team has stood beside me every step of the way. Was it "too stressful" at times? You bet! But every day is a blessing now that I wake up and see her smiling face!*



²⁵Holburn, S. (2001). How science can evaluate and enhance person-centered planning. *Research and Practice for Persons with Severe Disabilities*, 27(4), 250-260.

²⁶Osher, T., Osher, D. & Blau, G. (2005a). Family-driven Care: A working definition. Alexandria, VA: Federation of Families for Children's Mental Health. http://ffcmh.org/systems_whatism.htm.

F. Functioning as a Recovery Guide

The sentiment that “we’re not cases, and you’re not managers”²⁷ has been accepted increasingly as a fundamental challenge to the ways in which behavioral health care is conceptualized within a recovery-oriented system. During this time, the predominant vehicle for offering services to many adults with serious disabilities has evolved from the team-based and *in vivo* approach of intensive case management to the introduction of strengths-based and rehabilitative forms of case management that attempt to shift the goals of care from stabilization and maintenance to enhanced functioning and community integration.

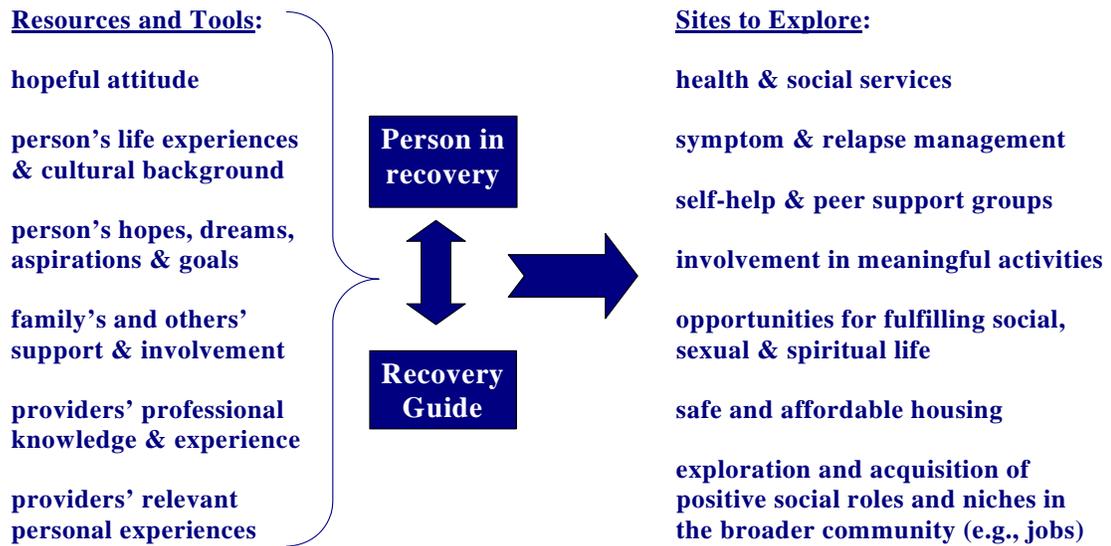
From the perspective of recovery, however, even these inherited models of case management limit the progress that otherwise could be made in actualizing the shift from a deficit- and institution-based framework to a recovery paradigm. This paradigm calls for innovative models of community-based practice that move beyond the management of cases, and beyond merely semantic changes that introduce new terms for old practices, to the creation of a more collaborative model which respects the person’s own role in directing his or her life and, within that context, his or her own treatment (in much the same way that people, in collaboration with their health care professionals, make decisions about their own medical care for other conditions such as hypertension). One such model that is emerging within DMHAS is that of the community or recovery guide.

Rather than replacing any of the skills or clinical and rehabilitative expertise that practitioners have obtained through their training and experience, the recovery guide model offers a useful framework in which these interventions and strategies can be framed as tools that the person can use in his or her own recovery. In addition, the recovery guide model, as depicted on the following page, offers both providers and people in recovery a map of the territory they will be exploring together.

Prior to attempting to embark with a client on his or her journey of recovery, however, practitioners appreciate that the first step in the process of treatment, rehabilitation, or recovery is often to engage in a relationship a reluctant, disbelieving, but nonetheless suffering, person. In this sense, practitioners accept that most people with behavioral health disorders will not know that they have an addiction or psychiatric disorder at first, and therefore will frequently not seek help on their own. The initial focus of care is thus on the person’s own understanding of his or her predicament (i.e., not necessarily the events or difficulties which brought him or her into contact with care providers), and on the ways in which the practitioner can be of assistance in addressing this predicament, regardless of how the person understands it at the time.

²⁷Everett, B. & Nelson, A. (1992). We’re not cases and you’re not managers. *Psychosocial Rehabilitation Journal*, 15(4), 49-60.

Figure 1. Conceptual Model for the Recovery Guide



It also is important to note that within this model, care incorporates the fact that the lives of people in recovery did not begin with the onset of their disorders, just as their lives are not encompassed totally by substance abuse or psychiatric treatment and rehabilitation. Based on recognition of the fact that people were already on a journey prior to the onset of their disorders, and therefore prior to coming into contact with care, the focus of care shifts to the ways in which this journey was impacted or disrupted by each person's disorder(s).

For example, practitioners strive to identify and understand how the person's substance use or psychiatric disorder has impacted on or changed the person's aspirations, hopes, and dreams. If the person appears to be sticking resolutely to the hopes and dreams he or she had prior to onset of the disorder, and despite of or without apparent awareness of the disorder and its disabling effects, then what steps need to be taken for him or her to get back on track or to take the next step or two along this track? Rather than the reduction of symptoms or the remediation of deficits—goals that we assume the person will share with care providers—it is the person's own goals for his or her life beyond or despite his or her disability that drive the treatment, rehabilitation, and recovery planning and efforts.

**You will know that you are functioning
as a Recovery Guide when:**

- F.1.** The primary vehicle for the delivery of most behavioral health interventions is the relationship between the practitioner and the person in recovery. The care provided must be grounded in an appreciation of the possibility of improvement in the person's condition, offering people hope and/or faith that recovery is "possible for me." Practitioners convey belief in the person even when he or she cannot believe in him or herself and serve as a gentle reminder of his or her potential. In this sense, staff envision a future for the person beyond the role of "mental patient" or "addict" based on the person's own desires and values and share this vision with the person through the communication of positive expectations and hope.
- F.2.** Providers assess where each person is in relation to the various stages of change (e.g., pre-contemplation, preparation, etc.) with respect to the various dimensions of his or her recovery. Interventions are appropriate to the stages of change relevant to each focus of treatment and rehabilitation (e.g., a person may be in an action phase related to his or her substance use disorder but be in pre-contemplation related to his or her psychiatric disorder).
- F.3.** Care is based on the assumption that as a person recovers from his or her condition, the addiction or psychiatric disorder then becomes less of a defining characteristic of self and more simply one part of a multi-dimensional sense of identity that also contains strengths, skills, and competencies. Services elicit, flesh out, and cultivate these positive elements at least as much as, if not more than, assessing and ameliorating difficulties. This process is driven by the person in recovery through inquiries about his or her hopes, dreams, talents, and skills, as well as perhaps the most important question of "How can I be of help?"
- F.4.** Interventions are aimed at assisting people in gaining autonomy, power, and connections with others. Practitioners regularly assess the services they are providing by asking themselves: "Does this person gain power, purpose (valued roles), competence (skills), and/or connections (to others) as a result of this interaction?" and, equally important: "Does this interaction interfere with the acquisition of power, purpose, competence, or connections to others?"
- F.5.** Opportunities and supports are provided for the person to enhance his or her own sense of personal and social agency. For example, practitioners understand that medication is only one tool in a person's "recovery tool box" and learn about alternative methods and self-management strategies in which people use their own experiences and

knowledge to apply wellness tools that work best for them. Sense of agency involves not only feeling effective and able to help oneself but also being able to positively impact the lives of others. Providers can achieve this by thoughtfully balancing when to do for someone, do with someone, or when to let someone do for him or herself. Knowing when to hold close and support and protect, when to encourage someone while offering support, when to let someone try alone and perhaps stumble, and when to encourage a person strongly to push themselves is an advanced, but essential, skill for practitioners to develop. While these are intuitive skills that all practitioners must struggle to refine over time, prior to taking action it is always beneficial for practitioners to ask the question: “Am I about to do for this person something she or he could manage to do more independently.” Strong messages of low expectations and incapability are given, and reinforced, every time unnecessary action is undertaken for a person, instead of with them.

- F.6.** Individuals are allowed the right to make mistakes, and this is valued as an opportunity for them to learn. People in recovery report that they have found meaning in adverse events and failures and that these have subsequently helped them to advance in their recovery. In accordance with this, practitioners recognize that their role is not necessarily to help people avoid adversity or to protect them from failure. For example, the re-experiencing of symptoms can be viewed as a part of the recovery process and not necessarily a failure or setback. The “dignity of risk” ensues following a thoughtful and proactive planning process in which practitioners work collaboratively with individuals to develop relapse prevention plans, including advance directives which specify personal and treatment preferences in the event of future crises.
- F.7.** People are allowed to express their feelings, including anger and dissatisfaction, without having these reactions attributed to symptoms or relapse.
- F.8.** Care is not only attentive to cultural differences across race, ethnicity, and other distinctions of difference (e.g., sexual orientation), but incorporates this sensitivity at the level of the individual. Only an individual-level process can ensure that practitioners avoid stereotyping people based on broad or inaccurate generalizations (e.g., what all lesbians want or need), and enable them instead to tailor services to the specific needs, values, and preferences of each person, taking into account each individual’s ethnic, racial, and cultural affiliations.

- F.9.** Rather than dwelling on the person’s distant past or worrying about the person’s long-term future, practitioners focus on preparing people for the next one or two steps of the recovery process by anticipating what lies immediately ahead, by focusing on the challenges of the present situation, and by identifying and helping the person avoid or move around potential obstacles in the road ahead. Although the practitioner deemphasizes the person’s early personal history (because it may not be relevant) and long-term outcome (because it cannot be predicted), either of these perspectives may be invoked should they prove useful in the current situation. Especially as these issues pose barriers to recovery, practitioners utilize appropriate clinical skills within the context of a trusting relationship in order to enhance the person’s capacity to overcome, compensate for, or bypass these barriers (see section #H below).
- F.10.** Interventions are oriented toward increasing the person’s recovery capital as well as decreasing his or her distress and dysfunction (see Sections #C and #H). Grounded in a person’s “life-context,” interventions take into account each person’s unique history, experiences, situations, developmental trajectory, and aspirations. In addition to culture, race, and ethnicity, this includes less visible but equally important influences on each person’s development, including both the traditional concerns of behavioral health practitioners (e.g., family composition and background, history of substance use and relapse triggers) as well as less common factors such as personal interests, hobbies, and role models that help to define who each person is as an individual and as a member of his or her network.
- F.11.** Practitioners are willing to offer practical assistance in the community contexts in which their clients live, work, and play. In order to effectively address “individuals’ basic human needs for decent housing, food, work, and ‘connection’ with the community,” practitioners are willing to go where the action is, i.e., they get out of their offices and out into the community²⁸. They are prepared to go out to meet people on their own turf and on their own terms, and to “offer assistance which they might consider immediately relevant to their lives”²⁹.

²⁸Curtis, L.& Hodge, M. (1994). Old standards, new dilemmas: Ethics and boundaries in community support services. *Psychosocial Rehabilitation Journal*, 18(2), 13-33.

²⁹Rosen, A. (1994). Case management: The cornerstone of comprehensive local mental health services. *Australian Hospital Association, Management Issues Paper No. 4*. April, 47-63.

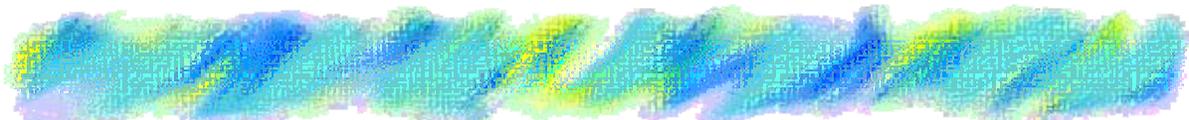
- F.12.** Care is not only provided in the community but is also oriented toward increasing the quality of a person's involvement in community life. Thus, the focus of care is considered more important than locus of where it is provided. The focus of care includes the process of overcoming the social and personal consequences of living with psychiatric and/or substance use disorders. These include gaining an enhanced sense of identity and meaning and purpose in life and developing valued social roles and community connections despite a person's continued symptoms or disability. Supporting these goals requires that practitioners have an intimate knowledge of the communities in which their clients live, the community's available resources, and the people who are important to them, whether it is a friend, parent, employer, landlord, or grocer. Practitioners also are knowledgeable about informal support systems that are in communities such as support groups, singles clubs, and other special interest groups, and actively pursue learning more about other possibilities that exist to help people connect.
- F.13.** Efforts are made to identify sources of incongruence between the person and his or her environment and to increase person-environment fit. This is done both by helping the person assimilate into his or her environment (through symptom management, skill acquisition, etc.) and by helping the community to better accommodate people with disabilities (through education, stigma reduction, the creation of niches, etc.), with the common goal being to develop "multiple pathways" into and between members of communities.
- F.14.** In order to counteract the often hidden effects of stigma, practitioners explicitly draw upon their own personal experiences when considering the critical nature of various social roles in the lives of all individuals (e.g., being a parent, a worker, a friend, etc), continuing to view people in recovery squarely within the context of their daily lives (i.e., as opposed to within institutional settings).
- F.15.** Community-focused care supplements, and is not meant to be a substitute for, the practitioner's existing expertise and services. Rather than devaluing professional knowledge and experience, the "recovery guide" approach moves psychiatry much closer to other medical specialties in which it is the health care specialist's role to assess the person, diagnose his or her condition, educate the person about the costs and benefits of the most effective interventions available to treat his or her condition, and then provide the appropriate interventions. There is an expectation that practitioners engage in on-going professional education so that they are aware of, and can deliver, a wide range

of evidence-based and emerging practices. But no matter how expert or experienced the practitioner, it is then ideally left up to the person and his or her loved ones to make decisions about his or her own care.

- F.16.** Recovery is viewed as a fundamentally social process, involving supportive relationships with family, friends, peers, community members, and practitioners. Interventions serve to minimize the role that professionals play in people’s lives over time and maximize the role of natural supports. While the provider-person relationship can be a powerful component of the healing and recovery process, individuals must also develop and mobilize their own natural support networks to promote sustained recovery and independent community life.

What you will hear from people in recovery when you are functioning as a recovery guide:

- *She believed in me, even when I didn’t believe in myself. Hope was the biggest gift she could have given me... and it saved my life.*
- *When he asked me, “So how can I best be of help!” I thought, “Oh great, I’ve really got a green one. You are supposed to be the professional—you tell me!” But I get it now. I need to decide what I need to move ahead in my recovery. And I needed to know it was OK to ask people for that. That was the key.*
- *When she ever showed up on my doorstep with a bag of clothes so my baby could start kindergarten, I knew this one was different. I couldn’t care about myself or my recovery until I knew my kids were OK. She didn’t pity me, or look for a pat on the back. She just knew, this was what I needed and it made all the difference in my recovery.*
- *I was terrified of going back to that hospital. My case manager couldn’t guarantee me that it wouldn’t happen again. But we sat down together and did a plan for how to make things different if there ever was a “next time.” Knowing my dog would get fed, making sure somebody talked to my landlord so I wouldn’t get evicted, and being able to write down how the staff could help me if I lost control... All those things made the idea of going back less scary.*



G. Community Mapping and Development

Given its focus on life context, one tool required for effective recovery planning is adequate knowledge of the person's local community, including its opportunities, resources, and potential barriers. This knowledge is to be obtained and updated regularly at a community-wide level for the areas in which a program's service recipients live, but also is to be generated on an individual basis contingent on each person's interests, talents, and needs.

Historically falling under the purview of social work and rehabilitation staff, the function of identifying, cataloguing, and being familiar with community resources both within and beyond the formal behavioral health system can be carried out by staff from any discipline with adequate training and supervision. In most cases, however, this expertise will reside with local community-based providers rather than with inpatient or residential staff located at a distance from the person's community of origin. In such cases, close coordination between inpatient/residential and outpatient staff will be required to obtain and integrate this information into the individualized recovery plan. Regardless of how it is provided, a comprehensive understanding of the community resources and supports that are available to address the range of a person's needs as he or she identifies them is essential to the recovery planning process across the continuum of care.

Asset-based community development is one essential strategy for developing this comprehensive understanding of local resources and supports. Based on the pioneering work of Kretzmann and McKnight ("Building Communities from the Inside Out"), asset-based community development (ABCD) is a widely recognized capacity-focused approach to community development that can help open doors into communities for persons who have been labeled or otherwise marginalized, and through which people in recovery can build social capital and participate in community life as citizens rather than clients.

Through the cultivation of mutually beneficial relationships, ABCD has been shown to be an effective technology for capitalizing upon the internal capacities of low-income urban neighborhoods and rural communities, particularly as the depth and extent of associational life in these communities is often vastly underestimated³⁰. Whereas community development has historically been deficit- or problem-based and fueled by "needs assessments" and "needs maps," ABCD operates on the premise that every person in a community has gifts, strengths, skills, and resources to be contributed to the community and that community life is shaped, driven, and

³⁰Kretzmann, J.P. & McKnight, J.L. (1993). Building Communities from the Inside Out. Chicago, IL. ACTA Publications.

sustained by the contributions of an involved and interdependent citizenry. Capacity, strength, and resources are also derived from community associations (religious, civic, recreational, political, social, etc.) and from community institutions (schools, police, libraries, parks, human services, etc.).

Asset-based community development is a fully participatory process that involves all persons in mapping the resources and capacities of a community's individuals, its informal associations, and its structured institutions, as a means of identifying existing, but untapped or overlooked, resources and other potentially hospitable places in which the contributions of people with disabilities will be welcomed and valued³¹. Information about individuals, community associations, and institutions is collected through the sharing of stories and in one-on-one interviews that foster the development of personal relationships.

The relationships, resource maps, and capacity inventories that result from this process serve to guide on-going community development and provide a means by which people can expand their existing social networks and involvement in community activities. Pride in past achievements is strengthened, new opportunities for creative endeavor are discovered, resiliency is experienced, and hope is sustained. It is important to note that the primary producers of outcomes in this process are not institutions but individuals strengthened by enhanced community relationships. ABCD ultimately helps people in recovery derive great benefit from access to a range of naturally occurring social, educational, vocational, spiritual, and civic activities involved in their return to valued roles in the life of their community.

**You will know you are engaged in
community mapping and development when:**

- | | |
|---------------------------------------|--|
| <p>G.1.</p> <p>G.2.</p> | <p>People in recovery and other labeled and/or marginalized persons are viewed primarily as citizens and not as clients and are recognized for the gifts, strengths, skills, interests, and resources they have to contribute to community life.</p> <p>Community leaders representing a range of community associations and institutions work together with people in recovery to carry out the process of community development.</p> |
|---------------------------------------|--|

³¹McKnight, J. (1992). Redefining community. *Journal of Social Policy, Fall/Winter*, 56-62.

- G.3.** People in recovery and other community members experience a renewed sense of empowerment and social connectedness through voluntary participation in civic, social, recreational, vocational, religious, and educational activities in the community. Therefore, opportunities for employment, education, recreation, social involvement, civic engagement, and religious participation are regularly identified and are compiled in asset maps, capacity inventories, and community resource guides. These informational resources are made available to individuals on their initial agency orientation and are updated over time as knowledge about the local community grows.
- G.4.** Asset maps and capacity inventories created collaboratively by actively involved community stakeholders reflect a wide range of *natural* gifts, strengths, skills, knowledge, values, interests, and resources available to a community through its individuals, associations, and institutions. In other words, they are not limited to social and human services or professional crisis or emergency services.
- G.5.** High value is placed on the less formal aspects of associational life that take place, for instance, in neighborhood gatherings, block watch meetings, coffee clatches, salons, barbershops, book groups, knitting and craft circles, restaurants, pubs, diners, etc.
- G.6.** Institutions do not duplicate services that are widely available in the community through individuals and associations.
- G.7.** Community development is driven by a creative, capacity-focused vision identified and shared by community stakeholders. It is neither deficit-oriented nor driven by needs assessments and needs maps.
- G.8.** The relational process of gathering information about community assets and capacities through personal interviews and sharing of stories is recognized as being as important as the information that is collected.

What you will hear from people in recovery when you are engaged in community mapping and development:

- *I just wanted to get back to my life: my friends, and my job, and my church activities. My recovery was important, but it didn't matter so long as I didn't have those things in my life to look forward to. It was those things that kept me going in my darkest days.*

- *Just having a place to hang out, where I blend in with the crowd... where no one knows me as a patient on the ACT team. That is when I am most peaceful.*
- *It wasn't enough for me to just get better. I appreciated everyone's help, but I felt like such a charity case all the time. What really made a difference was when my counselor helped me to get a volunteer position at the local nursing home. Sometimes I read to the folks, or we play cards. It may not be fancy, but it feels right to me. I don't just have to take help from everybody else, I have valuable things to give back in return.*
- *I knew all about the places where folks could go to get help if you had a problem with drugs or mental illness. What I had forgotten about was how to have FUN! My case manager gave me this terrific list of low-cost activities that happen right around the corner from my apartment, and I never even knew this stuff was right under my nose. It's opened up a whole new world for me. I made some great friends, and one of them is even looking for some part-time help in her art store--so I'm gonna get a job out of it too! Things happen in the strangest ways sometimes...*
- *My yoga class at the mental health center got cancelled, and instead, they gave us a coupon to try out some free lessons at the city Rec Department. At first I was so disappointed. But once I tried it out, I loved it. I now take pilates in addition to yoga and I also joined a hiking club. I feel healthier physically and mentally...*



H. Identifying and Addressing Barriers to Recovery

To this point, our guiding assumption has been that behavioral health disorders are illnesses like any others and that, with few exceptions, seeking and receiving care for these disorders should resemble care provided for other medical conditions. Although we have made a point of stressing the need for outreach and engagement to ensure access to care, we otherwise may have given the reader the impression that people with behavioral health disorders are educated consumers of health care and that they will naturally act on their own behalf in making appropriate choices in this and other domains.

Experienced providers will no doubt consider such a perspective simplistic and naïve, and will suggest that up to 80% of the work entailed in treating behavioral health disorders is devoted to helping people to arrive at such a position of being willing to receive care for their conditions. Once a person accepts that he or she has a behavioral health disorder and agrees to participate in treatment and/or rehabilitation, the bulk of the more difficult work may appear to be done. We appreciate this sentiment, and agree that it may take a generation or more before many more people experiencing these conditions will be able to access and benefit from care in such a straightforward and uncomplicated manner.

For the foreseeable future, there will continue to be two major sources of complications—and of considerable suffering—that make accessing and benefiting from care a labor intensive and difficult process. These two types of barriers to recovery reside both external to the person, in societal stigma and discrimination and in the ways in which care has historically been structured and provided, and internal to the person, intrinsic to the nature of the illnesses themselves. In order to promote recovery, providers must be able to identify and address the variety of barriers encountered in each of these domains.

In terms of external barriers, there currently are elements and characteristics of the service delivery system and the broader community that unwittingly contribute to the exacerbation of symptoms and the creation and perpetuation of chronicity and dependency in individuals with behavioral health disorders. Foremost among these is the discrimination that continues to affect people with mental illnesses and/or addictions in society at large and, even more importantly, within the behavioral health system itself.

This discrimination results in people with behavioral health disorders being viewed and treated as second-class citizens in a variety of life domains. One byproduct of repeated discrimination is that people come to view and treat themselves as second-class citizens as well. What advocates within the mental health community have come to call “internalized stigma” presents a significant obstacle to

recovery, undermining the self-confidence and self-esteem required for the person to take steps toward improving his or her life. The demoralization and despair that are associated with internalized stigma and feelings of inferiority also tap the person's sense of hope and initiative, adding further weight to the illness and its effects.

Beyond the impact of stigma and discrimination, there are a variety of ways in which the health care system and the broader community make recovery more difficult. These range from the lack of affordable housing and accessible, high quality medical care to the employment disincentives built in to entitlement programs, to the punitive aspects of some care settings and programs (e.g., in which people are discharged for manifesting the symptoms of their illness). Identifying and assisting the person to overcome these barriers to the degree that is possible is an important component of the work of the recovery-oriented behavioral health care practitioner.

In terms of internal barriers, there are several aspects of behavioral health disorders and their place within contemporary society that complicate and undermine the person's efforts. For example, while trauma may not be intrinsic to behavioral health per se, there is considerable evidence that suggests that people experiencing behavioral health disorders at the present time have a greatly increased chance of having experienced a history of trauma earlier in their lives, as well as being at increased risk for exposure to trauma and victimization currently.

Perhaps more directly as a consequence of the illness itself, there also are symptoms of behavioral health disorders that pose their own barriers. The hallucinations and delusions often found in psychotic illnesses, for example, may compete as a source of information with that being offered to the person by health care practitioners, thereby discouraging the person from taking prescribed medications or otherwise participating in treatment or rehabilitation. The heightened sense of creativity and self-importance that often accompanies episodes of mania similarly may lead a person down a path that diverges from the one preferred by his or her loved ones and care providers. As destructive as they may appear to the person's loved ones or care providers, giving up delusions or mania often comes with its own costs. As a young man with a psychotic disorder once poignantly asked: "If you had the choice between being a CIA operative or a mental patient, which would you choose?"

Accepting that these and other elements associated with the disorders themselves undermine a person's efforts to cope with his or her illness, recovery-oriented practitioners become familiar with these issues and adept in working proactively with the person to overcome or bypass their destructive impact. Many of the skills and techniques traditionally utilized by clinicians within the context of office-based practice find their greatest utility and effectiveness in this domain, whether offered inside, or outside, of the office.

**You will know you are addressing
external and internal barriers to recovery when:**

- H.1.** **There is a commitment at the local level to embrace the values and principles of recovery-oriented care and to move away from the dominant illness-based paradigm. The practices identified throughout this document can only grow in a culture that fully embraces recovery principles and values. Systemic changes that reflect this paradigm shift include the following:**
- H.1.1.** Stakeholders understand the need for recovery-oriented system change as a civil rights issue which aims to restore certain elementary freedoms (e.g., self-determination, community inclusion, etc.) to American citizens with psychiatric diagnoses and/or addictions.
- H.1.2.** Stakeholders work together to move away from the criteria of “medical necessity” toward “human need,”³⁵ from managing illness to promoting recovery, from deficit-oriented to strengths-based, and from symptom relief to personally-defined quality of life. Perhaps most critical is the fundamental shift in power involved in realigning systems to promote recovery-oriented care—the shift away from prioritizing expert knowledge over respect for personal autonomy and self-determination³².
- H.1.3.** The possibility of recovery, and the responsibility to deliver recovery-oriented care, must be embraced by all stakeholders at all levels of the system. While many exciting things are occurring in agencies across the country, recovery-oriented change tends to occur in a fairly fragmented manner with a relatively small number of progressive practitioners or advocates taking on a large amount of responsibility for carrying out the recovery mission. For example, certain programs and staff in behavioral health systems (e.g., peer staff, rehabilitation providers, community-based case managers, etc.) are uniquely positioned to be leaders in the mission to provide recovery-oriented care, and the contributions of these programs should be respected and capitalized upon. Taking a lead in the recovery mission is a natural fit for such programs for a variety of reasons including their structure as private-

³⁵ Tondora, J., Pocklington, S., Gorges, A., Osher, D. & Davidson, L. (2005). *Implementation of person-centered care and planning: From policy to practice to evaluation*. Washington D.C.: Substance Abuse and Mental Health Services Administration.

³⁶ Osher, T. & Osher, D. (2001). The paradigm shift to true collaboration with families. *The Journal of Child and Family Studies*, 10(3), 47-60; WNYCCP. (2005). *Foundations of person-centeredness. Training curriculum*, Western New York Care Coordination Program. Rochester, NY: Coordinated Care Services.

non profit entities, their rehabilitation expertise, lower pressure and demands to deliver only medically necessary care, and their direct affiliations with the state or national consumer/recovery movement. However, agencies and systems must guard against the complacency which results when recovery is seen as being a “nice add-on,” but “not part of my job” or as being manifest only in “special” (sometimes “token”) programs that are split off from the functioning of the agency as a whole. Recovery-oriented system change will only take hold and thrive if it is understood that it is the shared mission of all stakeholders and that the task of promoting recovery—as the overarching aim of all behavioral health services—is a part of everyone’s job. Resources and guidelines are emerging which define exactly what that job is depending on what one’s role is as a practitioner (e.g., primary clinician, peer specialist, supported employment specialist) within the system.

H.2. Systemic structures and practices which inhibit the adoption of recovery-oriented practices are identified and addressed. Representative change strategies in this area include the following:

H.2.1. Well intentioned efforts to provide a full “continuum” of care have led to a system in which people are sometimes expected to enter in, and progress through, a range of services in a sequential fashion as they “stabilize” and move toward enhanced functioning and greater independence. The misapplication of this model has led to systems of care in which individuals are then expected to jump through hoops in order to earn their way into less restrictive settings (e.g., an expectation that they prove they can prepare three meals a day or keep their living space clean before they can move out of a group home) or to earn the right to participate in preferred services (e.g., an expectation that they comply with medication or outpatient psychotherapy groups before they will be referred to a supported employment program).

In addition to there being an accumulating body of evidence which demonstrates the failure of such a continuum approach, this sequential movement through a pre-existing continuum of supports is inconsistent with the civil rights perspective noted above and it contradicts current knowledge suggesting that recovery is neither a linear process or a static end product or result. Rather, it is for many a life-long experience that involves an indefinite number of incremental steps in various life domains, with people moving fluidly between the various domains over time (as opposed to moving through these dimensions in a systematic, linear process). Rather than a pre-established continuum of services,

what is necessary is a flexible array of supports that each person can choose from at different points in time depending upon his or her phase of recovery and unique needs and preferences. This array should be constantly evolving based on the input of persons in recovery, the experience of practitioners, and the research literature.

- H.2.2.** There is often a lack of clarity regarding system priorities when agencies attempt to implement numerous initiatives simultaneously, e.g., evidence-based practice versus recovery-oriented programming. While such initiatives may not be incompatible, competing demands—even complementary ones—can diffuse the effort and resources of the agency and inhibit the adoption of any new practices. It is critical that there are coordinating structures to attend to both the prioritization and integration of new initiatives, policies, and procedures.
- H.2.3.** The structure of certain outcome indicators places significant pressures on agency staff to operate in a manner that they see as inconsistent with recovery-oriented care. For example, staff might like to support persons in making choices regarding their housing preferences, such as moving to a less intensive level of supported housing. They may legitimately be concerned; however, that they will be held accountable should the result of such an individual’s choice ultimately be a negative one. This accountability is not limited to the potential adverse events themselves, but is further accentuated through the agency’s collection of mandatory performance data, such as statistics regarding the number of individuals who move from “housed” to “homeless.” The resulting need to portray the agency’s performance on such indicators as positive creates a strong incentive for the maintenance of stability as a desired outcome in and of itself. In contrast, a desired goal of recovery-oriented care is to promote growth, independence, and wellness; goals which sometimes involve the taking of reasonable risks that may result in interim setbacks. At both the agency and system level, quality management tools and outcome indicators should be examined and mechanisms should be built in to track the trade-off which sometimes exists as we support individuals in taking risks to grow and advance in their recovery.
- H.2.4.** Processes for continual quality assurance and independent audits by people in recovery and families trained in recovery-oriented care need to be funded and coordinated. Outcomes and assessment of quality should not focus solely on the rating of services/supports, but on whether the choices people make are personally meaningful and whether recovery-oriented care leads to a valued community life.

- H.2.5.** Initial placement and service design currently is driven by practitioners' assessments of what the individual seeking services needs. While this assessment should remain a critical element of the referral process, it should be coupled with questions, directed to the person and answered in his or her own words, which solicit the individual's perception of what services and supports would be most helpful. Individuals must be engaged as active partners in their care from the outset of treatment. This can only be achieved with greater transparency in the system of care as a whole and with greater involvement of the person and family in all important, decision-making processes, including the decision of initial level of care and team/program assignment.
- H.2.6.** Recovery plans respect the fact that services and practitioners should not remain central to a person's life over time. Currently, many behavioral health systems lack clearly defined exit criteria and it is not uncommon for individuals to feel as if they will be attached to the formal system for life following their entry into care. This perpetuates a sense of chronicity through which individuals lose hope that they will be able to resume a meaningful and productive daily life beyond treatment. In contrast, exit criteria should be established and used to engage people in a collaborative decision-making process regarding the potential advantages and risks of moving to a lower level of care, with effort being made to respect the individual's desire to "graduate" whenever possible. When an individual is strongly advised by the recovery team against "graduation," there should be evidence in the recovery plan of concrete steps being taken by the individual and the team to reach this ultimate goal. In establishing exit criteria, agencies must take caution to avoid punitive measures by which individuals are discharged from services for displaying symptoms of their illness or addiction.
- H.2.7.** Despite legislative advances in the past decade, the structure of federal and state disability, benefits, and vocational programs continue to impede the wish of many individuals of entering, or reentering, the workforce, thereby excluding them from an activity which many have described as a cornerstone of recovery. Rigid definitions of disability, earnings limits which perpetuate poverty, a lack of supported employment programs, and complex referral procedures drastically reduce the likelihood that individuals will access necessary services and return to meaningful employment. To integrate employment within the larger system of care, the task of assisting people in entering employment and education must be inherent in the responsibilities of the entire practitioner network, including those not specifically charged with work service or supported education activities.

H.3. The implementation of recovery-oriented care is facilitated, rather than impeded, by funding, reimbursement, and accreditation structures. Intrinsic to any dialogue regarding systemic barriers to recovery-oriented care is the need to address funding structures that recognize a limited range of clinical interactions as reimbursable services, and documentation requirements that hinder creative formulation of recovery-oriented goals and objectives. Necessary change strategies to address these barriers include the following:

H.3.1. Rules and regulations dictating eligibility and reimbursement for Medicaid and other public supports must be adapted at the federal and state level over time for greater relevance to innovative, recovery-oriented approaches. Even though Medicaid is funded by federal dollars, it remains primarily a state-administered program, and considerable flexibility exists already in using these dollars to support innovative, community-based, recovery-oriented services and supports.

H.3.2. Within existing funding structures, training and technical assistance can be provided to practitioners attempting to implement recovery-oriented practices to assist them in learning how to translate the wishes of people in recovery into reimbursable service goals and to describe their interventions in a manner that will generate payment.

H.3.3. Operating in this manner is consistent with the growing understanding that recovery-oriented practices cannot be an add-on to existing care for which additional funding must always be secured. Rather, recovery-oriented care begins with discovering ways to be creative and flexible within the constraints of existing resources. In some cases, for example, braiding funds may enable collaborations to move beyond funding silos to provide people with flexible, highly individualized services³³. Programs that successfully utilize such alternatives must be explored for expansion³⁴.

H.3.4. Self-directed funding opportunities should be considered both on a collective basis and through individualized budget programs. The Florida “Self-Directed Care” initiative is an example of such a program

³³Osher, D., Dwyer, K. & Jackson, S. (2004). *Safe, supportive, and successful schools step by step*. Longmont, CO: Sopris West; Poirier, J., Osher, D. & Tierney, M. (in press). Understanding the new environment of public school funding: How pupil services are funded. In C. Franklin, M.B. Harris & C. Allen-Meares (Eds.) *School social work and mental health workers training and resource manual*. New York: Oxford University Press.

³⁴Blessing, Tierney, Osher, Allegretti-Freeman, & Abrey. (2005). *Person-centered planning: Learning from other communities*, Washington D.C.: Substance Abuse and Mental Health Services Administration. .

which shifts fiscal control from the hands of service providers to the hands of service users. Within this program, participants are given control of their service dollars and then are free to shop around to weave together the type and frequencies of services that may best respond to their individual interests and preferences. While this approach has proponents, there is also an inherent tension and uncertainty about whether there is any guarantee that high quality services will be available to purchase if there are no consistent funding underpinnings. A robust practitioner network is needed and it must be easily accessible³⁵.

H.4. Training and staff development is prioritized as an essential function to increase individual practitioners' competency in providing recovery-oriented care. Necessary change strategies to address this issue include the following:

H.4.1. As consensus emerges regarding the knowledge and skills needed to implement recovery-oriented care, this information must lead to the development of competency models, and these models must be disseminated broadly as guidance for training programs and licensing bodies which prepare and accredit future and current providers of mental health care. For example, competency models regarding the delivery of recovery-oriented care should be used to address training gaps in pre-certification curriculum as well as ongoing professional development activities.

H.4.2. Once established, competency models—which are largely under-utilized in general in behavioral health—should be incorporated in all human resource activities (e.g., hiring, routine performance evaluation, promotion decisions, staff development targets, etc.) as a means of promoting accountability and quality improvement.

H.4.3. An analysis of staff's current competencies and self-perceived training needs should guide the development of on-going skill-building activities at the agency level. For example, practitioners are frustrated by the fact that they are overwhelmed by a constant stream of change mandates for which they receive little or no training or support. There

³⁵Jonikas, J., Cook, J., Fudge, C., Hiebechuk, F. & Fricks, L. (2005). *Charting a meaningful life: Planning ownership in person/family-centered planning*. Washington D.C.: Substance Abuse and Mental Health Services Administration.

are beneficial, self-reflective tools (e.g., the CAI, RSA, RKI, etc.³⁶) that can be used to conduct a training needs analysis which identifies both strengths and areas in need of improvement as it relates to the provision of recovery-oriented care. Gaps in skill sets can be identified and prioritized for development by training administrators.

H.4.4. Training in and of itself will not allow providers to develop the enhanced skill set and the increased sense of efficacy that will allow them to carry out the complex responsibilities and roles of the recovery-oriented practitioner. Competency-based training must be coupled with on-going mentor support, enhanced supervision, recovery-oriented case conferences, and opportunities for peer consultation.

H.4.5. Directors of clinical services and agency leaders should be involved in ongoing training initiatives so that there is consistency in proposed recovery-oriented practices and the system's administrative structures. This allows direct care staff to feel supported and respected and it allows agency leadership the opportunity to proactively identify, and address, any systemic barriers that prohibit the adoption of recovery-oriented practices.

H.4.6. Training and staff development activities must be sensitive to the role confusion which can result with the adoption of recovery-oriented practice. Recovery-oriented care does *not* imply that there is no longer any role for the practitioner to play in the treatment and recovery process. Rather, the provider's role has changed from that of all-knowing, all-doing caretaker to that of coach, architect, cheerleader, facilitator, mentor, or shepherd³⁷—roles that are not always consistent with one's clinical training or experiences. One effective educational strategy may be using a combination of literature, outcomes/efficacy data, and personal accounts such as recovery dialogues to help practitioners learn the new roles of advisor, mentor, or supports broker³⁸.

³⁶Campbell-Orde, T., Chamberlin, J., Carpenter, S. & Leff, S. (2005). *Measuring the promise: A compendium of recovery measures, Volume II*. Boston: Human Services Research Institute.

³⁷Adams, N. & Grieder, D. (2005). *Treatment planning for person-centered care: The road to mental health and addiction recovery*. San Diego, CA, US: Elsevier Academic Press; Davidson, L., Tondora, J., Staeheli, M., O'Connell, M.J., Frey, J. & Chinman, M.J. (2006). Recovery guides: An emerging model of community-based care for adults with psychiatric disabilities. In A. Lightburn & P. Sessions (Eds.), *Community-based clinical practice*. Oxford University Press, New York.

³⁸Jonikas, Cook, Fudge, Hiebecuk & Fricks. (2005). *op cit*.

Further, those involved in educating providers about self-determination and recovery-oriented care have found that acknowledging staff's fears and doubts, rather than dismissing or shaming them, is more likely to lead them to accept a new role in their clients' lives³⁹. The application of sophisticated and effective clinical practices in the larger context of collaborative partnerships and self-determination is a training area that requires ongoing attention.

H.4.7. No matter how competent the workforce, no matter how ripe the culture, and no matter how compatible the funding mechanisms, recovery-oriented care will not become a reality unless people in recovery and their families understand it, are supported in using it, and come to demand it as a basic expectation of quality care. It is imperative that training initiatives regarding recovery-oriented care not neglect the needs of people in recovery and families to develop their own capacity to self-direct their treatment and life decisions. Some may already do this with great skill and acumen. Others may be reluctant to assume the seat of power, having been socialized by their culture⁴⁰ or taught by professionals and agencies that their preferred role is one of deferential compliance⁴¹. Ideally, training initiatives put all stakeholders, including people in recovery, families, and practitioners, at the same table.

H.5. Forces at the societal level (e.g., stigma, discrimination, lack of basic resources, etc.) which undermine recovery and community inclusion are identified and addressed. Necessary change strategies to address this issue include the following:

H.5.1. A lack of basic resources and opportunities (e.g., jobs, affordable housing, primary medical care, educational activities) in the broader community significantly complicates the task of recovery for persons with behavioral health disorders. This lack of resources and opportunities often stems from inadequate knowledge and skills on the part of community organizations regarding how to create welcoming and accessible environments for all people. Behavioral health practitioners have significant expertise to address this skill and knowledge gap, and should be prepared to offer supportive guidance and feedback at both

³⁹Holburn, S. & Vietze, P. (2002). *Person-centered planning: Research, practice, and future directions*. Baltimore: Paul Brookes Publishing.

⁴⁰Harry, B., Kalyanpur, M. & Day, M. (1999). *Building cultural reciprocity with families*. Baltimore, MD: Paul Brookes.

⁴¹Katz, E. & Danet, B. (1973). *Bureaucracy and the public*. New York: Basic Books.

the individual and community level. For example, consultation with a community employer regarding the impact of a certain medication on an individual's stamina can lead to a reasonable accommodation in the work place which allows greater productivity and success on the job—an outcome which is ultimately beneficial to both the individual and the employer. Provided appropriate support and consultation, many community members are excellent collaborators and can become facilitators of the recovery and community inclusion process.

H.5.2. Despite the promise of such collaborations, discrimination against people with behavioral health disorders will most likely continue for the foreseeable future. Community collaborations and education must therefore be coupled with efforts on the part of behavioral health practitioners to recognize instances of discrimination, to understand relevant disability legislation (e.g., the Americans with Disabilities Act), and to effectively utilize state and local resources (e.g., the Connecticut Legal Rights Project, the Office of Protection and Advocacy, the Equal Opportunity Employment Commission, advocacy organizations, etc.). This type of knowledge also must be built within the consumer community so that people in recovery can protect themselves by recognizing and rectifying experiences of discrimination.

H.5.3. Agencies are cautioned to avoid the establishment of 'one stop shopping' service programs. In an effort to respond simultaneously to individuals' multi-dimensional needs while also protecting them from the experience of stigma and discrimination, there is a tendency for agencies to develop "in-house" alternatives to community activities based on concern that the community will never accept or welcome individuals with behavioral health disorders. As a result, agencies often create in artificial settings, activities that already exist in the natural community. For example, developing in house medical clinics, movie nights, GED classes, social events, etc. Agencies which fall into this trap of providing a one stop shop for the needs of people with mental illness or addiction inadvertently contribute to the development of chronic "patient hood" as well as the perpetuation of discriminatory and unethical practices on the part of community members. We must continue to work with community partners to uphold their obligation to respect people with behavioral health disorders as citizens who have the right to be treated according to the principles of law that apply to all other individuals⁴².

⁴²National Council on Disability. (2000). *From privileges to rights: People labeled with psychiatric disabilities speak for themselves*. Downloaded from <http://www.ncd.gov/newsroom/publications/privileges.html>

H.5.4. A focus on promoting access to community opportunities is consistent not only with recovery-oriented principles but with the need for fiscal efficiency. Professionals and service recipients should be mindful of the limited resources available for specialized services and should focus on community solutions and resources first by asking “Am I about to recommend or replicate a service or support that is already available in the broader community?” At times this has direct implications for the development of service interventions within recovery plans, e.g., creating on-site health and fitness opportunities such as exercise classes without first exploring to what extent that same opportunity might be available in the broader community through public recreational departments, YMCAs, etc. If natural alternatives are available in the community, the individual should be informed of these opportunities and then supported in accessing them based on his or her preferences.

H.6. Certain internal barriers unique to behavioral health disorders are identified and addressed. Necessary change strategies to address these barriers include the following:

H.6.1. It is important to acknowledge that people with behavioral health disorders may be reluctant to assume some of the rights and responsibilities promoted in recovery-oriented systems. They may initially express reluctance, fears, mistrust, and even disinterest when afforded the right to take control of their treatment and life decisions. It is critical to explore and address the multiple factors influencing such responses, as they often result from a complex interaction of the person’s conditions and his or her past experiences in the behavioral health care system. As suggested by Jonikas and colleagues⁴³, there are many factors involved when people in recovery “resist” recovery-oriented system change, including a lack of trust that human service systems or various care providers will cede control, service eligibility criteria that require an emphasis on illness and crisis in order to receive assistance; learned helplessness consequent from years of dependency (especially for those in institutional settings); an inability to, or discomfort with, articulating personal preferences and ideas; and feelings of pressure that they must “get it right the first time” or else be blamed for their failures when assuming greater control in the recovery process. Significant training and skill building within the recovery community is necessary to

⁴³Jonikas, Cook, Fudge, Hiebechuk & Fricks. (2005). *op cit*.

address this internal barrier and to support people in embracing expanded roles and responsibilities. Education and ongoing support and mentoring is perhaps best offered through mental health advocacy organizations and peer-run programs.

H.6.2. Individuals with serious behavioral health disorders often have histories of trauma which impact on treatment and recovery. For example, while trauma may not be intrinsic to behavioral health per se, there is considerable evidence that suggests that people living with behavioral health disorders at the present time have a greatly increased chance of having experienced a history of trauma earlier in their lives as well as being at increased risk for future victimization⁴⁴. Evidence also suggests that the failure to attend to a person's history of sexual and/or physical abuse will seriously undermine the treatment and rehabilitation enterprise, leading to a poor prognosis, while approaches that are responsive to trauma significantly improve treatment effectiveness and outcomes. Similar processes resulting from patterns of relating in a person's family context or immediate social environment may pose additional barriers to the person's recovery. Within the context of urban poverty and violence, e.g., the only incentive offered by abstinence may be a decreased immunity to the horrors that a person faces on a daily basis.

H.6.3. The above barriers represent more of an interaction between a person's condition and his or her experiences in the behavioral health system and the community at large. In addition, the symptoms of certain illnesses themselves may also pose direct impediments to the recovery process. As we described above, for example, hallucinations and delusions may compete with the information a person is receiving from health care professionals, thereby discouraging the person from taking prescribed medications or participating in other treatment or rehabilitation. Similarly, impairments in such areas as working memory, executive processes, language, attention and concentration, and problem solving⁴⁵ can undermine a person's abilities to articulate and assert his

⁴⁴Sells, D., Rowe, M., Fisk, D. & Davidson, L. (2003). Violent victimization of persons with co-occurring psychiatric and substance use disorders. *Psychiatric Services*, 54(9), 1253-1257.

⁴⁵Saykin, A., Gur, R.C., Gur, R.E., Mozley, D., Mozley, R.H., Resnick, S., Kester, B. & Stafinick, P. (1991). Neuropsychological function in schizophrenia: Selective impairment in memory and learning. *Archives of General Psychiatry*, 48, 618-624.; Bell, M. & Lysaker, P. (1995). Psychiatric symptoms and work performance among people with severe mental illness, *Psychiatric Services*, 46(5), 508-510; Westermeyer, J. & Harrow, M. (1987). Factors associated with work impairments in schizophrenic and nonschizophrenic patients. In R. Grinker & M. Harrow (Eds.), *Clinical research in schizophrenia: A multidimensional approach*. p. 280-299. Springfield: Charles Thomas Books; Cornblatt, B. & Erlenmeyer-Kimling, L. (1984). Early attentional predictors of adolescent behavioral disturbances in children at risk for schizophrenia. In Watt, N.F., James, A.E. (eds.). (1984). *Children at risk for schizophrenia: A longitudinal perspective*. (pp. 198-211). New York,

or her personal wants, needs, and preferences in the context of a relationship with a clinical practitioner. Such cognitive impairments may be further aggravated by negative symptoms that are currently considered to be among the most unremitting and malignant of the impairments associated with psychosis⁴⁶. These include a lack of goal-directed activity, withdrawal, apathy, and affective flattening, all of which can create the impression that individuals are not interested in taking an active role in their care, thereby placing them at increased risk of being underestimated and undervalued as partners in the recovery planning process. In certain conditions, the elimination or reduction of symptoms may also come with great ambivalence, e.g., while episodes of mania can be destructive, they may include a heightened sense of creativity, self importance, and productivity that are difficult to give up. Being able to identify and address these and other sequelae requires knowledge and skill on the part of the clinical practitioner. There must be a commitment to ongoing professional development regarding emerging evidence-based and recovery-oriented practices which allow people to manage, or bypass, their symptoms to build a personally gratifying life in the community.

What you will hear from people when you are addressing external and internal barriers to recovery:

- *My mental illness was the least of my worries when it came to getting back to work after I got discharged from the hospital. I was terrified about losing my benefits and my employer gave me a really hard time when I asked if I could come in a half hour late one morning in order to see my doctor. My therapist and I sat down and he helped me sort out what would happen to my benefits and gave me some great information about how I could talk to my boss and request some accommodations that would help me be successful on the job. I have been back now for almost a year, and I just got the Employee of the Month Award.*
- *I used to get so pissed when I got asked to sign off on the treatment plans my doctor had to send to the insurance company. Half the time, I could barely tell that it was MY plan. It didn't reflect any of the things I had said were*

NY, US: Cambridge University Press; Seltzer, J., Cassens, G., Ciocca, C. & O'Sullivan, L. (1997). Neuro-psychological rehabilitation in the treatment of schizophrenia. *Connecticut Medicine*, 61(9), 597-608.

⁴⁶Torrey, E.F. (1988). *Surviving schizophrenia: A family manual (Rev. ed.)*. New York: Harper & Row.

important. My new doctor explained to me how the insurance and billing things work. And then we worked on the plan together. It still wasn't perfect, but at least I kind of knew where he was coming from and that he really HAD heard what I was trying to say.

- *All those years I spent in Social Skills groups, I met the same 20 people I knew from Clozaril Clinic and the Clubhouse. It didn't exactly expand my social horizons! Now I am playing basketball in one of the city leagues and there is this girl I've got my eye on who comes to the games. My therapist and I have been talking a lot about how I could strike up a conversation with her.*
- *The thought of getting discharged was so terrifying to me I almost didn't want to get well. But my case manager and I made sure that I had people and places I could go to for support when I needed it—and these folks had been involved in our work all along. It made a huge difference in my feeling good about taking the next step.*
- *I just didn't buy it when my clinician started talking to me about this thing called "consumer-driven care"... But she proved to me that she was for real in terms of making some changes in how we worked together— even referred me to a local self-advocacy center. I had been sitting back letting other folks call the shots, and then complaining when things got messed up. A Peer Specialist at the advocacy center called me out on it. I realized that I had gotten real comfortable letting other folks make decisions for me, and I know now that I gotta take charge of my own recovery and the Peers at the Center are helping me to do that...*



Recommended Resources for Further Reading



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APPENDIX

Glossary of Recovery-Oriented Language

Examples of Strength-Based Conceptualizations

Glossary of Recovery-Oriented Language

Creation of a recovery-oriented system of care requires behavioral health care practitioners to alter the way they look at mental illness and addiction, their own roles in facilitating recovery from these conditions, and the language they use in referring to the people they serve. The following glossary and associated tables are intended as tools for providers to use as they go about making these changes in practice.⁴⁷ Not meant to be exhaustive, this material will be further enhanced in the process of implementing recovery-oriented practices across the state.

Given its central role in the remaining definitions, we will start with the term “recovery” itself, followed by a list, in alphabetical order, of other key terms.

Recovery: there are several different definitions and uses of this term in behavioral health. In the addiction recovery community, for example, this term refers to the achievement and maintenance of abstinence from alcohol, illicit drugs, and other substances (e.g., tobacco) or activities (e.g., gambling) to which the person has become addicted, vigilance and resolve in the face of an ongoing vulnerability to relapse, and pursuit of a clean and sober lifestyle.

In mental health there are several other forms of recovery. For those fortunate people, for example, who have only one episode of mental illness and then return to their previous functioning with little, if any, residual impairment, the usual sense of recovery used in primary care is probably the most relevant. That is, such people recover from an episode of psychosis or depression in ways that are more similar to, rather than different from, recovery from other acute conditions.

Persons who recover from an episode of major affective disorder or psychosis, but who continue to view themselves as vulnerable to future episodes, may instead consider themselves to be “in recovery” in ways that are more similar to, than different from, being in recovery from a heart attack or chronic medical condition. Many others will recover from serious mental illness over a longer period of time, after perhaps 15 or more years of disability, constituting an additional sense of recovery found in some other medical conditions such as asthma. More extended periods of disability are often associated with concerns about the effects and side effects of having been labeled with a mental illness as well as with the illness itself, leading some people to consider themselves to be in recovery also from the trauma of having been treated as mental patients.

⁴⁷ Credit for many of the addiction entries goes to William White, with text appreciatively borrowed and adapted from his unpublished manuscript *The Language of Addiction Recovery: An Annotated Glossary*.

Finally, those people who view taking control of their illness and minimizing its disruptive impact on their lives as the major focus of their efforts might find the sense of recovery used in the addiction self-help community to be most compatible with their own experiences. Such a sense of recovery has been embraced, for instance, among some people who suffer from co-occurring psychiatric and addictive disorders who consider themselves to be in “dual recovery.”

For purposes of simplicity and clarity, the Connecticut Department of Mental Health and Addiction Services has adopted the following single definition to capture the common elements of these various forms of recovery:

“Recovery involves a process of restoring or developing a meaningful sense of belonging and positive sense of identity apart from one’s condition while rebuilding a life despite or within the limitations imposed by that condition.”

Other Key Terms

Abstinence-Based Recovery: is the resolution of alcohol- and other drug-related problems through the strategy of complete and enduring cessation of the non-medical use of alcohol and other drugs. The achievement of this strategy remains the most common definition of recovery in addiction, but the necessity to include it in this glossary signals new conceptualizations of recovery that are pushing the boundaries of this definition (see partial recovery, moderated recovery, and serial recovery).

Affirmative Business: see Social Cooperative/Entrepreneurialism

Asset-Based Community Development: a technology for identifying and charting the pathways and destinations in the local community most likely to be welcoming and supportive of the person’s efforts at community inclusion. A first step is the development of local resource maps (see below). A strategy of community preparation is then used to address gaps identified in the resource maps through educational and other community building activities aimed at decreasing stigma and creating a more welcoming environment in partnership with local communities.

Asset Mapping: part of asset-based community development (above) referring to the process of identifying opportunities in local communities for people in recovery to take up and occupy valued social roles in educational, vocational, social, recreational, and affiliational (e.g., civic, spiritual) life. Although not a literal “map” (i.e., as in contained on a piece of paper), asset mapping involves developing and utilizing virtual or mental landscapes of community life that highlight resources, assets, and opportunities that already exist in the person’s local community.

Choice: a key concept in recovery-oriented care, choice refers to the central role people with psychiatric disabilities and/or addictions play in their own treatment, rehabilitation, recovery, and life. Within the behavioral health system, people in recovery need to be able to select services and supports from among an array of meaningful options (see menu below) based on what they will find most responsive to their condition and effective in promoting their recovery. Both inside and outside of the behavioral health system, people in recovery have the right and responsibility for self-determination and making their own decisions, except for those rare circumstances in which the impact of the illness or addition contributes to their posing imminent risks to others or to themselves.

Citizenship: a strong connection to the rights, resources, roles, and responsibilities that society offers people through public institutions and associational life.

Community Supports: material and instrumental resources (including other people), and various forms of prostheses that enable people to compensate for enduring disabilities in the process of pursuing and being actively involved in naturally-occurring community activities of their choice.

Consumer: literally means someone who purchases services or goods from others. Historically has been used in mental health advocacy to offer a more active and empowered status to people who otherwise were being described as “clients” or “mental patients.” Given the fact that people in recovery have not really viewed themselves as consumers in the traditional sense (ala Ralph Nader), this term has never really generated or been met with wide-spread use.

Continuity of Care/Contact: is a phrase used to underscore the importance of sustained, consistent support over the course of recovery. Such support can come from living within a community of shared experience and hope, but also can refer to the reliable and enduring relationship between the individual in recovery and his or her recovery coach. Such sustained continuity is in marked contrast to the transience of relationships experienced by those who have moved through multiple levels of care or undergone multiple treatment relationships.

Disparities in Healthcare: differences in access, quality, and/or outcomes of health care based on such issues as race, ethnicity, culture, gender, sexual or religious orientation, social class, or geographic region.

Empowerment: is the experience of acquiring power and control over one’s own life decisions and destiny. Within the addiction recovery context, there are two different relationships to power. Among the culturally empowered (those to whom value is ascribed as a birthright), addiction-related erosion of competence is often countered by a preoccupation with power and control. It is not surprising then that

the transformative breakthrough of recovery is marked by a deep experience of surrender and an acceptance of powerlessness. In contrast, the culturally disempowered (those from whom value has been systematically withheld) are often attracted to psychoactive drugs in their desire for power, only to discover over time that their power has been further diminished. Under these conditions, the initiation of recovery is often marked by the assumption of power and control rather than an abdication or surrender of power.

Within the mental health context, empowerment typically refers to a person first taking back control of his or her own health care decisions prior to regaining control of his or her major life decisions and destiny. As such, “empowerment” has been used most by advocacy groups in their lobbying efforts to make mental healthcare more responsive and person-centered. In either community, empowerment is meant to be inspiring, horizon-raising, energizing, and galvanizing. The concept of empowerment applies to communities as well as individuals. It posits that the only solution to the problems of addiction and/or mental health in disempowered communities lies within those very communities. It is important to note that, by definition, one person cannot “empower” another, as to do so undermines the very premise of the term, which attributes power over the person’s decisions, recovery journey, and life to the person him or herself.

Evidence-Based Practices: are clinical, rehabilitative, and supportive practices that have scientific support for their efficacy (under ideal conditions) and effectiveness (in real world settings). Advocacy of evidence-based practice is a commitment to use those approaches that have the best scientific support, and, in areas where research is lacking, a commitment to measure and use outcomes to elevate those practices that have the greatest impact on the quality of life of individuals, families and communities.

Faith-Based Recovery: is the resolution of alcohol and other drug problems within the framework of religious experience, beliefs, and rituals and/or within the mutual support of a faith community. Faith-based recovery frameworks may serve as adjuncts to traditional recovery support programs or serve as alternatives to them.

Harm Reduction (as a stage of recovery): is most often viewed as an alternative to, and even antagonistic to, recovery, but can also be viewed as a strategy of initiating or enhancing early recovery. The mechanisms through which this can occur include preventing the further depletion of recovery capital, increasing recovery capital when it does not exist, and enhancing the person’s readiness for recovery via the change-encouraging relationships through which harm reduction approaches are delivered.

Inclusion: refers to a person's right to be afforded access to, and to participate in, naturally occurring community activities of his or her choice.

Illness Self-management: is the mastery of knowledge about one's own illness and assumption of primary responsibility for alleviating or managing the symptoms and limitations that result from it. Such self-education and self-management shifts the focal point in disease management from the expert caregiver to the person with the illness.

Individualized Care: see Person-Centered Care.

Indigenous Healers and Institutions: are people and organizations in the natural environment of the recovering person who offer words, ideas, rituals, relationships, and other resources that help initiate and/or sustain the recovery process. They are distinguished from professional healers and institutions not only by training and purpose, but through relationships that are culturally-grounded, enduring, and often reciprocal and/or non-commercialized.

Initiating Factors: are those factors that spark a commitment to recovery and an entry into the personal experience of recovery. Factors which serve this recovery priming function are often quite different than those factors that later serve to sustain recovery. Recovery-initiating factors can exist within the person and/or within the person's family and social environment as well as in the behavioral health system. These factors can include pain-based experiences, e.g., anguish, exhaustion, and boredom with addictive lifestyle; death of someone close; external pressure to stop using; experiences of feeling humiliated; increased health problems; failures or rejections; or suicidal thoughts. Less well-recognized, however, are the hope- and pleasure-based experiences: pursuing interests and experiencing enjoyment and success; exposure to recovery role models; new intimate relationships; marriage, parenthood, or other major positive life change; a religious experience; or new opportunities.

Jump Starts: see Initiating Factors.

Menu (of services and/or supports): an array of options from which people can then choose to utilize those services and/or supports they expect will be most effective in assisting them to achieve their goals and most responsive to their individual, familial, and socio-cultural values, needs, and preferences.

Micro Enterprise: see Social Cooperative/Entrepreneurialism.

Moderated Recovery: is the resolution of alcohol or other drug problems through reduction of alcohol or other drug consumption to a sub-clinical level (shifting the

frequency, dosage, method of administration, and contexts of drug use) that no longer produces harm to the individual or society. The concept takes on added utility within the understanding that alcohol and other drug problems exist on a wide continuum of severity and widely varying patterns of acceleration and deceleration. The prospects of achieving moderated recovery diminish in the presence of lower age of onset, heightened problem severity, the presence of co-occurring psychiatric illness, and low social support. The most common example of moderated resolution can be found in studies of people who develop alcohol and other drug-related problems during their transition from youth to adulthood. Most of these individuals do not go on to develop enduring substance-related problems, but instead moderate their use through the process of maturation.

Motivational Interventions: is a non-confrontational approach to eliciting recovery-seeking behaviors that was developed by Miller and Rollnick. This approach emphasizes relationship-building (expressions of empathy), heightening discrepancy between an individual's personal goals and present circumstances, avoiding argumentation (activation of problem-sustaining defense structure), rolling with resistance (emphasizing respect for the person experiencing the problem and his or her sense of necessity and confidence to solve the problem), and supporting self-efficacy (expressing confidence in the individual's ability to recover and expressing confidence that they will recover). As a technique of preparing people to change, motivational interviewing is an alternative to waiting for an individual to "hit bottom" and an alternative to confrontation-oriented intervention strategies.

Multiple Pathways of Recovery: reflects the diversity of how people enter into and pursue their recovery journey. Multiple pathway models contend that there are multiple pathways into psychiatric disorder and addiction that unfold in highly variable patterns, courses and outcomes; that respond to quite different treatment approaches; and that are resolved through a wide variety of recovery styles and support structures. This is particularly true among ethnic minority and religious communities, but diversity is to be found wherever there are people of different backgrounds.

Mutual Support/Aid Groups: are groups of individuals who share their own life experiences, strengths, strategies for coping and hope about recovery. Often called "self-help" groups, they more technically involve an admission that efforts at self-help have failed and that the help and support of others is needed. Mutual aid groups are based on relationships that are personal rather than professional, reciprocal rather than fiduciary, free rather than fee-based, and enduring rather than transient (see also Indigenous Healers and Institutions).

Natural Recovery: is a term used to describe those who have initiated and sustained recovery from a behavioral health disorder without professional intervention or

involvement in a formal mutual aid group. Since people in this form of recovery neither access nor utilize behavioral health services, it is difficult to establish the prevalence or nature of this process, but it is believed to be common.

New Recovery Advocacy Movement: depicts the collective efforts of grassroots recovery advocacy organizations whose goals are to: 1) provide an unequivocal message of hope about the potential of long term recovery from behavioral health disorders, and 2) to advocate for public policies and programs that help initiate and sustain such recoveries. The core strategies of the New Recovery Advocacy Movement are: 1) recovery representation, 2) recovery needs assessment, 3) recovery education, 4) recovery resource development, 5) policy (rights) advocacy, 6) recovery celebration, and 7) recovery research.

Natural Support: technical term used to refer to people in a variety of roles who are engaged in supportive relationships with people in recovery outside of behavioral health settings. Examples of natural supports include family, friends, and other loved ones, landlords, employers, neighbors, or any other person who plays a positive, but non-professional, role in someone's recovery.

Partial Recovery: is 1) the failure to achieve full symptom remission (abstinence or the reduction of alcohol/drug use below problematic levels), but the achievement of a reduced frequency, duration, and intensity of use and reduction of personal and social costs associated with alcohol/drug use, or 2) the achievement of complete abstinence from alcohol and other drugs but a failure to achieve parallel gains in physical, emotional, relational, and spiritual health. Partial recovery may precede full recovery or constitute a sustained outcome.

Peer: within behavioral health, this term is used to refer to someone else who has experienced first-hand, and is now in recovery from, a mental illness and/or addiction.

Peer-Delivered Services: any behavioral health services or supports provided by a person in recovery from a mental illness and/or addiction. This includes, but is not limited to, the activities of peer specialists or peer support providers (see below), encompassing also any conventional behavioral health intervention which a person in recovery is qualified to provide. Examples of these activities range from medication assessment and administration by psychiatrists and nurses who disclose that they are in recovery to illness management and recovery education by peers trained in providing this evidence-based psychosocial intervention. An underlying assumption here is that there is "value added" to any service or support provided by someone who discloses his or her own recovery journey, as such disclosure serves to combat stigma and inspire hope.

Peer-Operated or Peer-Run Programs: a behavioral health program that is developed, staffed, and/or managed by people in recovery. In contrast to peer-run businesses (described below) which are self-sustaining and able to generate profits, peer-run programs are typically private-non-profit and oriented to providing behavioral health services and supports such as respite care, transportation to and from healthcare appointments, recovery education, and advocacy.

Peer-Run Businesses: see Social Cooperative/Entrepreneurialism

Peer Specialist: a peer (see above) who has been trained and employed to offer peer support to people with behavioral health conditions in any of a variety of settings. These settings may range from assertive or homeless outreach in shelters, soup kitchens, or on the streets, to part of a multi-disciplinary inpatient, intensive outpatient, or ambulatory team, to roles within peer-run or peer-operated programs (see below).

Peer Support: while falling along a theoretical continuum, peer support differs both from traditional mutual support groups as well as from consumer-run drop-in centers or businesses. In both mutual support groups and consumer-run programs, the relationships peers have with each other are thought to be reciprocal in nature; even though some peers may be viewed as more skilled or experienced than others, all participants are expected to benefit. Peer support, in contrast, is conceptualized as *involving one or more persons who have a history of significant improvement in either a mental illness and/or addiction and who offers services and/or supports to other people with mental illnesses or addictions who are considered to be not as far along in their own recovery process.*

Person-Centered Care: behavioral health care that is based on the person's and/or family's self-identified hopes, aspirations, and goals, which build on the person's and/or family's own assets, interests, and strengths, and which is carried out collaboratively with a broadly-defined recovery management team that includes formal care providers as well as others who support the person's or family's own recovery efforts and processes, such as employers, landlords, teachers, and neighbors.

Person in Recovery: a person who has experienced a mental illness and/or addiction and who has made progress in learning about and managing his or her behavioral health condition and in developing a life outside of, or in addition to, this condition.

Recovery Capital: is the quantity and quality of internal and external resources that one can bring to bear on the initiation and maintenance of recovery from a life-changing disorder. In contrast to those achieving natural recovery, most people with

psychiatric or addictive disorders entering treatment have never had much recovery capital or have dramatically depleted such capital by the time they seek help.

Recovery Celebration: is an event in which recovered and recovering people assemble to honor the achievement of recovery. Such celebrations serve both healing and mutual support functions but also (to the extent that such celebrations are public) serve to combat social stigma attached to addiction or mental illness by putting a human face on behavioral health disorders and by conveying living proof of the possibility and enduring nature of recovery from these disorders.

Recovery Coach/Guide (Recovery Support Specialist): is a person who helps remove personal and environmental obstacles to recovery, links the newly recovering person to the recovery community and his or her broader local community, and, where not available in the natural community, serves as a personal guide and mentor in the management of personal and family recovery.

Recovery Community (Communities of Recovery): is a term used to convey the sense of shared identity and mutual support of those persons who are part of the social world of recovering people. The recovery community includes individuals in recovery, their family and friends, and a larger circle of “friends of recovery” that include both practitioners working in the behavioral health fields as well as recovery supporters within the wider community. Recovery management is based on the assumption that there is a well-spring of untapped hospitality and service within this community that can be mobilized to aid those seeking recovery for themselves and their families. “Communities of recovery” is a phrase coined by Kurtz to convey the notion that there is not one but multiple recovery communities and that people in recovery may need to be introduced into those communities where the individual and the group will experience a goodness of “fit.” The growth of these divergent communities reflects the growing varieties of recovery experiences.

Recovery Management: is the provision of engagement, education, monitoring, mentoring, support, and intervention technologies to maximize the health, quality of life, and level of productivity of persons with severe behavioral health disorders. Within the framework of recovery management, the “management” of the disorder is the responsibility of the person with the disorder. The primary role of the professional is that of the recovery consultant, guide, or coach.

Recovery-Oriented Practice: a practice oriented toward promoting and sustaining a person’s recovery from a behavioral health condition. DMHAS policy defines recovery-oriented practice as one that “*identifies and builds upon each individual’s assets, strengths, and areas of health and competence to support the person in managing his or her condition while regaining a meaningful, constructive, sense of membership in the broader community.*”

Recovery-Oriented Systems of Care: are systems of health and human services that affirm hope for recovery, exemplify a strengths-based orientation, and offer a wide spectrum of services and supports aimed at promoting resilience and long term recovery from behavioral health disorders.

Recovery Planning and Recovery Plans: in contrast to a treatment or service plan, is developed, implemented, revised, and regularly evaluated by the client. Consisting of a master recovery plan and regular implementation/action plans, the recovery plan covers life domains in addition to behavioral health issues (e.g., physical, finances, employment, legal, family, social life, personal, education, and spiritual). In mental health settings, recovery planning follows the principles described above under person-centered care.

Recovery Priming: see Initiating Factors.

Recovery Support Services: are designed to 1) remove personal and environmental obstacles to recovery, 2) enhance identification and participation in the recovery community, and 3) enhance the quality of life of the person in recovery. Such services include outreach, engagement and intervention services; recovery guiding or coaching, post-treatment monitoring and support; sober or supported housing; transportation; child care; legal services; educational/vocational supports; and linkage to leisure activities.

Serial Recovery: is the process through which individuals with multiple concurrent or sequential problems resolve these problems and move toward optimum level of functioning and quality of life. Serial recovery refers to the process of sequentially shedding two or more drugs, or to the overlapping processes involved in recovering from addiction and co-occurring psychiatric or other physical disorders.

Social Cooperative/Entrepreneurialism: the development and operation of small businesses (“micro enterprises”) by people in recovery based on their talents and interests and in partnership with their local community. The resulting businesses offer goods and services to the general public and may be either for profit or not for profit, but should be at least financially self-sustaining, although perhaps subsidized through tax breaks or other government means.

Spirituality: refers to a system of religious beliefs and/or a heightened sense of perception, awareness, performance, or being that informs, heals, connects, or liberates. For people in recovery, it is a connection with hidden resources within and outside of the self. There is a spirituality that derives from pain, a spirituality that springs from joy or pleasure, and a spirituality that can flow from the simplicity of daily life. For many people, the spiritual has the power to sustain them through adversity and inspire them to make efforts toward recovery. For some, this is part of

belonging to a faith community, while for others it may be the spirituality of fully experiencing the subtlety and depth of the ordinary as depicted in such terms as harmony, balance, centeredness, or serenity. All of these can be part of the many facets of recovery.

Triggering Mechanisms: see Initiating Factors.

User/Service Recipient: a person who receives or uses behavioral health services and/or supports, preferred by some people as an alternative to “consumer” or “person in recovery.”

Valued-Based Practice: a practice which has not yet accrued a base of evidence demonstrating its effectiveness in promoting recovery, but for which there are other persuasive reasons to view it as having been a helpful resource, and as being a helpful resource in the future, for people with behavioral health conditions. Examples of value-based practices include peer-based services that offer hope, role modeling, and mentoring and culturally-specific programs oriented toward cultural subgroups.

WRAP (Wellness Recovery Action Planning): a self-help approach to illness management and wellness promotion developed by Mary Ellen Copeland.

Moving from a Deficit-Based to a Strengths-Based Approach to Care

The following are examples of how language, thinking, and practice shift in the evolution of a recovery-oriented system of care

Presenting Situation	Deficit-based Perspective		Recovery-oriented, Asset-based Perspective	
	Perceived Deficit	Intervention	Perceived Asset	Intervention
Person re-experiences symptoms	Decompensation, exacerbation, or relapse	Involuntary hospitalization; warning or moralizing about “high risk” behavior (e.g., substance use or “non-compliance”)	Re-experiencing symptoms as a normal part of the recovery journey; an opportunity to develop, implement, and/or apply coping skills and to draw meaning from managing an adverse event	Express empathy and help person avoid sense of demoralization; highlight how long it may have been since symptoms had reappeared; provide feedback about the length of time it takes to achieve sustained change; offer advice on strategies to cope; reinforce sense of self-efficacy
Person demonstrates potential for self-harm	Increased risk of suicide	Potentially intrusive efforts to “prevent suicide”	Indicators of potential for self-harm are important signals to respond differently. The person is likely to have a weakened sense of efficacy and feel demoralized, and thus may require additional support. On the other hand, the person has already survived tragic circumstances and extremely difficult ordeals, and should be praised for his or her prior resilience and perseverance.	Rather than reducing risk, the focus is on promoting safety. Supportive, ongoing efforts are oriented to “promote life,” e.g., enabling people to write their own safety/prevention plans and advance directives. Express empathy; reinforce efficacy and autonomy; enhance desire to live by eliciting positive reasons and motivations, with the person, not the provider, being the source of this information.
Person takes medication irregularly	Person lacks insight regarding his or her need for meds; is in denial of illness; is non-compliant with treatment; and needs monitoring to take meds as prescribed.	Medication may be administered, or at least monitored, by staff; staff may use cigarettes, money, or access to resources as incentives to take meds; person is told to take the meds or else he or she will be at risk of relapse or decompensation, and therefore may need to be hospitalized.	Prefers alternative coping strategies (e.g., exercise, structures time, spends time with family) to reduce reliance on medication; has a crisis plan for when meds should be used. Alternatively, behavior may reflect ambivalence regarding medication use which is understandable and normal, as approximately half of people with any chronic health condition (e.g., diabetes, asthma) will not take their medication as prescribed.	Individual is educated about the risks and benefits of medication; offered options based on symptom profile and side effects; and is encouraged to consider using meds as one tool in the recovery process. In style and tone, individual autonomy is respected and decisions are ultimately the person and his or her loved ones to make. Explore person’s own perspective on symptoms, illness, and medication and invite him or her to consider other perspectives. Person is resource for important ideas and insights into the problem and is invited to take an active role in problem solving process.

Presenting Situation	Deficit-based Perspective		Recovery-oriented, Asset-based Perspective	
	Perceived Deficit	Intervention	Perceived Asset	Intervention
Person makes poor decisions	Person's judgment is impaired by illness or addiction; is non-compliant with directives of staff; is unable to learn from experience	Potentially invasive and controlling efforts to "minimize risk" and to protect the person from failure, rejection, or the other negative consequences of his or her decisions	Person has the right and capacity for self-direction (i.e., Deegan's "dignity of risk" and the "right to fail"), and is capable of learning from his or her own mistakes. Decisions and taking risks are viewed as essential to the recovery process, as is making mistakes and experiencing disappointments and set backs. People are not abandoned to the negative consequences of their own actions, however, as staff stand ready to assist the person in picking up the pieces and trying again.	Discuss with the person the pros, cons, and potential consequences of taking risks in the attempt to maximize his or her opportunities for further growth and development. This dialogue respects the fact that all people exercise poor judgment at times, and that making mistakes is a normal part of the process of pursuing a gratifying and meaningful life. Positive risk taking and working through adversity are valued as means of learning and development. Identify discrepancies between person's goals and decisions. Avoid arguing or coercion, as decisions made for others against their will potentially increase their learned helplessness and dependence on professionals.
Person stays inside most of the day	Person is withdrawing and becoming isolative; probably a sign of the illness; can only tolerate low social demands and needs help to socialize	Present the benefits of spending time outside of the house; offer the person additional services to get the person out of the house to a clubhouse, drop-in center, day program, etc.	Person prefers to stay at home; is very computer savvy; and has developed skills in designing web pages; frequently trades e-mails with a good network of NET friends; plays postal chess or belongs to collectors clubs; is a movie buff or enjoys religious programs on television. Person's reasons for staying home are seen as valid.	Explore benefits and drawbacks of staying home, person's motivation to change, and his or her degree of confidence. If staying home is discordant with the person's goals, begin to motivate for change by developing discrepancies. If leaving the house is important but the person lacks confidence, support self-efficacy, provide empathy, offer information/advice, respond to confidence talk, explore hypothetical change, and offer to accompany him or her to initial activities.
Person denies that he or she has a mental illness and/or addiction	Person is unable to accept illness or lacks insight	Educate and help the person accept diagnoses of mental illness and/or addiction; facilitate grieving loss of previous self	Acceptance of a diagnostic label is not necessary and is not always helpful. Reluctance to acknowledge stigmatizing designations is normal. It is more useful to explore the person's understanding of his or her predicament and recognize and explore areas for potential growth.	In addition to exploring person's own understanding of his or her predicament, explore symptoms and ways of reducing, coping with, or eliminating distress while eliciting ways to live a more productive, satisfying life.

Presenting Situation	Deficit-based Perspective		Recovery-oriented, Asset-based Perspective	
	Perceived Deficit	Intervention	Perceived Asset	Intervention
Person sleeps during the day	Person's sleep cycle is reversed, probably due to illness; needs help to readjust sleep pattern, to get out during the day and sleep at night.	Educate the person about the importance of sleep hygiene and the sleep cycle; offer advice, encouragement, and interventions to reverse sleep cycle	Person likes watching late-night TV; is used to sleeping during the day because he or she has always worked the night shift; has friends who work the night shift so prefers to stay awake so she or he can meet them after their shift for breakfast. Person's reasons for sleeping through the day are viewed as valid.	Explore benefits and drawbacks of sleeping through the day, the person's motivation to change, the importance of the issue and his or her degree of confidence. If sleeping through the day is discordant with the person's goals, begin to motivate change by developing discrepancy, as above.
Person will not engage in treatment	Person is non-compliant, lacks insight, or is in denial	Subtle or overt coercion to make person take his or her medications, attend 12-step or other groups, and participate in other treatments; alternatively, discharge person from care for non-compliance	Consider range of possible reasons why person may not be finding available treatments useful or worthy of his or her time. It is possible that he or she has ambivalence about treatment, has not found treatment useful in the past, did not find treatment responsive to his or her needs, goals, or cultural values and preferences. Also consider factors outside of treatment, like transportation, child care, etc. Finally, appreciate the person's assertiveness about his or her preferences and choices of alternative coping and survival strategies	Compliance, and even positive behaviors that result from compliance, do not equate, or lead directly, to recovery. Attempts are made to understand and support differences in opinion so long as they cause no critical harm to the person or others. Providers value the "spirit of noncompliance" and see it as sign of the person's lingering energy and vitality. In other words, he or she has not yet given up. Demonstrate the ways in which treatment could be useful to the person in achieving his or her own goals, beginning with addressing basic needs or person's expressed needs and desires; earn trust.
Person reports hearing voices	Person needs to take medication to reduce voices; if person takes meds, he or she needs to identify and avoid sources of stress that exacerbate symptoms	Schedule appointment with nurse or psychiatrist for med evaluation; make sure person is taking meds as prescribed; help person identify and avoid stressors	Person says voices have always been there and views them as a source of company, and is not afraid of them; looks to voices for guidance. Alternatively, voices are critical and disruptive, but person has been able to reduce their impact by listening to walkman, giving them stern orders to leave him or her alone, or confines them to certain parts of the day then they pose least interference. Recognize that many people hear voices that are not distressing.	Explore with person the content, tone, and function of his or her voices. If the voices are disruptive or distressing, educate person about possible strategies for reducing or containing voices, including but not limited to medication. Ask person what has helped him or her to manage voices in the past. Identify the events or factors that make the voices worse and those that seem to make the voices better or less distressing. Plan with the person to maximize the time he or she is able to manage or contain the voices.

Recovery and the Conspiracy of Hope

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I would like to thank you for this opportunity to speak with you today. It is a special pleasure to be here in your lovely country. I feel the theme of our conference is very important and in many ways reflects the main message in all of my writings. That theme is, "There is a person in here". In many respects, coming to know that there is a person in here is the easy part. Remembering to always listen for and to reverence the person over there - that can be the more difficult part.

Let me begin by telling you a little about the part of the country I live in. I live in the northeastern part of the United States that we call New England. Where I live, we have four very distinct seasons ranging from the bitter cold of snowy winter, to the muddy season of unfolding colors that we call spring, to the simmering days of summer right through to the spectacular unfolding of autumn when all of the leaves on the trees burst into bright yellows and oranges and reds and then fall to the ground leaving the trees naked and stark and bare. There is always a lesson for me in the cycle of the seasons. I am always reminded that growth happens in a context and that in order for growing things to emerge, environments must change to accommodate that growth.

One spring, after a long and icy winter, I wrote this:

It is springtime and hope is everywhere. It is springtime and it feels like all living things are trembling into being, still wet and new and fragile and determined to put down roots and grow.

I think of a sea rose I watched growing out at a beach near my home this past summer. It is a fragile and tender life, that sea flower. I love to see it. At dawn it moves in a slow upsway as it turns toward the morning star. That sea rose is a light seeker. It bends toward the light. It is a light-seeker whose roots reach way down into the darkness of the earth. In fact, it was in darkness that his new life began.

Way back in January and February, when the icy winds lashed across those dunes and the days were short and the light gave no warmth, even then, way down under the ground, this new life was waiting. Nobody could see it, nobody was there to witness it, and yet this promise of a sea flower waited. It waited in that icy darkness for the sands to begin to thaw. It waited for the rains to come and loosen the earth. And then, ever so slowly, it began to stir. Moving one grain of sand at a time, it began to grow.

It did not grow straight toward the light at first. No. First its growth sought a downward course, reaching, stretching, blindly groping through shifting sands to find a solid place. A place to be rooted. A good soil to cling to and to be nurtured by. A home soil that could sustain it even in driving rains and tormenting winds. And then, having rooted itself in this way, the sea rose began its journey toward the light. Poking through the darkness, that sea flower emerged tiny and lovely and insistent and courageous. On frail and trembling limbs, this small thing rose to a new life...

That sea rose teaches us a lot about hope. It teaches us that hope emerges out of darkness. It teaches us that hope can grow in nurturing environments that allow one to become rooted and secure. And I have come here today to celebrate the hope symbolized by that sea rose.

I believe it is a spirit of hope that gathers us here together today. We come from the far corners of the world : from Australia, New Zealand, the United States, Canada, Sweden, Ireland China and many other countries. We are direct service workers and administrators, policy makers and family members, service users and mental health professionals. Fifteen years ago you would never have caught us all in the same room together! Indeed, ten years ago we would hardly even speak to each other! But here we are, gathered together - social workers sitting next to family members who are sitting next to policy makers, who are sitting next to casemanagers, who are sitting next to academicians who are sitting next to service users . . . What is going on here? Are the old rules being broken? Is the old order shaking a bit at the foundation? **IS THERE A CONSPIRACY GOING ON?**

I love the word conspiracy. It comes from the Latin "conspirare" which means to breath the spirit together. What is the spirit we are breathing together here today?

It is a spirit of hope. Both individually and collectively we have refused to succumb to the images of despair that so often are associated with mental illness. We are a conspiracy of hope and we are pressing back against the strong tide of oppression which for centuries has been the legacy of those of us who are labeled with mental illness. We are refusing to reduce human beings to illnesses. We recognize that within each one of us there is a person and that, as people, we share a common humanity with those who have been diagnosed with mental illness. We are here to witness that people who have been diagnosed with mental illness are not things, are not objects to be acted upon, are not animals or subhuman life forms. We share in the certainty that people labeled with mental illness are first and above all, human beings. Our lives are precious and are of infinite value. And as we progress through this conference we will be learning that those of us with psychiatric disabilities can become experts in our own self care, can regain control over our lives, and can be responsible for our own individual journey of recovery. And finally, as the sea rose teaches us, we are learning that the environment around people must change if we are to be expected to grow into the fullness of the person who, like a small seed, is waiting to emerge from within each of us.

If we plant a seed in a desert and it fails to grow, do we ask, "What is wrong with the seed?" No. The real conspiracy lays in this: to look at the environment around the seed and to ask, "what must change in this environment such that the seed can grow?" The real conspiracy that we are participating in here today is to stop saying what's wrong with psychiatric survivors and to start asking: "How do we create hope filled, humanized environments and relationships in which people can grow?".

But before speaking further of hope and humanity, I want to share with you what it is like to be diagnosed at a young age with mental illness and to lose all hope. I want to tell you about the dark winter of anguish and apathy when we give up hope and just sit and smoke and drink coffee.

For those of us who have been diagnosed with mental illness and who have lived in the sometimes desolate wastelands of mental health programs and institutions, hope is not just a nice sounding euphemism. It is a matter of life and death. We know this because, like the sea rose, we have known a very cold winter in which all hope seemed to be crushed out of us. It started for most of us in the prime of our youth. At first we could not name it. It came like a thief in the night and robbed us of our youth, our dreams, our aspirations and our futures. It came upon us like a terrifying nightmare that we could not awaken from.

And then, at a time when we most needed to be near the one's we loved, we were taken away to far off places. At the age of 14 or 17 or 22 we were told that we had a disease that had no cure. We were told to take medications that made us slur and shake, that robbed our youthful bodies of energy and made us walk stiff like zombies. We were told that if we stayed on these medications for the rest of our lives we could perhaps maintain some semblance of a life. They kept telling us that these medications were good for us and yet we could feel the high dose neuroleptics transforming us into empty vessels. We felt like will-less souls or the walking dead as the numbing indifference and drug induced apathy took hold. At such high dosages, neuroleptics radically diminished our personhood and sense of self.

As these first winds of winter settled upon us we pulled the blankets up tight around our bodies but we did not sleep. During those first few nights in the hospital we lay awake. You see, at night the lights from the houses in the community shine through the windows of the mental institution. Life still went on out there while ours crumbled all about us. Those lights seemed very, very far away. The Zulu people have a word for our phrase "far away". In Zulu "far away" means, "There where someone cries out : 'Oh mother, I am lost" (Buber 1958, p. 18). And indeed, this is how far away it felt in the mental hospital. The road back home was not clear. And as we lay there in the darkness we were scared and could not even imagine the way out of this awful place. And when no one was looking we wept in all of that loneliness.

But when morning came we raged. We raged against the bleak prophesies that were being made for our lives. They are wrong! They are wrong! We are not crazy. We are not like those other ones over there who have been in this hospital too long. We are

different. We will return home and everything will be just the same. It's just a bad dream. A temporary setback.

In time we did leave the hospital. We stood on the steps with our suitcases in hand. We had such courage - our youthful optimism waved like triumphant flags at a homecoming parade. We were going to make it. We were never going to come back to the hospital again.

Some did make it. But most of us returned home and found that nothing was the same anymore. Our friends were frightened of us or were strangely absent. They were overly careful when near us. Our families were distraught and torn by guilt. They had not slept and their eyes were still swollen from the tears they cried. And we, we were exhausted. But we were willing to try. And I swear, with all the courage we could muster we tried to return to work and to school, we tried to pick up the pieces, and we prayed for the strength and perseverance to keep trying. But it seemed that God turned a deaf ear to our prayers. The terrible distress came back and our lives were shattered once again.

And now our winter deepened into a bone chilling cold. Something began to die in us. Something way down deep began to break. Slowly the messages of hopelessness and stigma which so permeated the places we received treatment, began to sink in. We slowly began to believe what was being said about us. It seemed that the system tried to break our spirit and was more intent on gaining, even coercing our compliance, than listening to us and our needs.

We found ourselves undergoing that dehumanizing transformation from being a person to being an illness: "a schizophrenic", "a multiple", "a bi-polar" (Deegan 1992). Our personhood and sense of self continued to atrophy as we were coached by professionals to learn to say, "I am a schizophrenic"; "I am a bi-polar"; "I am a multiple". And each time we repeated this dehumanizing litany our sense of being a person was diminished as "the disease" loomed as an all powerful "It", a wholly Other entity, an "in-itself" that we were taught we were powerless over.

Professionals said we were making progress because we learned to equate our very selves with our illness. They said it was progress because we learned to say "I am a schizophrenic". But we felt no progress in this. We felt time was standing still. The self we had been seemed to fade farther and farther away, like a dream that belonged to somebody else. The future seemed bleak and empty and promised nothing but more suffering. And the present became an endless succession of moments marked by the next cigarette and the next.

So much of what we were suffering from was overlooked. The context of our lives were largely ignored. The professionals who worked with us had studied the science of physical objects, not human science. They did not understand what the neurologist Oliver Sacks (1970) so clearly articulates: "To restore the human subject at the center - the suffering, afflicted, fighting, human subject - we must deepen a case history to a

narrative or tale; only then do we have a 'who' as well as a 'what', a real person, a patient, in relations to disease - in relations to the physical. . . the study of disease and identity cannot be disjoined. . . (stories) bring us to the very intersection of mechanism and life, to the relation of physiological processes to biography" (p.viii). But no one asked for our stories. Instead they thought our biographies as schizophrenics had been already been written nearly a century before by Kraeplin and Blueler.

Yet much of what we were going through were simply human experiences - experiences such as loss and grief and shock and fear and loneliness. One by one our friends, relatives and perhaps even families left us. One by one the professionals in our lives moved on and it became too difficult to trust anyone. One by one our dreams and hopes were crushed. We seemed to lose everything. We felt abandoned in our ever-deepening winter.

The weeks, the months or the years began to pass us by. Now our aging was no longer marked by the milestones of a year's accomplishments but rather by the numbing pain of successive failures. We tried and failed and tried and failed until it hurt too much to try anymore. Now when we left the hospital it was not a question of would we come back, but simply a question of when would we return. In a last, desperate attempt to protect ourselves we gave up. We gave up trying to get well. Giving up was a solution for us. It numbed the pain. We were willing to sacrifice enormous parts of ourselves in order to say "I don't care". Our personhood continued to atrophy through this adaptive strategy of not caring anymore. And so we sat in chairs and smoked and drank coffee and smoked some more.. It was a high price to pay for survival. We just gave up. And winter settled in upon us like a long cold anguish.

I'm sure that many of us here today know people with psychiatric disabilities who are lost in the winter of anguish and apathy I have just described. It is a time of real darkness and despair. Just like the sea rose in January and February, it is a time when nothing seems to be growing except the darkness itself. It is a time of giving up. Giving up is a solution. Giving up numbs the pain because we stop asking "why and how will I go on?". Even the simplest of tasks is overwhelming at this time. One learns to be helpless because that is safer than being completely hopeless.

The winter of anguish and the atrophy of the sense of self that I am describing is a hell not only for the ones living it, but also for the one's who love and care for us: friends, relatives and even professionals. I have described what it feels like on the inside as it is being lived. But friends, relatives and professionals see the anguish and indifference from the outside.

From the outside it appears that the person just isn't trying anymore. Very frequently people who show up at clubhouses and other rehabilitation programs are partially or totally immersed in this despair and anguish. On good days we may show up at program sites but that's about all. We sit on the couch and smoke and drink coffee. A lot of times we don't bother showing up at programs at all. From the outside we may appear to be among the living dead. We appear to be apathetic, listless, lifeless. As

professionals, friends and relatives we may think that these people are "full of excuses", they don't seem to try anymore, they appear to be consistently inconsistent, and it appears that the only thing they are motivated toward is apathy. At times these people seem to fly into wishful fantasies about magically turning their lives around. But these seem to us to be only fantasies, a momentary refuge from chronic boredom. When the fantasy collapses like a worn balloon, nothing has changed because no real action has been taken. Apathy returns and the cycle of anguish continues.

Staff, family and friends have very strong reactions to the person lost in the winter of anguish and apathy. From the outside it can be difficult to truly believe that there really is a person over there. Faced with a person who truly seems not to care we may be prompted to ask the question that Oliver Sacks (1970, p. 113) raises: "Do you think William (he) has a soul? Or has he been pithed, scooped-out, de-souled, by disease?" I put this question to each of us here today. Can the person inside become a disease? Can schizophrenia pith or scoop-out the person so that nothing is left but the disease? Each of us must meet the challenge of answering this question for ourselves. In answering this question, the stakes are very high. Our own personhood, our own humanity is on the line in answering this question. Let me explain:

Sitting in the day room, literally couched in a cigarette smoke screen, the profound apathy and indifference we may encounter in another person will challenge our own humanity and our own capacity to be compassionate. We may question whether there really is a person over there. In such an encounter Martin Buber (1958) would instruct us that the I - Thou relationship is challenged. If we relate to a person as if they were a disease then we enter an I - It relationship. The I-It relationship diminishes our own humanity. Of course, the great work that faces us is to hold the sanctity of the person as Thou, even when the person may be lost to themselves. That is the great act of compassion. To hold the personhood of a person even when they may be lost to themselves. This deepens our humanity or, to paraphrase Martin Buber - I become I by saying Thou (p.11).

However, when faced with a person lost in anguish and apathy, there are a number of more common responses than finding a way to establish an I-Thou relationship. A frequent response is what I call the "frenzied savior response". We have all felt like this at one time or another in our work. The frenzied savior response goes like this : The more listless and apathetic the person gets, the more frenetically active we become. The more they withdraw, the more we intrude. The more will-less they become, the more willful we become. The more they give up, the harder we try. The more despairing they become, the more we indulge in shallow optimism. The more treatment plans they abort, the more plans we make for them. Needless to say we soon find ourselves burnt out and exhausted. Then our anger sets in.

Our anger sets in when our best and finest expectations have been thoroughly thwarted by the person lost in anguish and apathy. We feel used and thoroughly unhelpful. We are angry. Our identities as helping people are truly put to the test by people lost in the winter of anguish and indifference. At this time it is not uncommon for

most of us to begin to blame the person with the psychiatric disability at this point. We say things like : "They are lazy. They are hopeless. They are not sick, they are just manipulating. They are chronic. They need to suffer the natural consequences of their actions. They like living this way. They are not mad, they are bad. The problem is not with the help we are offering, the problem is that they can't be helped. They don't want help. They should be thrown out of this program so they can 'hit bottom'. Then they will finally wake up and accept the good help we have been offering."

During this period of anger and blaming a most interesting thing happens. We begin to behave just like the person we have been trying so hard to save. Frequently at this point staff simply give up. We enter into our own despair and anguish. Our own personhood begins to atrophy. We too give up. We stop trying. It hurts too much to keep trying to help the person who seems to not want help. It hurts too much to keep trying to help and failing. It hurts too much to keep caring about them when they can't even seem to care about themselves. At this point we collapse into our own winter of anguish and a coldness settles into our hearts.

We are no better at living in despair than are people with psychiatric disabilities. We cannot tolerate it so we give up too. Some of us give up by simply quitting our jobs. We reason that high tech computers do as they are told and, besides, the pay is better. Others of us decide not to quit, but rather we grow callous and hard of heart. We approach our jobs like the man in the Dunkin Donuts commercial: "It's time to make the donuts, it's time to make the donuts". Still others of us become chronically cynical. We float along at work like pieces of dead wood floating on the sea, watching administrators come and go like the weather; taking secret delight in watching one more mental health initiative go down the tubes; and doing nothing to help change the system in a constructive way. These are all ways of giving up. In all these ways we live out our own despair.

Additionally entire programs, service delivery systems and treatment models can get caught up in this despair and anguish as well. These systems begin to behave just like the person with a psychiatric disability who has given up hope. A system that has given up hope spends more time screening out program participants than inviting them in. Entry criteria become rigid and inflexible. If you read between the lines of the entry criteria to such programs they basically state: If you are having problems come back when they are fixed and we will be glad to help you. Service systems that have given up hope attempt to cope with despair and hopelessness by distancing and isolating the very people they are supposed to be serving. Just listen to the language we use: In such mental health systems we have "gatekeepers" whose job it is to "screen" and "divert" service users. In fact, we actually use the language of war in our work. For instance we talk about sending "front-line staff" into the "field" to develop treatment "strategies" for "target populations".

Is there another alternative? Must we respond to the anguish and apathy of people with psychiatric disability with our own anguish and apathy? I think there is an alternative. The alternative to despair is hope. The alternative to apathy is care. Creating

hope filled, care filled environments that nurture and invite growth and recovery is the alternative.

Remember the sea rose? During the cold of winter when all the world was frozen and there was no sign of spring, that seed just waited in the darkness. It just waited. It waited for the soil to thaw. It waited for the rains to come. When the earth was splintered with ice, that sea rose could not begin to grow. The environment around the sea rose had to change before that new life could emerge and come into being.

People with psychiatric disabilities are waiting just like that sea rose waited. We are waiting for our environments to change so that the person within us can emerge and grow.

Those of us who have given up are not to be abandoned as "hopeless cases". The truth is that at some point every single person who has been diagnosed with a mental illness passes through this time of anguish and apathy, even if only for a short while. Remember that giving up is a solution. Giving up is a way of surviving in environments which are desolate, oppressive places and which fail to nurture and support us. The task that faces us is to move from just surviving, to recovering. But in order to do this, the environments in which we are spending our time must change. I use the word environment to include, not just the physical environment, but also the human interactive environment that we call relationship.

From this perspective, rather than seeing us as unmotivated, apathetic, or hopeless cases, we can be understood as people who are waiting. We never know for sure but perhaps, just perhaps, there is a new life within a person just waiting to take root if a secure and nurturing soil is provided. This is the alternative to despair. This is the hopeful stance. Marie Balter expressed this hope when asked, "Do you think that everybody can get better?" she responded: "It's not up to us to decide if they can or can't. Just give everybody the chance to get better and then let them go at their own pace. And we have to be positive - supporting their desire to live better and not always insisting on their productivity as a measure of their success". (Balter 1987, p.153).

So it is not our job to pass judgment on who will and will not recover from mental illness and the spirit breaking effects of poverty, stigma, dehumanization, degradation and learned helplessness. Rather, our job is to participate in a conspiracy of hope. It is our job to form a community of hope which surrounds people with psychiatric disabilities. It is our job to create rehabilitation environments that are charged with opportunities for self-improvement. It is our job to nurture our staff in their special vocations of hope. It is our job to ask people with psychiatric disabilities what it is they want and need in order to grow and then to provide them with good soil in which a new life can secure its roots and grow. And then, finally, it is our job to wait patiently, to sit with, to watch with wonder, and to witness with reverence the unfolding of another person's life.

That sounds good but how do we do it? I have some very concrete suggestions as to how to enter into a conspiracy of hope and build communities of hope around people who have lost hope.

First we must be committed to changing the environments that people are being asked to grow in. We must recognize that real change can be quite uncomfortable and sometimes I worry we will content ourselves with superficial change. I worry about new and catchy words like consumer integration, empowerment, clubhouse models and partnership. It seems to me that over the decades we keep coming up with all kinds of trendy words and names to call each other. For instance in the fifties it was the doctors and the patients. In the sixties it was the staff and the clients. In the seventies it was the providers and the consumers. In the eighties it was the staff and the members. Now in the nineties we have "shareholders" and the Managed Care Corporations.

Yes, the names we call each other have certainly changed. But I would argue that the fundamental relationship between those labeled with mental illness and those who are not, has remained essentially unchanged. There is a wise old monk who lives in the Nova Nada community, out in Kemptville, Nova Scotia. His name is Fr. William MacNamara. When talking about our attempts to bring about change, he says: "It's like we keep rearranging the chairs on the deck of the Titanic but all we really achieve through this effort is a better view while going down". That's the big danger of simply using the newest program designs and politically correct language. If we're not careful, all this will amount to is rearranging the chairs on the deck of a sinking ship. Somebody has got to say, "Stop! Wait! Forget the catchy words. There's a big gaping hole in this boat we call the mental health system and we are all going down with it!"

You see, I would argue that until the fundamental relationship between people who have been psychiatrically labeled and those who have not changes, until the radical power imbalance between us is at least equalized, until our relationships are marked by true mutuality, until we stop using barbaric practices such as restraint and seclusion while trying to convince people that such torture is for their own good, and until we recognize the common ground of our shared humanity and stop the spirit breaking effects of dehumanization in the mental health system, then that gaping hole will continue to sink the best of our efforts.

The human-interactive environment of mental health programs and the community must change if people are going to move from just surviving to the journey of recovery. We must stop exercising "power over" the people we work with. This only produces unnecessary dependency and learned helplessness. Instead we must join with people like Dr. Jean Baker Miller (1976) and other scholars at the Stone Center at Wellesley College. Following their lead we must begin to think in terms of having "power with" or "creating power together" rather than having "power and control over" the people we work with. In this way traditional power relationships, which have historically been so oppressive for people with psychiatric disabilities, will change. Specifically, this means we must stop using the phrase, "I judge this to be in the client's

best interest" and instead ask people what they want for their own lives and provide them with the skills and support to achieve it.

We must commit ourselves to removing environmental barriers which block people's efforts towards recovery and which keep us locked in a mode of just trying to survive. For instance, I would suggest examining the following questions:

1. Are the people we work with overmedicated? Very often the apathy, lack of motivation, and indifference we observe is an effect of neuroleptics. Are we teaching consumer/survivors about this drug effect and helping them effectively advocate for medication changes and/or reductions? The multinational drug industry is literally making a fortune through the sales of these drugs. Our priority is not to increase their quarterly profit margins. Our priority is to support people in their recovery process. It is not possible to actively participate in our own recovery process when we are in state of drug induced mental Parkinsonism, apathy and indifference.
2. Are consumer/survivors in both community based and hospital programs involved in evaluating staff work performance? Who better knows how effective a staff person is than those receiving services from that staff person? Additionally, are we providing consumer survivors with the skills training and support to conduct such evaluations?
3. Are program participants and hospital inpatients receiving peer skills training on how to participate in and effectively get what they want from a treatment team? Are we allowed to sit through the entire treatment--planning meeting and are staff committed to speaking in plain English so we can understand the conversation? Are there peer advocates who are available to come to the treatment planning meetings with us? Are there opportunities to meet prior to the team meeting in order to strategize what we want to get out of the meeting and how to go about presenting our ideas? Is there time to role-play speaking up and dealing with questions prior to the treatment-planning meeting?
4. Are there separate toilets or eating space for staff and program participants? If there are, they should be eliminated. This is called segregation and creates second-class citizens.
5. Who can use the phones? Who makes what decisions? Who has the real power in this program? Information is power and having access to information is empowering. What are the barriers to getting information in the program?
6. Do we understand that people with psychiatric disabilities possess valuable knowledge and expertise as a result of their experience? Do we nurture this important human resource? Are peer run, mutual help groups available? Are we actively seeking to hire people with psychiatric disabilities and to provide the supports and accommodation they may request?

7. Have we created environments in which it is possible for staff people to be human beings with human hearts? Do we offer supervision or staff surveillance? Perhaps we could help create more humanized work environments if we sought to view working with people as a journey in which we both move and are moved by the people we seek to serve. Perhaps we could offer our workers what Jean Vanier (1988) calls "accompaniment". Accompaniment means offering to walk with our staff as they make that sometimes painful, sometimes joyous journey of the heart we call the "direct care relationship". Directly caring. Ah! Now there's true change.
8. Do we work in a system which rewards passivity, obedience and compliance? Is compliance seen as a desirable outcome? As a friend who is a consumer/survivor told me, "Tell those casemanagers that they have it all wrong. Tell them to stop saying that compliance is the road to independence". And indeed, compliance is not the road to independence. Learning to become self-determining is an outcome that is indicative of environments that support opportunities for recovery and empowerment.
9. Have we embraced the concept of the "dignity of risk" and the "right to failure"? "Chronically normal people" (CNP's !), or people who have not been psychiatrically labeled, are allowed to make dumb, un insightful decisions all the time in their lives. My favorite example is Elizabeth Taylor who just got her eighth divorce. We might say, "She lacks insight! She is failing to learn from past experience!" However, when she embarks on marriage #9, no SWAT team of nurses with Prolixin injections will descend upon her "in her best interest". But just imagine if a person with a psychiatric disability were to announce to their treatment team that they were about to get married for the 9th time! People learn, and sometimes don't learn from failures. We must be careful to distinguish between a person making (from our perspective) a dumb or self-defeating choice, and a person who is truly at risk.
10. Are there opportunities within the mental health system for people to truly improve their lives? Are there a range of affordable, normal housing situations from which people can choose a place to live? Is there work available? A person who just recently went back to work after many years of hospitalization said to me, "What's all this talk about empowerment? I can tell you the definition of empowerment: "It's a decent paycheck at the end of the week".

These are just some suggestions about how to create environments in which it is possible for people to grow.

Then, as we build these hope filled environments, we must recognize that people with psychiatric disabilities do not "get rehabilitated" in the same sense that cars "get tuned up" (Deegan 1988). We are not passive objects which professionals are responsible for "rehabilitating". Many of us find this connotation of the word

rehabilitation to be oppressive. We are not objects to be acted on. Rather we are fully human subjects who can act, and in acting can change our situation.

We are not objects to be fixed. Such a connotation robs us of our own sense of autonomy and self-determination. It places responsibility in the wrong place. It perpetuates the myth that we are not and cannot be responsible for our own lives, decisions and choices.

The truth is that nobody has the power to rehabilitate anybody else's life. This is clearly evidenced in the fact that we can make the finest and most advanced rehabilitation technologies and programs available to people with disabilities and still fail to help them. As it is said, "You can lead a horse to water but you can't make it drink". Something more than just good services is needed. That "something more" is what I call recovery.

The concept of recovery differs from that of rehabilitation in as much as it emphasizes that people are responsible for their own lives and that we can take a stand toward our disability and what is distressing to us. We need not be passive victims. We need not be "afflicted". We can become responsible agents in our own recovery process. That is why it is so dangerous to reduce a person to being an illness. If we insist that a person learn to say, "I am a schizophrenic", then in essence we are insisting that the person equate their personhood with illness. Through such a dehumanizing reduction the disease takes on what is called a "master status" in terms of identity. Thus when a person learns to believe "I am a schizophrenic", when their identity is synonymous with a disease, then there is no one left inside to take on the enormous work of recovery. That is why we must always help people to use person first language i.e., I am a person labeled with schizophrenia; I am a person diagnosed with mental illness, etc. Person first language always reminds us that first and foremost we are human beings who can take a stand toward what is distressing to us.

Each person's journey of recovery is unique. Indeed, each of us must discover for ourselves what promotes our recovery and what does not. Some of us find that intermittent or ongoing treatment is an important part of our recovery process. However others find that they no longer require mental health services and leave the system entirely (Ogawa, 1987)

For some of us who have historically used or abused drugs of alcohol, or who have grown up in alcoholic families, or who have survived childhood sexual, emotional and/or physical abuse, participation in various self help and twelve step programs may play a vital role in our recovery process.

Many of us find that social and vocational rehabilitation programs offer us unique opportunities and we use these services as part of our recovery process. Most of us find that developing friendships based on love and mutual respect is very important to our recovery. Of course, permanent, affordable and fully integrated housing is fundamental to the recovery process. Many of us find that participating in a spiritual community of our choice gives us the strength and hope to keep working hard in our recovery process.

Finally, many of us find it important to participate in consumer/survivor run support networks and advocacy groups in an effort to help change the mental health system, to establish alternatives to traditional services, to make government aware of our needs, to fight for our full civil rights and to collectively struggle for social justice. In fact, I use the term recovery to refer not only to the process of recovering from mental illness, but also to refer to recovering from the effects of poverty, second class citizenship, internalized stigma, abuse and trauma sustained at the hands of some "helping professionals", and the spirit breaking effects of the mental health system. Indeed, self help and social action cannot be arbitrarily separated. At some point helping ourselves includes joining together as a group to fight the injustices that devalue us and keep us in the position of second class citizens.

Recovery does not refer to an end product or result. It does not mean that one is "cured" nor does not mean that one is simply stabilized or maintained in the community. Recovery often involves a transformation of the self wherein one both accepts ones limitation and discovers a new world of possibility. This is the paradox of recovery i.e., that in accepting what we cannot do or be, we begin to discover who we can be and what we can do. Thus, recovery is a process. It is a way of life. It is an attitude and a way of approaching the day's challenges. It is not a perfectly linear process. Like the sea rose, recovery has its seasons, its time of downward growth into the darkness to secure new roots and then the times of breaking out into the sunlight. But most of all recovery is a slow, deliberate process that occurs by poking through one little grain of sand at a time.

As the sea rose teaches us, the work of growth is slow and difficult but the result is beautiful and wondrous. We have chosen very difficult work. Sometimes I think we are a little weird for choosing this line of work. I mean, computers don't ask that we grow and the pay is certainly better. But we stick with this work and are faithful to it. Why? Because we are part of a conspiracy of hope and we see in the face of each person with a psychiatric disability a life that is just waiting for good soil in which to grow. We are committed to creating that good soil. And so I celebrate you. I celebrate the strong and fiercely tenacious spirit of people with psychiatric disabilities. I celebrate the person within each of us. I celebrate hope. I celebrate our conspiracy. And I think we all deserve a round of applause. Thank you!

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The Maine and Vermont Three-Decade Studies of Serious Mental Illness

I. Matched Comparison of Cross-Sectional Outcome

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Background. This study compared long-term outcome of serious mental illness in two states using a matched design to assess psychiatric rehabilitation programmes; Vermont subjects participated in a model psychiatric rehabilitation programme, while the Maine group received more traditional care.

Method. Maine and Vermont subjects ($n = 269$) were matched by age, sex, diagnosis, and chronicity. Demographic, illness, and life history information were abstracted from hospital records by clinicians blind to outcome. DSM-III criteria were applied retrospectively. Outcome was assessed by clinicians blind to history.

Results. Vermont subjects alive at follow-up ($n = 180$) were more productive ($P < 0.0009$), had fewer symptoms ($P < 0.002$), better community adjustment ($P < 0.001$) and global functioning ($P < 0.0001$) than Maine subjects ($n = 119$).

Conclusions. Outcome differences may be due to Vermont's model programme and a policy of allowing an earlier opportunity for community life.

Long-term studies of serious mental illness have provided a clearer understanding of the wide heterogeneity of outcome that is possible (Huber *et al*, 1975; Ciompi & Müller, 1976; Bleuler, 1978; Tsuang *et al*, 1979; Harding *et al*, 1987*a,b*). This appreciation has been especially helpful for schizophrenia, which, until recently, had been thought to be defined by a uniformly poor outcome (Kraepelin, 1902; American Psychiatric Association, 1980). However, comparing long-term studies is difficult owing to differences of method concerning, for example: diagnostic criteria, outcome definitions, instrumentation, strategies for missing and deceased subjects, protocols for collection of follow-up information, and treatment eras (Strauss & Carpenter, 1972; Angst, 1988; McGlashan, 1988).

To address some of the above issues, this paper compares the long-term outcome of matched groups from two recent long-term studies in the USA. The average length of follow-up for Vermont and Maine subjects was 32 years (Harding *et al*, 1987*a,b*) and 36 years, respectively. Identical protocols and instrumentation were used, along with reliability studies. The Vermont subjects participated in a model rehabilitation programme (Chittick *et al*, 1961), while the Maine group received traditional in-patient treatment and aftercare (DeSisto *et al*, 1991). A major aim of the study was to determine the effect of Vermont's rehabilitation programme. The study relied on a quasi-experimental design which used group matching and covariance procedures to control for the effect of policy and unmatched group differences.

Background to the study

The foundation for this work was established over 30 years ago. Before the policy of deinstitutionalisation, mental health centres, and entitlement programmes, Vermont's State Hospital and the Vocational Rehabilitation Division jointly initiated a pioneering rehabilitation programme (Chittick *et al*, 1961). The programme was comprehensive and eclectic (Harding *et al*, 1987*a,b*). Concepts from social psychiatry were integrated with those from medicine and vocational rehabilitation. All services were organised around the goal of self-sufficiency. New strategies were used in the hospital which included 'blurring of roles', intensified relationships, and new expectations for both patients and staff. Vocational rehabilitation provided new community residences, work options, and case management. Continuity of care across settings was assured as teams of hospital and vocational workers established halfway houses, found job openings, made job placements, and linked patients to natural supports in the community. The programme created a comprehensive system of care before the creation of community mental health centres and community support systems.

The early 1980s follow-up

In the early 1980s, Harding *et al* (1987*a,b*) assessed the long-term outcome of the Vermont cohort at an average of 32 years after first admission. Of the original 269 patients, 262 (97%) were traced. Outcome for the cohort was widely heterogeneous.

Of those interviewed, 55% were rated as having little or no social impairment, were asymptomatic, had close relationships, were employed or otherwise productive, and were living independently. Sixty-eight per cent were rated as functioning 'pretty well', defined as a score over 61 on the Global Assessment Scale (GAS; Endicott *et al*, 1976). These findings raised questions about whether the favourable outcome was due to the rehabilitation programme (Chittick *et al*, 1961), Vermont's rural environment (Zubin, 1985), or the characteristics of the Vermont sample (McGlashan, 1988, and corrected McGlashan, 1991).

A detailed historical comparison of the evolution of the Maine and Vermont mental health systems revealed that Maine did not develop a comprehensive rehabilitation programme that was linked to the depopulation of its hospital. Instead, Maine patients received more 'traditional care', in the form of modern drug treatment (beginning in 1955-56) and aftercare (provided first by hospital social workers and then by community mental health centres), with little or no involvement in vocational rehabilitation. Also, the development of alternative residences, such as community halfway houses, came 16 years after that in Vermont (DeSisto *et al*, 1991). Since the sociocultural composition of rural Maine and Vermont appeared similar, in order to explore outcome correlates, a cohort in rural Maine, matched to Vermont patients by age, sex, diagnosis, and length of hospital stay, was followed with the same protocol developed by Harding *et al* (1987a).

Method

Subjects

All of the over 8000 summary cards for Maine hospital admissions were screened to exclude patients born before 1890, those with organic, drug and alcohol disorders, those on criminal mandates, and

those not admitted between 1956 and 1961. This period represented the treatment era during which persons were referred and discharged from the Vermont rehabilitation programme.

This strategy resulted in a pool of 1944 possible matches for the Vermont subjects. Exact matching by sex, diagnosis, and age was conducted, followed by closest matching on hospital stay (Table 1). In each group there were 125 men and 144 women, and 190 subjects had schizophrenia according to DSM-II criteria (American Psychiatric Association, 1968), 9 had schizoaffective disorder, 20 had affective disorders, and 50 had other disorders.

Field work

Vermont's protocols, instrumentation, and standardised procedures were used (Harding *et al*, 1987a). To assure comparability between states, a Vermont clinician field worker (PL) trained the two Maine field workers in the interview process. Two inter-rater reliability trials were conducted between the Maine clinicians (with 48 subjects) and between the two Maine clinicians and the Vermont clinician (with 20 subjects). The overall kappa (Fleiss, 1973) agreement for the Maine data set was 0.71, while the overall agreement between Maine and Vermont was 0.61.

The clinician field workers, blind to record information, conducted two interviews about one week apart in each subject's place of residence. The first interview involved an assessment of current functioning across outcome domains. The second interview involved a structured year-by-year documentation of domains in a life-chart format (Leighton & Leighton, 1949; Meyer, 1951; Harding *et al*, 1989). Relatives, friends, and carers of live and deceased subjects were also interviewed. Death certificates validated status. In order to obtain a more balanced view of the long-term course for the entire cohort, a surrogate instrument for deceased subjects was used to document the lives and levels of functioning until the time of death.

Table 1
Comparisons of matching variables

Variable	Mean	Standard deviation	Mean difference	t value	P value	No. of cases
Year of birth						
Maine	1918	10.74				
Vermont	1919	10.81	-0.08	-0.54	0.59	269
Time in hospital to January 1961 (months)						
Maine	88.69	68.47				
Vermont ¹	90.36	84.45	-1.67	0.58	0.56	267

1. Time in hospital for two Vermont cases (4 and 94) was not available at the time of this analysis.

Record review

Two Maine clinicians, blind to outcome, were trained by a Vermont clinician record reviewer (JF) to extract information for all admissions using Vermont protocols. Each record was reviewed independently, and then rated jointly to achieve a consensus between the clinicians. The reliability of the record review data for Maine was determined using two separate ratings, conducted six months apart, of the index admission and life history sections of the Hospital Record Review Form for 21 randomly selected cases. Kappas were 0.54 for index admission and 0.76 for the life history section.

DSM-III rediagnosis

Following the Vermont protocols, primary case records for the index hospital admission, from which all references to diagnosis were deleted, were used by blinded psychiatrists to assign DSM-III (APA, 1980) diagnoses to all Maine patients. Kappa inter-rater reliability for classification of cases as schizophrenia, schizoaffective disorder, affective disorder, or other for 40 randomly selected cases was 0.69 for Maine and 0.65 for Vermont. Kappa levels for classification of cases as schizophrenia or not schizophrenia were 0.69 for Maine and 0.78 for Vermont.

Reliability of individual variables

Of the 40 individual variables reported here, 10 (25%) showed very good inter-rater agreement (kappa range 0.81–1.00), 23 (58%) good agreement (kappa range 0.61–0.80), 5 (12%) moderate agreement (kappa range 0.41–0.60), and 2 (5%) only fair agreement (0.21–0.40). Variables showing moderate and fair agreement included: social ratings (frequency of social contacts, number of social relations, degree of interdependence in social relationships); symptom ratings (verifiable delusion or hallucination, symptoms in past month); the person's awareness of any abnormal involuntary movements; and the ratings of number of years the person was compliant with prescribed medication.

Construction, internal consistency, and reliability

Of the outcome scale battery of interview instruments – the Vermont Community Questionnaire–Cross-sectional (VCQ-C; Harding & Brooks, 1984; Harding *et al*, 1987a) – was used to assess current functioning. It was constructed by combining 15 established scales described in the literature. The items from these scales were organised across the domains of residence, work, finances, social functioning, social supports,

weekly activities, self-care, use of treatment/social services, satisfaction, environmental stressors, competence, and psychopathology.

Outcome scales for self-care ('Do-for-self'), 'Work', 'Social functioning', and 'Symptoms' were constructed by adding items after dichotomisation. The Appendix summarises the items used to construct the scales. Cronbach's α coefficients (Cronbach, 1951) demonstrated good internal consistency, with values ranging from 0.74 to 0.89.

In addition to the constructed scales, the GAS was used as a measure of overall functioning, the Community Adjustment Scale (CAS; Harding & Brooks, 1986) was employed to assess adjustment to life in the community, and the Mini-Mental State Examination (MMSE; Folstein *et al*, 1975) was used to measure overall cognitive functioning.

The reliability of the GAS, CAS, and MMSE, and the constructed scales, was assessed using the intraclass correlation coefficient (ICC; Bartko, 1966). Coefficients between the one Vermont clinician interviewer who trained the Maine team and between each of the two Maine clinician interviewers for all the outcome scales (20 cases) ranged from 0.75 to 0.98 ($P < 0.0001$).

Regression analysis (Pedhazur, 1982) was used to determine the contribution of differences in important unmatched variables and to make covariance adjustments. The covariates used included the matching variables, variables listed in Table 3, and the interaction terms of the grouping variable (state) with each covariate. The scores for each covariate were standardised to z scores using the grand means for the combined samples. Since all covariates were transformed to z scores, the regression coefficient for the grouping variable, state, was the difference in the outcome variable adjusted to the grand mean of the covariate.

Results

Status of the cohorts at follow-up

Table 2 shows the status of the Vermont and Maine subjects at follow-up. Both cohorts showed attrition by death, more so in Maine because follow-up was seven years later.

The remainder of this report focuses on outcome comparisons of the subjects who were interviewed at follow-up. A separate paper will describe the trajectories for deceased subjects. However, the assumption that the most severely ill subjects died first, leaving a group better suited for recovery, was tested first by comparing the matching variables and covariates of all 299 alive and all 191 deceased subjects.

Table 2
Status of the 269 Maine and 269 Vermont probands at follow-up

	Vermont <i>n</i> (%)	Maine <i>n</i> (%)
Interviewed	180 (66) ¹	119 (44)
Deceased; family and significant others interviewed	71 (26)	120 (45)
Alive; refused participation	11 (5)	14 (5)
Not located	7 (3)	16 (6)
Total	269 (100)	269 (100)

1. The data files used in the extensive analyses for this report include data for two Vermont subjects who completed the interviews but who then withdrew from participation in the study. The University of Vermont Institutional Review Board determined that since these persons were not identifiable in any way and had consented to be interviewed, but then withdrew, the data from the interviews could be used in these analyses without harm to the subjects.

There were no differences except that the deceased group was almost six years older ($t = -6.34$, $P < 0.0001$) and had more subjects with DSM-III schizophrenia ($t = 2.23$, $P < 0.02$). An analysis of variance with age and diagnosis entered as covariates was then used to compare the GAS and the CAS scores by state (Maine, Vermont) and status (alive, deceased). There was no difference between the alive and deceased for the GAS ($F = 0.130$, $P = 0.718$) or the CAS ($F = 0.319$, $P = 0.573$). However, Vermont subjects had higher GAS ($F = 67.64$, $P < 0.0001$) and CAS scores ($F = 44.67$, $P < 0.0001$). There were no significant differences in the survival rates of the cohorts as measured by the Lee-Desu statistic (1.690, d.f. = 1, $P = 0.194$).

Matching variables and covariate comparisons

Table 3 shows the comparisons for 119 Maine and 180 Vermont subjects interviewed at follow-up for the matching variables and other covariates. As expected, there were no significant differences between the cohorts in the matching variables, and in economic status rated at index admission. However, Vermont subjects were discharged three years earlier from the index hospital stay ($P = 0.0001$), and were better educated than Maine subjects ($P = 0.0001$). More Vermont subjects had a rural origin ($P = 0.0001$), while more Maine subjects came from small cities. As a result, more fathers of Maine subjects were industrial workers. In addition, more Maine subjects had an acute onset of illness ($P = 0.0003$). Finally, outcome data for the Vermont subjects were gathered seven years before the Maine data, so there was a significant seven-year difference in follow-up year ($P = 0.0001$).

Table 3
Comparisons of matching variables and covariates from interviewed subjects

	Vermont (<i>n</i> = 180)	Maine (<i>n</i> = 119)	<i>t</i> -value	d.f. ¹	<i>P</i> value
Hospital stay (months)					
mean	87.7	78.6	1.06	296.0	0.29
s.d.	87.1	61.0			
Year of birth					
mean	1921	1922	-1.43	259.3	0.15
s.d.	10.3	9.9			
Sex ²					
mean	1.51	1.54	-0.45	253.0	0.65
s.d.	0.50	0.50			
Diagnosis ³					
mean	1.54	1.64	-1.73	259.0	0.09
s.d.	0.50	0.48			
Index year of discharge					
mean	1961	1964	-5.08	185.1	0.0001
s.d.	4.6	6.9			
Education ⁴					
mean	1.84	1.34	4.89	269.2	0.0001
s.d.	0.91	0.83			
Urban/rural origin ⁵					
mean	3.09	2.16	6.44	262.3	0.0001
s.d.	1.26	1.19			
Acute onset ⁶					
mean	0.19	0.39	-3.72	215.5	0.0003
s.d.	0.40	0.49			
Interview year ⁷					
mean	1981	1988	-156	303.0	0.0001
s.d.	0.46	0.32			
Father industrial worker ⁸					
mean	0.15	0.32	-3.35	206.5	0.001
s.d.	0.36	0.47			
Economic status ⁹					
mean	0.72	0.70	0.38	260.0	0.70
s.d.	0.48	0.46			

1. Fractional d.f. based upon unequal variance *t*-test.

2. 1 = male, 2 = female.

3. 1 = DSM-schizophrenia, 2 = not schizophrenia.

4. 0 = none, 1 = primary, 2 = secondary, 3 = post-secondary, 4 = college. Data not available for seven Vermont patients.

5. 1 = metropolitan, 2 = small urban, 3 = farm, 4 = village, 5 = isolated. Data not available for one Vermont subject.

6. 0 = no, 1 = yes.

7. Not used for matching 1-1 overlap.

8. 0 = no, 1 = yes.

9. 1 = low, 2 = middle, 3 = high. Data not available for two Vermont and one Maine subjects.

Outcome comparisons

Do-for-self

Younger and better-educated subjects, and subjects discharged earlier, did more for themselves at follow-up in both Maine and Vermont. There was no significant difference between the states in self-care, over and above these covariates ($t = -0.81$, $P = 0.421$).

Table 4
Maine and Vermont independent sample covariance analysis¹

	Outcome variables						
	Work	Do-for-self	Social functioning	Symptoms	CAS	MMSE	GAS
Adjusted comparisons 1 = VT, 2 = ME	-3.35 0.0009	-0.81 0.421	-1.43 0.153	-3.10 0.0021	-3.31 0.0011	0.89 0.37	-4.73 <0.0001
<i>Covariates</i>							
Diagnosis	-	-	2.12 0.035	-	3.12 0.002	2.21 0.028	-
Sex	-	-	2.53 0.012	-	-	-	-
Hospital stay	-	-	-	-2.45 0.015	-2.80 0.0055	4.69 <0.0001	-3.28 <0.0012
Year of birth	4.34 <0.0001	3.82 0.0002	4.44 <0.0001	-	-	-4.70 <0.0001	-1.68 0.094
Index year of discharge	-2.43 0.016	-6.58 <0.0001	-5.05 <0.0001	-5.59 <0.0001	-3.61 0.0004	-	-5.20 <0.0001
Education	2.38 0.018	2.33 0.021	2.18 0.030	-	2.12 0.035	-6.25 <0.0001	-
Urban/rural origin	-	-	-	-	-	-	-
Acute onset	-	-	-	-	-2.89 0.0041	-	-2.40 0.017
Father industrial worker	-	-	-	-	-	-	-
Economic status	-	-	-	-	-	-	-
<i>Interaction terms</i>							
State year of birth	-	-	-	-	-	-	2.35 0.020
State hospital stay	-	-	-	-	-	-	2.21 0.028
State index year of discharge	-	-	-	-	2.36 0.019	-	-
State acute onset	-	-	-	-	2.82 0.0052	-	2.35 0.020
<i>Model statistics</i>							
R ²	16.9%	23.8%	23.1%	22.2%	31.1%	37.5%	32.2%
Error d.f.	287	287	285	295	283	238	290
F	14.55	22.5	14.26	28.11	15.95	28.62	17.2
P	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001

1. Maine and Vermont combined into one sample, covariates standardised to z scores, *t* values, and probabilities. The covariates and interaction terms are listed on the left and outcome variables are listed across the top. Model statistics are presented on the bottom. Final state comparisons are displayed in the first row.

Work

Younger and better-educated subjects and subjects discharged earlier in both states were doing more work at follow-up. However, there was still a 'state' effect over and above these covariates ($t = -3.35$, $P < 0.0009$), with more Vermont subjects ($n = 79$, 47%, compared with $n = 31$, 26%, for Maine) working in some capacity at follow-up.

Social functioning

In both states, women, DSM-III non-schizophrenic subjects, younger subjects, better-educated subjects, and subjects discharged earlier received higher ratings of social functioning. There was no significant

difference in social functioning between the states over and above these covariates ($t = -1.43$, $P = 0.153$).

Symptoms

Subjects discharged earlier and those with a shorter hospital stay had fewer symptoms, regardless of state. There was still a significant difference between the states over and above these covariates, with Vermont subjects displaying fewer symptoms at follow-up ($t = -3.10$, $P < 0.002$).

MMSE

Younger, better-educated subjects, those with a shorter hospital stay, and those with a DSM-III

diagnosis of schizophrenia from both states had better cognitive functioning. There was no significant difference in cognitive functioning between the states over and above these covariates ($t=0.89$, $P=0.37$).

CAS

Better-educated subjects, non-DSM-III schizophrenic subjects, and subjects with a shorter hospital stay showed better community adjustment at follow-up. Overall, subjects discharged earlier had a better community adjustment, but this effect was stronger in Vermont than Maine (state by year of discharge interaction shows an ordinal relationship). Acute onset was associated with poorer community adjustment in Vermont and better community adjustment in Maine. There was still a significant difference in community adjustment between the states over and above these covariates ($t=-3.31$, $P<0.001$), with Vermont subjects displaying better adjustment at follow-up.

GAS

Subjects discharged earlier, regardless of state, had better global functioning. In Maine, but not in Vermont, younger subjects had better global functioning (state by year of birth and state by hospital-stay interactions). In Vermont, but not in Maine, subjects with a longer index hospital stay had worse global functioning. In Vermont, acute onset was once again associated with poorer global functioning, while in Maine, acute onset was associated with better global functioning (state by acute-onset interaction). However, there was a significant difference in global functioning between the states over and above these covariates ($t=-4.73$, $P<0.0001$). Of the Vermont subjects, 68% (114) were functioning at least 'pretty well' (GAS score >61) compared with 49% (58) for Maine.

Discussion

This study represents the first attempt to conduct a long-term outcome comparison between states using matched samples and the same protocols. Several elements of the method that are keys to interpreting any differences in outcome have been included, such as: sample definitions; operationally defined diagnostic criteria; multiple demographic, predictor, and outcome measures; blind ratings of illness and outcome factors; and reliability testing.

However, there are several caveats to consider: (a) a distinct bias toward long-stay patients; (b) reported moderate response to phenothiazines in Vermont

and undetermined response in Maine; (c) both present-state and retrospective data elements in Maine and Vermont; (d) clinical referral of known 'back-ward' patients to the rehabilitation programme in Vermont; and (e) computer matching on only a few key variables in Maine. Also, a retrospective, but necessary, modern rediagnosis for both cohorts from clinical records was conducted.

Vermont subjects functioned significantly better at follow-up across all the domains studied, except cognitive functioning, which was the same. These initial differences were modulated when differences in unmatched subject variables and the major policy difference between the states, index year of discharge, were covaried. After adjustment for these differences, Vermont subjects still displayed greater productivity, better adjustment to the community, and better global functioning.

The regression models for the adjusted comparisons show that different combinations of subject variables were linked to specific outcome domains. For example, subjects with more education had better cognitive and social functioning and better work records. Subjects with more education and less time in hospital had better community adjustment. The goal of this study was not prediction of outcome but instead control of differences in subject variables to determine the effect of the Vermont programme on outcome. However, the data support the notion that predictors of outcome vary according to the outcome domain studied (McGlashan, 1986).

The analysis examined the relationship between the original matching variables - age, sex, diagnosis, and length of hospital stay - and the outcome domains studied. Younger subjects from both states had better cognitive functioning than older subjects. Also, in Maine but not in Vermont, younger subjects had better global functioning at follow-up. However, follow-up in Maine was seven years later than in Vermont. This allowed the effects of age on functioning to become more pronounced for Maine subjects. Women had better social functioning. This relationship between sex and social outcome has been found by other investigators (e.g. McGlashan & Bardenstein, 1990). Better-educated and non-schizophrenic subjects and those with less time in hospital showed better community adjustment. Non-schizophrenic subjects in both states displayed better social functioning at follow-up. The better cognitive functioning for subjects with a DSM-III diagnosis of schizophrenia is due to the inclusion of 23 subjects in each state with an organic diagnosis among the non-DSM-III schizophrenic group. These subjects had been removed in the data analysis for Vermont (Harding *et al*, 1987a,b). Finally, subjects from

both states with less time in hospital had fewer symptoms and better community adjustment at follow-up.

Given these findings, what was the effect of the Vermont rehabilitation programme on outcome? Can the case be made that the adjusted differences were the result of Vermont's model programme, the hallmarks of which were the early opportunity to adapt to living and working in the community and the long-term continuity of care?

First, Vermont subjects had fewer symptoms than Maine subjects at follow-up. The initial impetus for Vermont's model programme was the rehabilitation of a group of 'back-ward' patients who had made only a modest response to treatment with chlorpromazine (Brooks, 1956). In fact, 178 other patients had responded to the new drug therapy and were released - leaving behind the 269 members of the Vermont cohort. Thus, the Vermont sample was selected clinically, while the Maine sample was selected by computer matching, and thus the drug-responsiveness of subjects in Maine was not known beforehand. This sampling difference may have resulted in the difference in symptoms (Vermonters subjects less ill) 30 years later. However, the Maine cohort was also selected from the bottom third (longer-stay) of the hospital population. A controlled look at the question of early drug responsiveness on long-term course and outcome is a question for future studies.

Vermont subjects had a better work outcome. The major policy difference between the states, index year of discharge, was entered by the regression analysis as an adjuster for all domains except work and cognitive functioning. Are the robust differences in work outcome the result of the Vermont programme, with its emphasis on vocational rehabilitation and the opportunity to work? Are the differences the result of the selection of already good workers for rehabilitation in Vermont (erroneously suggested and corrected by McGlashan, 1991)? Was there a difference in the work ethic between the states, or the availability of jobs and other sociocultural factors? The evidence suggests that the differences in work outcome are not due to differences in sociocultural factors or work ethic between the states. More Vermont subjects came from family farms or small towns and more Maine subjects came from small cities and had fathers who were unskilled or semiskilled industrial workers. However, there was no significant statistical difference in the percentage of the samples that were ever employed before index admission (83% for Maine and 72% for Vermont). Unskilled industrial or service work accounted for most of the jobs in both states. Further, Vermont

subjects worked more in agriculture and skilled clerical or craftsman jobs. Therefore, it does not appear that work ethic or opportunity can account for the differences in work outcome. It is possible that in Vermont patient selection was based partly on favourable industrial work in Vermont, but most literature does not support the notion that this form of work therapy has any effect on community work at follow-up (e.g. Kunce, 1970). Even if this were not the case, and although Maine subjects were not selected on the basis of hospital work performance, 82% of them were involved in hospital work, with 10% in highly skilled jobs. Perhaps the most convincing evidence against a subject-selection explanation for the observed differences in work outcome is that the difference is mainly the result of a difference in volunteer work and not paid work. The Vermont programme specifically targeted boarding home residents for volunteer work. This suggests that there may have been a greater effect of the programme on more poorly functioning patients.

To summarise, the results suggest that differences in outcome between the states were the result of several factors. However, even after covariance adjustments, Vermont subjects were more productive, had fewer symptoms, and displayed better overall functioning and community adjustment. While it is always possible that other, unknown differences contributed to the differences in outcome, it can be argued that the differences in outcome are likely to be attributable to the Vermont programme, since it provided an opportunity for community adaptation in the context of an array of residential, work, and social opportunities which were all managed to ensure continuity. The analysis of differences in the long-term course trajectories discussed in part II adds further support for this conclusion.

Appendix

Listing of outcome scale variables

Do-for-self. Get around on own; buy own groceries; cook for self; do own laundry; shop for clothes; housekeeping; manage own money; independence. Alpha = 0.89 for Maine and 0.85 for Vermont.

Work. Volunteer work; hours per week volunteer; hours per week for pay; employment status in past month; quantity of useful work in past year. Alpha = 0.84 for Maine and 0.74 for Vermont.

Social functioning. Interdependence in relationships; degree of social activity; quality of companionship; relations with children; relations with relatives; relations with friends; number of social relations; fullness of life. Alpha = 0.85 for Maine and 0.89 for Vermont.

Symptoms. Emotional withdrawal; conceptual disorganisation, guilt feelings; mannerisms/posturing;

grandiosity; depressed mood; hostility; hallucinatory behaviour; unusual thought content; blunted affect; disorientation; auditory hallucinations; rating of degree of psychopathology; valid/verifiable hallucinations or delusions; absence of symptoms in past month. Alpha = 0.76 for Maine and 0.81 for Vermont.

The Maine and Vermont Three-Decade Studies of Serious Mental Illness

II. Longitudinal Course Comparisons

MICHAEL DESISTO, COURTENAY M. HARDING, RODNEY V. McCORMICK,
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Background. This paper supplements the cross-sectional outcome comparisons of the companion paper by providing a brief account of the longitudinal courses of the Maine and Vermont samples across several outcome domains.

Method. A Life Chart method was used to document changes in individual lives over the domains of residence, work, income source, and use of community resources over a 20-year period. Reliability studies between states were conducted.

Results. Throughout much of the period, more Vermont subjects lived independently, were working, and were less likely to use community resources compared to Maine subjects.

Conclusions. Differences in both policies and programmes contributed to course differences between the groups. System characteristics that may lead to better outcomes are discussed.

The companion paper has demonstrated major outcome differences between the Maine and Vermont groups. This paper fills out these statistical outcome differences by providing a more detailed descriptive comparison of the longitudinal courses of the two samples across several outcome domains.

The evolution of developments in each state are also documented to account for policy and programme events extraneous to the rehabilitation programme (DeSisto *et al.*, 1991). These events are then overlaid with the longitudinal course data for both groups to study the interplay between the natural history of individuals and the systems of care.

Methods and procedures

A modified version of the Meyer-Leighton Life Chart (Leighton & Leighton, 1949; Meyer, 1951) was used to document retrospectively the yearly course of several life domains for each subject. The entire instrument battery has been described previously (Harding *et al.*, 1987a). The Life Chart (Harding *et al.*, 1981) documented cohort statuses over a 32-year period in Vermont and a 36-year period in Maine. Outcome domains included work; source of income; residence; hospitalisations; medication; and community resources used. Life-event domains included: presence of significant others; deaths;

health; relationships; legal entanglements; finances; and changes in family structure.

A trained clinician interviewer and the subject worked together over a 75 to 90 min period to complete the Life Chart and other elements of the longitudinal questionnaire. A specific set of probes was asked for each year beginning with the most recent year and working back to earlier years. All data were verified by informants who knew the subject well. For deceased subjects, the Life Chart was completed with family members and significant others. Most subjects and families gave good accounts of their histories, a phenomenon noted earlier by others (Bleuler, 1978; Harding, 1986).

Inter-rater reliability trials resulted in an overall agreement (kappa; Fleiss, 1973) between Maine clinicians of 0.75 ($n=48$ cases), between Vermont clinicians of 0.79 ($n=36$ cases), and 0.65 ($n=20$) between Maine and Vermont clinicians.

Data reduction of the Life Chart was conducted as follows:

Residence. Residence categories included: hospital; independent living; rehabilitation or halfway house; and boarding or nursing home. The percentage of any year that a person resided in a category was coded. For example, if in a particular year a subject spent 4 months in the hospital and 8 months living

independently, then 'hospital' would be coded as 33% and 'independent living' as 67%.

Work. The work domain had three categories: full-time (30 hours or more with pay); part-time or unpaid (combining housewife, volunteer, part-time, and volunteer full-time); and unemployed. For a particular year, a subject was classified into one of these categories if it represented their status for more than six months.

Community resources. Scores reflected receipt of services from any of the following: community mental health centre; vocational rehabilitation (VR); private practitioner.

The status of the Maine and Vermont groups for each outcome domain was compared by determining the percentage of subjects that were in a particular status for each year from 1960 to 1980. A Bonferroni adjusted chi-square comparison of proportions using an $\alpha = 0.0024$ was performed to achieve a nominal 0.05 alpha overall for the 21 year period.

A similar format was used to document the year-by-year developments in mental health policies and programmes for each state. The domains included: policy and legal changes; hospital programmes; community residential programmes; vocational programmes; mental health centres; and entitlements. Information about changes in these domains was obtained from a review of state laws, hospital annual reports, published hospital and programme histories, and personal interviews with period policy makers and division heads.

Results

Table 1 briefly summarises domain and period-specific differences between the Maine and Vermont subjects.

Due to mortality, the total number of Life Charts available from 1960 to 1980 for Maine and Vermont ranged from 224 to 143, and 243 to 173, respectively.

Residence. Maine subjects spent significantly more time (50% v. 13%) in the hospital from 1960 through 1975 compared to Vermont subjects. The Vermont residential experience consisted predominantly of more independent living between 1960 and 1971, more residence in halfway houses between 1960 and 1963, and more use of boarding homes from 1963 to 1971.

Work and income source. A significantly greater percentage of Vermont subjects were employed full-time between 1960 and 1975 (30.9% v. 12.7%). In

Table 1
Life chart course comparisons summary

Domain	Years ¹	Maine (%) ²	Vermont (%) ²
Residence			
Hospital	60-75	50.0	13.0
Independent	60-71	25.6	46.4
Halfway house	60-63	0.3	6.2
Boarding home	63-71	3.9	14.4
Work			
Full-time	60-75	12.7	30.9
Part-time	60	1.8	7.9
Unemployed	74, 75, 77-79	60.2	41.3
Community resources used			
None	60-78	12.9	43.3
VR	60-70	0.0	16.9
CMHC	62, 64-69	11.0	2.7

1. Years for which significant differences between Maine and Vermont were observed.

2. Average percentage for years where significant differences were observed.

VR = vocational rehabilitation; CMHC = community mental health centre.

contrast, more Maine subjects were unemployed from 1974 to 1975, and 1977 through 1979 (60.2% v. 41.3%). Naturally, the proportion of individuals described as unemployed would tend to increase over time as individuals age.

Community resources. On average, throughout most of the period from 1960 to 1978, Vermont subjects were not making use of community programmes at the same level as Maine subjects (43.3% v. 12.9%). However, more Vermonters were enrolled in VR between 1960 and 1970. This can be contrasted to the higher percentage of Mainers enrolled in community mental health centre programmes in 1962 and between 1964 and 1969.

Discussion

The longitudinal course comparisons demonstrate clearly that the Vermont programme had a significant impact on the course for Vermont subjects compared to that of Maine subjects. Perhaps the most important aspect of the programme was that it gave Vermont patients an earlier opportunity to adapt to life in the community. This opportunity, when combined with an array of residential, work, and social opportunities, resulted in a more diverse and favourable course compared to the Maine group across the domains studied.

Early differences in residential status can be attributed directly to the policy and programme

differences between the states. The Vermont rehabilitation programme, which began in 1955, had both a rehabilitation goal and a depopulation goal. Therefore, alternative residences such as independent living, boarding homes, and halfway houses were needed and developed much earlier in Vermont. Depopulation was not pursued in Maine until 1971, and alternative residences were not available or used until this time. Therefore, Maine subjects spent more time in hospital between 1960 and 1975, while Vermont subjects spent more time in independent residences between 1960 and 1971, in boarding homes between 1963 and 1971, and in halfway houses between 1960 and 1963. Once Maine pursued a policy of depopulation, these differences in residential status disappear.

Over the entire period, the percentage of Vermonters engaged in some form of employment, either full-time or part-time paid work or volunteer work, ranged between 35 and 60%. For full-time work alone, the range was 25 to 30%. For Maine subjects, the range for some kind of employment was 12 to 30%, and for full-time work, 10 to 12%. While not directly comparable, employment rates from short-term cross-sectional studies have ranged from 20 to 30% for full-time employment one year post-discharge (Anthony *et al*, 1972). The Vermont rehabilitation programme was an eclectic programme that integrated the knowledge from social psychiatry, including principles of milieu therapy, therapeutic community, and interpersonal psychiatry, with the use of medicine and vocational rehabilitation (Chittick *et al*, 1961). The programme created a comprehensive system of care prior to the development of community mental health centres and community support systems (Morrissey & Goldman, 1984; DeSisto *et al*, 1991).

The relationship with vocational rehabilitation was abandoned in 1970 when Vermont pursued a policy of regionalisation which made mental health centres the primary referral and aftercare agents. This paradigm shift (Kuhn, 1962) from a rehabilitation programme which emphasised work and self-sufficiency, to a treatment programme which emphasised cure of illness through treatment by mental health centres, resulted in some loss of continuity and comprehensiveness.

The Vermont legacy is not to be found, as Bachrach (1989) has suggested, in the details of the programme or the methods used. Instead, its legacy is the values and principles which guided it. Perhaps the most important value was that the programme had a pervasive attitude of hope and optimism about human potential, through the vision that, if given the opportunity, persons with mental illness could

become self-sufficient. Anecdotal literature and personal accounts in both the medical and psychiatric fields support the notion that hope is an important factor in recovery (Deane & Brooks, 1963; Cousins, 1979; Lovejoy, 1984). With this hope and optimism, however, there were realistic expectations that not everyone would proceed at the same pace. There was the assumption that people were unique, and that the dignity and integrity of the person must be respected. This respect was honoured by asking sufferers about what they wanted, how things were going, whether the programme was meeting their needs, and by involving them in programme planning. Thus, collaboration was the hallmark of the programme. In addition, services had to be comprehensive, deal with all aspects of life, be flexible because needs and situations changed over time, and have long-term continuity. Finally, there was a concern about what happened to people over the long-term and a recognition of the need to keep in touch in order to find out.

Both the Maine and Vermont cohorts became ill during a period when law and society allowed long periods of hospitalisation. They were hospitalised prior to the availability of modern pharmacological treatment and changes in family structure and demography that have occurred over the past 30 years. Nonetheless, the individual Life Charts and course trajectories for both groups confirm the heterogeneity of the long-term course of serious mental illness (Ciompi & Müller, 1976; Bleuler, 1978; Harding *et al*, 1987*a,b*; Harding, 1988; Harding *et al*, 1989). In addition, the accumulated domain-specific courses in this report have demonstrated that the natural history of individuals and policy and programme events affect the course of specific outcome domains.

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AN EXAMINATION OF THE COMPLEXITIES IN THE MEASUREMENT OF RECOVERY IN SEVERE PSYCHIATRIC DISORDERS

Courtenay M. Harding

Results from five recent investigations studying the very long-term "outcome" of schizophrenia (in Switzerland, Germany, and the United States) indicate that no matter how chronic the cohorts were, approximately 25% of the subjects achieved recovery at follow-up, with an additional 25 - 40% improved, with achievement of wide heterogeneity as the rule rather than the exception (Bleuler, 1972; Ciompi and Moller, 1976; Harding et al., 1987b, Huber et al., 1979; Tsuang et al., 1979). In fact, these studies and other shorter ones (Bland and Orn, 1980; Gardos et al., 1982; Hawk et al., 1975, Strauss and Carpenter, 1974; Strauss et al., 1978; WHO, 1979) have shown that the course of severe psychiatric disorder is a complex, dynamic, and heterogeneous process, which is non-linear in its patterns moving toward significant improvement over time and helped along by an active, developing person in interaction with his or her environment (Harding and Strauss, 1985).

Our new appreciation about this process evokes many questions. For instance, just what is meant by the use of the word "recovery"? Is the subject simply no longer symptomatic? Is she or he considered to be "recovered" or just "in remission"? Has the person re-found (or recovered) all his or her initial levels of functioning which were lost during a psychotic episode or do we mean that he or she is functioning more soundly and stronger than ever before? Against which

baseline do we make such judgments? Is a new episode after "recovery" considered to be a new illness? What do we mean when we discuss "outcome"?

After the completion of two three-decade studies of the long-distance course of schizophrenia, the author examines some of these questions which arise in the measurement of recovery from severe psychiatric disorder. She suggests that constructs such as "outcome" and "end state" often lead to inaccurate conclusions about disorders. In contrast to cross-sectional measures, longitudinal assessments are portrayed as essential to an accurate understanding of prolonged illness.

To cope with these challenges, puzzled investigators have employed four primary strategies to determine the amount of recovery and improvement. The strategies comprise the following: (1) measurement against each subject's own baseline, (2) employment of grouped means, (3) comparison across studies, and (4) assessment against a construct of "normal" behavior. This chapter will discuss these strategies and present additional suggestions proposed by the Vermont and Maine Longitudinal Research Project teams as we attempted to undertake this prodigious task ourselves. We have organized our thinking along five major themes and propose that: (1) the concept of outcome is a research artifact, (2) "two cross-sectionals do not a longitudinal make", (3) global measures of psychopathology and recovery are not sufficient, (4) double standards are often employed in assessments, and (5) a rater's epistemological framework about illness, recovery, and human beings plays an important role in measurement in that "what you are trained to ask about and observe, strongly determines what you ask about and observe". The author concludes with the suggestion that these factors do indeed color the judgment of which patients are considered to be recovered and which are not.

AN OVERVIEW OF THE VERMONT AND MAINE LONGITUDINAL STUDIES OF SEVERE PSYCHIATRIC DISORDER

In the Vermont Project, 269 Vermont State Hospital patients with severe and persistent psychiatric disorders (especially with schizophrenia) were originally selected for very chronic disability, rehabilitated in a model demonstration program, and released to the community in the mid-1950s (Chittick et al., 1961). At the time of entry into this project in the 1950's, these subjects had an average of six years of continuous psychiatric hospitalization and sixteen years of disability. A five to ten-year follow-up study in the 1960s revealed that two thirds of the subjects were in the community maintained by considerable investment of time, money, and effort (Deane and Brooks, 1967).

Twenty to twenty-five years after their entry into this program, 97% of this group were located and assessed. The catamnestic period averaged 32 years. Two field interviews were conducted by raters blind to record information. The first interview provided a multivariate cross-sectional assessment of outcome. The second interview included a Meyerian/Leighton Life Chart (Leighton and Leighton, 1949; Meyer, 1919) and contributed a longitudinal documentation of patterns, shifts, and trends in the course of life for members of the cohort. These patterns were derived from a multidimensional year-by-year documentation of the 20 to 25-year period. Close relatives and others, who knew the subjects well, were interviewed to verify current status and historical data for both the live and deceased subjects. New and traditional scales were used to provide structured measures of outcome. Hospital and Vocational Rehabilitation records were independently reviewed with the Hospital Record Review Form battery (HRRF), compiled from a modification of WHO's Psychiatric and Personal History form (WHO, 1979) and Strauss's Case Record Rating Scale (Strauss and Harder, 1981). The record raters were blind to outcome and field data. All batteries were subjected to inter-rater trials and inter-item concordance testing (Harding et al., 1987a; 1987b).

In order to make our subjects comparable to today's patients we then, applied the DSM-III criteria (APA, 1980) to their index status with records that were stripped of all previous diagnostic assignments (Harding et al., 1987b). John Strauss at Yale and Alan Breier at NIMH completed the rediagnostic work after two sets of inter-rater trials. Analysis of the long-term outcome for those subjects, who once qualified for DSM-III schizophrenia, revealed wide heterogeneity. For one-half to two-thirds of the group, course was neither downward nor marginal. This finding was remarkable because these patients represented those in the "bottom third" of the schizophrenia spectrum and the back wards in the hospital. Most people resided in the community, were able to care for themselves, had become actively involved with family and friends, and made productive contributions to their families and communities with little or no residual display of symptomatology (Harding et al., 1987b). These findings mirrored those derived for the full cohort, which included patients with a wide variety of other DSM-III diagnoses (Harding et al., 1987a). Thus, the more stringent criteria of DSM-III were not associated with uniformly poor outcome as expected (APA, 1980). The definition of recovery included the following factors measured at follow-up: no signs or symptoms of psychiatric disorder, no psychotropic medications, working or retired appropriately after a work history (especially important because the average age at follow-up was 61 ranging up to 79 years of age), maintaining mutually satisfying interdependent relationships, the absence of behavioral or contextual indicators that they were former mental

patients, and integration into the community as full-fledged citizens. We agreed with Vaillant's conclusion after his ten-year study, that "diagnosis and prognosis should be treated as two different dimensions of psychosis" (Vaillant, 1975).

The Vermonters received a ten-year pioneering and comprehensive psychosocial and vocational rehabilitation program. We were unable to determine if the program had made an impact upon the outcome findings because all the patients, who were in the back wards of the state's only state hospital, were selected with the exception of those on legal mandates, developmental disabilities, or over 62 years of age. However, Augusta State Hospital in Maine was another New England hospital with a similar catchment area and hospital which did not give a rehabilitation program to its patients. We achieved a comparison sample, person by person computer-matched to the Vermont cohort members on age, sex, diagnosis, and length of hospitalization during the window of 1956-61. The Maine cohort was then followed with the same protocol, the same diagnostic criteria, and instrument batteries with both intra- and inter-project reliabilities established as well as blindness in the data collection. Ninety-four per cent of the Mainers were assessed at an average of 36 catamnestic years. This event was the first time in longitudinal research that two such long-term studies had matched samples, protocols, diagnostic criteria, and historical periods (DeSisto et al., submitted, a).

The Mainers did significantly less well than did the Vermonters both in the quantity and quality of recovery, especially in areas of work, symptoms, global outcome (even covarying out other significant modifiers (e.g. acute onset, education, urban/rural settings). Longitudinal year by year patterns also showed more positive and independent trajectories for Vermonters. We concluded that rehabilitation and the opportunity to be out of the hospital joined with biological correction mechanisms to potentiate a return to the highest level of function possible for each person (DeSisto et al., submitted, b).

THE MEASUREMENT OF RECOVERY

Outcome is a Research Artifact

The Vermont and Maine Projects are considered to be studies about the long-term outcome of schizophrenia. They represent some of the longest studies in the world literature, with catamnestic of 22 to 62 years after first admission as well as projects with the most stringent methodology. Other studies have looked at 5, 10, 20, and 25 years post admission and each of those projects is also called an outcome study. I propose that each one of those studies is a research artifact;

that one investigator's "outcome" level is another investigator's "course". For example, those projects which have completed a 10-year follow-up consider a 5-year marker as part of the course; a 20-year follow-up considers both the 10-year and the 5-year points in time as part of the course of the 20 years (Harding and Strauss, 1985). The Vermont marker at 62 years has been superseded by Luc Ciompi's study at 64 years (Ciompi, 1980), ad infinitum, to its own logical conclusion. Therefore, we suggest that instead of assessing outcome we are actually studying markers in the course of life (Harding and Strauss, 1985) in which illness is only a part.

The largest misnomer to date is the so-called "end state", used by Manfred Bleuler (1978) and other Europeans to describe plateau states of five years in which subjects have achieved a certain level of recovery and a stabilized period. Use of the words "end state" gives the incorrect impression that a person will stay at that state and that it is the final state. In fact, Bleuler (1978) did not intend to imply such a finality (pp. 190 - 192). Bleuler, himself, said that there were sometimes late improvements after as many as 30 to 40 years of illness (Bleuler, 1978, pp. 228 - 233). In reality, the words usually denote an end state for the research project itself. Although an investigator's device, the phenomenon might be re-labeled and described from a different vantage point. The knowledge of plateaus and late improvements might be valuable contributions to the biopsychosocial understanding of the course of schizophrenia and should have a new name.

"Two Cross-Sectionals Do Not a Longitudinal Make"

Many investigations start by achieving a baseline measurement on all subjects, and then a number of years later secure another cross-sectional measurement at that point in time - or vice versa. These studies have been labeled longitudinal, and we have suggested that "two cross-sectionals do not a longitudinal make" (Harding and Strauss, 1985, p. 3421). By way of analogy, a cross-sectional could be likened to a black-and-white portrait. The observer can tell gender, approximate age, something about the surrounding background, but is unable to determine whether the wrinkles around the forehead and the eyes come from a lot of laughter or many frowns. Raters are unable to tell whether that background is a usual one or not; nor are they able to tell how the subject got to that spot where he or she is today. In the cross-sectional part of the interviews with both the Vermont and Maine cohorts, we were aware of the fact that the month we happened to interview people was purely arbitrary. We knew that we had found some people who were having a good month when they ordinarily did not, but we realized that the opposite was also true, and hoped they balanced out.

However, a longitudinal can be a follow-along or a follow-back through a block of time year after year with many measures across many domains. Because human life is very difficult to capture in all its dynamic ebbs and flows, and since it is a longitudinal process, a year-by-year accounting comes much closer to reality. Continuing the earlier analogy, this strategy would be more akin to watching a theater-in-the-round in which one can gain perspective from looking at the same person from different angles over time with characters interacting and changing. Given this distinct bias, I would venture an opinion that few judgments can be made about degrees of recovery or lack of it unless there is a longitudinal documentation of course.

Ways to Assess a Heterogeneous Process

Early investigators, such as E. Bleuler (1950), Holt and Holt (1952), Stephens (1970) and others, used global and often undefined terms of "recovered or "not recovered". Other researchers divided recovery into symptom recovery and social recovery, quite often loosely defined but at least a step in the right direction (e.g., Harris et al., 1956; Holmbe and Astrup, 1957; Lo and Lo, 1977; Rennie, 1939). The question remains, "How do we define and measure recovery?"

The Vermont and Maine Projects chose to triangulate data by using measures of functioning, such as the Global Assessment Scale (GAS) by Endicott et al. (1976); Levels of Function Scale (LOF), by Strauss and Carpenter (LOF) by Hawk, Carpenter and Strauss, (1975); the Brief Psychiatric Rating Scale (BPRS) by Overall and Gorham (1962), as well as 12 other classic scales rating twenty-one domains (Harding et al., 1987a). From the cumulative data acquired over three hours of field interviews with the probands themselves, we subsequently also rated them for adjustment - another guise for "recovery". The Community Adjustment Scale (CAS) was designed by Consalvo et al. (1981) to measure adjustment based on scores for productivity, intimacy, and behavior (see Figure 1 below).

The findings from this scale were significantly related to those generated by the GAS and Level of Function Scale in a chi-square analysis ($p = <.001$ [CAS vs. GAS] and $p = <.004$ [CAS vs. LOF]). A little over one quarter (29%) of the Vermont cohort were rated as functioning well across all domains. Recovery is not difficult to determine or defend with that group. A group of about 36% of the Vermonters, whose functioning across all domains was very poor, also was not difficult to define as "not recovered".

However, there were 35% in Vermont who were in between those two extremes. They presented serious problems for the rater. There were people who still had positive signs of schizophrenia (e.g., hallucinations, and/or delusions) but who were quite functional people. They retained mild impairment, but no disability. They worked, had families, friends, were generally satisfied with life, and had

Figure 1. Community Adjustment Scale (CAS)* (Consalvo et al., 1981)

1. Criteria

1. Degree of productivity based on work (housework, volunteer, avocation), or retired and functioning at a level appropriate to age and health. Rate on a one to five scale.
2. Degree of intimacy achieved, based on the nature of interpersonal relationships (e.g., marriage, friendship, kinship), and the possession of interpersonal skills. Rate on a one to five scale.
3. The relative absence of behavioral (e.g., bizarre speech, actions, appearance), or contextual (e.g., living in a boarding home), indications that they are former mental patients. Rate on a one to five scale.

2. Ratings for overall adjustment Use total points from above three criteria.

1. Well adjusted. Individuals in this group exhibit a moderate to high level of adjustment in all three areas and would be described as without any indications of being a former mental patient. Total range 12- 15 points.
2. Well adjusted but... Individuals in this group ordinarily have a moderate to high level of adjustment in all areas but one, or a marginally moderate level of adjustment in at least two of the three criteria categories. Such individuals would give no clear indication that they were ever former mental patients but their overall level of adjustment would not rule out that possibility. Total range 8- 11 points.
3. Maladjusted. These individuals display poor adjustment in at least two criteria areas and could at least be viewed as probable former mental patients. Total point range 3- 7 points.

* It should be noted that this scale was completed after a comprehensive structured interview across 21 areas of functioning and psychological status.

learned to control their symptoms. Would they be labeled recovered? We said they are significantly improved and rated them 'Well, but...' There was another group which was quite sociable, maintained supportive interpersonal relationships, had hobbies, and was quite happy, but did not work. They told us of the disincentives in the entitlement systems and its environmental impact on

their lives. Another group worked well, but was composed of self-described "loners" with no family and no friends with whom to interact. Is this group improved? Many raters would hastily say "No, not even improved." Let us suppose that some of those so-called loners have always been loners and preferred their own company to others? Was their behavior prodromal and now considered to be residual? Or, are there not substantial numbers of people, both outside of or working for the mental health system who live alone. They are quite happily functioning at work and caring for themselves and who do not maintain relationships? Are we not asserting our own conceptions about "normal" behavior?

STRATEGIES TO DETERMINE CURRENT STATUS

Strategy #1: Assessment of Abnormality Against Societal Norms

What then is the range of normal human functioning? Hogarty and Katz (1971) produced some work in the early 1970s assessing 450 non-patients in one Maryland county to acquire norms for their instruments. They discovered that patterns of behavior for age, marital status, social class, and gender must be taken into consideration when making judgments (e.g., normal adolescents were reported to show negativism, general psychopathology, and less stability). They asked: "Is it valid to point in absoluteness to the belligerence, negativism, and poor performance of juvenile offenders and otherwise 'disturbed adolescents' when corresponding norms of age-related behavior are so characterized?" (Hogarty and Katz, 1971, p.479). It is a very important question.

As another example, the difference in gender functioning has only recently become appreciated. Holstein and Harding (1992) have assessed the data for women only from the Yale Longitudinal Study in which we were following people intensively for the first two years after episode (Strauss et al., 1985). We found that those women who were rated as more symptomatic were often those who carried dual work roles and were quite functional in caring for home and family, as well as working. These dual roles, their stressors, and the level of function required, were complexities not accounted for in the primary analysis. We found that, while women's experience is now perceived as different from men's, this phenomenon is rarely investigated systematically or written into research protocols (Holstein and Harding, 1992). Some exceptions to the rule are the investigations by M. Bleuler (1978), Gilligan (1982), Seeman (1985), and Test and Berlin (1983).

Strategy #2: Comparison Across Similar Studies

The five studies cited earlier in the chapter possess the same goals but use different diagnostic systems for determining schizophrenia, varying lengths of follow-up and methodology, among other factors, which make comparison between them difficult. They give a strong indication of the trend toward recovery only when all five are clumped together because, despite their differences, the similarity of their findings is remarkable (see Table 1). One-half to two-thirds of nearly 1200 patients followed over two to three decades significantly improved or recovered. The reason that the Vermont/Maine comparison is so important is the fact that these are the only two studies in the very long-term literature of schizophrenia and other serious mental illness which were matched in sample, catchment area, treatment eras, diagnostic criteria, design, and methodology (DeSisto et al., submitted, a, submitted, b).

Table 1. Five Recent Long-Term Studies of Schizophrenia

Investigators	Sample size	Average length In years	% Subjects recovered and/or improved significantly
M. Bleuler (1972), Burghölzli - Zurich	208	23	(53 - 66)
Huber et al. (1979), Bonn Studies	502	22	57
Ciampi and Müller (1976), Lausanne investigations	289	37	53
Tsuang et al. (1979), Iowa 500	189	35	46
Harding et al. (1987), Vermont	118	32	62 - 68

Strategy #3: Subgroup Analysis Within the Same Study

A third technique has been to clump life course markers as grouped means within certain subgroup categories (e.g., type of onset, severity, degree of chronicity, diagnosis, age of onset, demographics, etc.). We discovered that with a seemingly simple sub-grouping such as dividing the cohort into age brackets and correlating these groups with outcome measures, we found no significant relationships. The between-subject heterogeneity in other time-related variables (such as age at admission and duration of time since first admission) washed out

the effects of presumed homogeneous subgroupings (Harding et al., 1987c). As an experiment, we then chose every subject with a 42-year course. Wide heterogeneity appeared. The age range for those subjects went from 57 to 84. When we subtracted the 42 years course from each person's age, we ranged from age 15 to age 42 as their ages at first admission. These differences should reflect diverse prognostic indicators. This problem of heterogeneity underlying key measures points to the need for an analysis in which the association of age with outcome is assessed by partialing out the effects of age at first admission and thus length of course (Harding, et al., 1987c). In pursuing this strategy, we discovered that the oldest subjects who had the shortest course (20 - 29 years) achieved the best Global Assessment Scale (Endicott, et al, 1986) scores at outcome. In addition to the importance of these methodologic questions for interpreting results, it should be pointed out that the relevant developmental issues confronting people at various ages of onset have not begun even to be characterized (Harding et al. 1987c). We have wondered if we finally achieve some sense of true homogeneous subgroups, whether our cell sizes will become too small to provide meaningful analyses at all?

Strategy #4: The Individual as His or her Own Control

Should a person be measured against his own baseline? Such a strategy might be a good idea, but engenders the following problems. First, the investigators should know the subjects across the period under scrutiny. In the Vermont Project, we were fortunate that the five clinicians of the original project team were able to maintain contact across 32 years with many members of the cohort and are in a good position to say, for example, that: "Barbara has come a long way. She was once withdrawn and apathetic and now, after several years of improvements and regressions, she consistently goes out once a week in the company of friends through her own initiative." M. Bleuler (1978) is also in a position to make such judgments.

In addition, we came to appreciate that a person's baseline keeps changing as he or she proceeds through developmental tasks. Looking for a return to premorbid status may not be as valid an indicator of recovery as we think it is. Who wants to be judged by their 18-year-old status when they are emerging from an illness at age 35? Further, adult development appears to proceed across domains of function in a fashion close to Piaget's notion of "horizontal decalage" (see Ginsberg and Opper, 1979). (We have re-interpreted his term to describe such natural adult behaviors as the use of *dialectical thinking* in a discussion on ethics; *formal operations* when dealing with the bank; *concreteness* when cooking lunch; and being *pre-operational* when dealing with statistics [all in the same hour]. Are not the varying degrees of functioning within the same person further

evidence for Strauss and Carpenter's idea of open-linked systems (Strauss and Carpenter, 1974)? Therefore, given all the underlying complexities, if we measure people against their own baselines, we would probably have 269 single case studies and lose our funding.

THE EFFECT OF THE RATER'S EPISTEMOLOGY

Underlying all efforts is the pervasive problem of recovery measured against the theoretical constructs evolved by the current state of the art and individually interpreted by the investigator. The epistemological framework would define whether recovery meant cured, in remission, or a retreat to underlying vulnerability (such as suggested by Zubin and Spring, 1977). To be cured would mean that a new episode would be considered a new illness. Some cultures believe in this idea very strongly, even about schizophrenia. For example, Waxler (1979) described the Sri Lankan viewpoint as a contributor to a better recovery rate due to the resulting higher expectation of functioning and the lightening of the psychological burden of on-going illness from the patient and his family.

We note that being "in remission" carries with it a heavy impending time bomb effect. Robert Cancro (1982) once commented that women are not considered to be latently pregnant. Further, he suggested that theoretical frameworks made you decide whether a Kansan who moved to Missouri could now be considered a Missourian, or if the person was *born* in Kansas, was he or she a Kansan no matter where he or she went or how long he or she lived elsewhere? Although Cancro was referring to the genetics of schizophrenia, we might refocus the discussion and pose the question, "How long is remission before recovery can be claimed?"

We suggest replacing the outlook, which views a person as having a lifetime of illness with intervals of remission included, with the view of a person with a life course of work and relationships, developmental lags and spurts with episodes of illness included. When considering a subject as having a "life", we then must focus on the person behind the disorder (Bleuler, 1978) and not on the illness itself. Paul Lieberman (1984) at Dartmouth has suggested. The same patient is never the same person at each admission". There seems to be a person x illness x environment interaction which continues to reshape the on-going process (Harding and Strauss, 1985; Strauss, et al. 1985).

DOUBLE STANDARDS IN JUDGING RECOVERY

Participation in case conferences and review of instrument batteries has led us to wonder if we, as clinicians and investigators, tend to have a double set of standards in judging how well someone is functioning? We all seem to have a certain but nebulous sense of what is "normal". I wonder if our standard for patients is not "super normal" (e.g., as in Maslow's (1954) self-actualized persons, few and famous? For example, the top rating for the Global Assessment Scale (91-100) uses the following criteria: "No symptoms, superior functioning in a wide range of activities, life's problems never seem to get out of hand, and is sought out by others because of his warmth and integrity" (Endicott et al., 1976).

Quite possibly we secretly harbor the idea that maybe everyone else we know is happier, handles things better, does not worry about the mortgage coming due, spreading waistlines, gray hair, or falling on one's face during an important presentation. When we do discover that other people worry too, get depressed, stumble and fall, only to laugh again, it is a celebration and quite often the glue that binds a friendship. For ourselves and our friends we may tend to accept the sets of idiosyncrasies and horizontal decalage because we know where we have come from and the direction in which we are going with a thorough-going appreciation of underlying continuities. Do these understandings permeate clinicians' judgments and investigators' ratings often, or do patients have to perform twice as well to be considered half as good?

SUMMARY

In summary, this chapter examined some of the complexities surrounding the measurement of recovery from severe psychiatric disorder. Investigators must be careful in employing the words "outcome" or "end state" because they end up being interpreted by clinicians and clients alike as a real phenomenon. It has been suggested that we substitute outcome with the phrase "markers of course" or simply "at this point in the life course." Longitudinal documentation comes closer to recapturing course of life than do two cross-sectional assessments.

Questions about the measurement and meaning of recovery can best be answered by assessment of multiple domains across long periods of time. The problems in declaring recovery begin with the realization that human beings develop differentially across domains of functioning and across time. Four strategies for assessment have been discussed: 1) a person might be measured against his or her own baseline; 2) the employment of grouped means within sub-samples; 3) the possibility of comparison of groups across studies; and 4) measurement

against some construct of normal behavior or outcome. The advantages and disadvantages of each approach were presented.

A philosophical look at the impact of epistemology upon one's view of recovery as cure, remission, or underlying vulnerability was discussed as well as a postulated double standard employed by clinicians for rating recovery in patients versus rating functioning in friends. We joke about the fact that no one we know as colleagues, including ourselves, could meet the GAS score of 91 to 100, yet we persisted in using this scale and others as earnest assessments of subjects. It should be noted that the Global Assessment of Functioning (GAF) which recently replaced the GAS has dropped the 91-100 rating (APA, 1987, pp 12 and 20).

In conclusion, I would venture to say that to designate someone as recovered from severe psychiatric disorder is a judgment call as challenging as the decision made about when to call behavior an illness. It is trying to pin down a constantly moving target. In addition, the process encompasses cultural expectations, the state of the art, and the personality of the investigator, all of which influence the theoretical framework in which he or she constructs and selects the questions for the assessment, the manner in which they are asked, and how the data are analyzed.

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Changes in Schizophrenia Across Time

Paradoxes, Patterns, and Predictors

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There exist two polar, yet accurate, views about the outcome of schizophrenia. Huber et al. (1979), after studying the outcome of schizophrenia in 502 patients for more than two decades, wrote: "Schizophrenia does not seem to be a disease of slow progressive deterioration. Even in the second and third decades of illness, there is still a potential for full or partial recovery" (p. 595). Nine other such studies agree. Yet today, we have dayrooms, shelters, and public mental health caseloads consistently overcrowded with persons chronically languishing with the diagnosis of schizophrenia. Furthermore, DSM-IV (American Psychiatric Association 1994) indicates that complete remission is likely uncommon, and they go on to describe a variable course of exacerbations and remissions for some patients and a chronic one for most persons. Although this is an improvement from earlier, more

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dire, predictions of a deteriorating course for all patients (e.g., American Psychiatric Association 1980, 1987; Kraepelin 1902), a significant discrepancy remains between the prognostic expectations of official psychiatry and the findings of 10 long-term studies completed during the last three decades of the twentieth century. Arguments against this paradox have often centered around the use of other diagnostic systems in these studies, although most are similar to the DSM-IV. This chapter shows that regardless how wide or narrow such systems are, patients still persist in improving across time and thus have much to teach us.

Some of the 10 catamnestic (or longitudinal follow-up) studies of schizophrenia analyzed particular areas of functioning, whereas others did not. Some of these reports were published in the authors' native languages and were only translated roughly by the author and colleagues. The end of the chapter will target a few implications for treatment and research. Other key factors that shape the long-term course of schizophrenia (but are not yet mentioned in DSM-IV) are discussed in more detail by other chapter authors. Other key factors that also shape the long-term course of schizophrenia (and that are not yet mentioned in the official diagnostic manual) are discussed in more detail by other chapter authors. These modifiers include 1) the neural plasticity and recalibration of the aging brain, 2) gender differences and the effects of hormones, 3) cognitive decline in the face of a nonstimulating environments, 4) medical comorbidities, and 5) misdiagnosis and other iatrogenic effects of treatment. Such crucial ingredients, which help or hinder forward progress in persons with schizophrenia, contribute further pieces of the puzzle inherent in the paradox.

Brief Overview of 10 Contemporary Follow-Up Studies of Two to Three Decades in Length

The common practice in psychiatric research is to follow samples of convenience for only those subjects who remain in treatment. However, the following longitudinal studies investigating schizophrenia and other serious mental illnesses followed intact cohorts across a period of two to three decades, regardless of whether the subjects were still in treatment. By not following samples of convenience and by maintaining follow-up for such a long time, these studies provide a new view of schizophrenia. They also give evidence that challenges our preconceptions about chronicity and allows us to rethink models and treatment. Each of these projects was reported within the past 30 years or so, during an era of keen interest and funding of such studies. Each provides significant evidence confirming the

wide heterogeneity of outcome, and each finds that approximately one-half to two-thirds of people with schizophrenia can achieve a state of significant improvement or even recovery (M. Bleuler 1972/1978; Ciompi and Müller 1976; DeSisto et al. 1995a, 1995b; Harding et al. 1987b, 1987c; Hinterhuber 1973; Huber et al. 1979; Kreditor 1977; Marinow 1974; Ogawa et al. 1987; Tsuano et al. 1979). Table 2-1 summarizes data from these studies.

As can be seen in the table, the studies were conducted in seven countries. Studies outside the United States consisted of primarily urban samples, whereas the American studies examined rural samples. Altogether, a total of 2,429 patients (sample range 115-502) were followed for an average of approximately 28 years (range 20-37 years). The percentage of patients showing significant clinical improvement ranged from 46% to 84% (median value 53%), and the percentage of patients who were considered socially recovered ranged from 21% to 77% (median value 49%). Thus, a wider range among studies was found for social response than for clinical response. Together, these studies help to rebalance the picture of schizophrenia.

Switzerland #1—The Burghölzli Hospital Studies

The first of these studies was conducted in Zurich, Switzerland. Manfred Bleuler (1972/1978) began following a sample of patients admitted to the Burghölzli Hospital between April 1942 and December 1943 and maintained follow-up over the next two decades, regardless of whether the patients remained in treatment—something his father did not do. His sample consisted of 100 males and 108 females with diagnoses of schizophrenic psychoses. The diagnostic criteria used were a combination of those from his father, Eugen Bleuler, and Emil Kraepelin and were considered to be narrower than those of the American DSM-II (American Psychiatric Association 1968) and wider than the DSM-III (American Psychiatric Association 1980). M. Bleuler excluded patients with brain disease, endocrine disorders, poisoning, latent schizophrenia, neurosis, mixed psychosis (schizoaffective), or a previous course. This strategy had been unavailable to Kraepelin. Sixty-eight of the 208 (33%) probands studied were considered first admissions. Their ages ranged from 16.0 to 67.5 years, with an average age of 40 years. After considerable research, M. Bleuler (1972/1978) concluded that these subjects came from “the same sectors of the population as do all schizophrenics hospitalized in the Canton of Zürich during the period in question” (p. 12). None of the probands in this study died of brain disease during the follow-up period.

The Burghölzli Hospital Study was conducted in a systematic and comprehensive manner using structured instruments as well as clinical in-

TABLE 2-1. Long-term studies of schizophrenia

Study	Sample size, n	Average length, years	Percentage of subjects recovered and/or significantly improved*	Percentage of subjects socially recovered
M. Bleuler 1972/1978, Switzerland	208	23	53-68	46-59 ^a
Hinterhuber 1973, Austria	157	30 (approx.)	75	77
Huber et al. 1975, Germany	502	22	57	56
Ciampi and Müller 1976, Switzerland	289	37	53	57
Kreditor 1977, Lithuania	115	20+	84	NI
Tsuang et al. 1979, United States	200	35	46	21 ^b
Marinow 1986, Bulgaria	280	20	75	NI
Harding et al. 1987b, 1987c, United States	269	32	62-68	68 ^c
Ogawa et al. 1987, Japan	140	22.5	56 ^d	47
DeSisto et al. 1995a, 1995b, United States	269	35	49	e

Note. *Recovered = no further symptoms, no use of psychotropic drugs, living independently in the community, working, and relating well to others, with no behaviors that are considered to be odd or unusual; significantly improved = all of the above, but one domain of functioning. NI = not enough information to rate.

^aMultiple admissions vs. first admissions.

^bMarital status only recorded.

^cLive interviewed DSM-III schizophrenia group—the hardest data.

^dDerived by adding 33% recovered with a conservative 23% as improved (from 43% listed).

^eWhen variables not chosen for matching criteria were covaried out of the Maine-Vermont comparison, differences in social functioning lost statistical significance.

Source. Adapted from Harding and Keller 1998.

interviews. M. Bleuler (1972/1978) found that 68% of the first-admission patients and 53% of the multiple-admission patients significantly improved or recovered. Among the many findings reported were that 1) life histories revealed that most patients had experienced “disturbances in their home life,” but no one particular type stood out and no direct causal linkages could be established; 2) genetics appeared to play a role, but only a partial one (citing discordant monozygotic twins and other family data); 3) therapy may or may not have played a key role in the recovery process; 4) E. Bleuler’s (1911/1950) “group of schizophrenias,” which implied different etiologies, was still elusive; and 5) gender differences played a role. Bleuler focused on getting to know these patients and their relatives personally, and further social functioning was determined from criteria of work, independence from care, and living in a nonsheltered environment. No social impairment was observed for 46% of the overall cohort and for 59% of members of the first-admission subsample. With regard to sex differences, Bleuler found a 6:1 female-to-male ratio of improvement, and females showed a slight edge over the males in the recovered and mild impairment categories. He said, “I have found the prognosis of schizophrenia to be more hopeful than it has long been considered to be” (M. Bleuler 1984).

Austria—Hinterhuber’s Study

Between 1930 and 1940, 157 people with schizophrenia were first admitted to the Innsbruck Psychiatric Clinic in Austria (Hinterhuber 1973). At follow-up, 99 (63%) of these patients had died or were presumed dead, and 58 (37%) were still alive. Data were extracted from several sources, including structured questionnaires, interviews with relatives, and biographies. Hinterhuber (1973) used diagnostic criteria from Bleuler, Kraepelin, and Schneider to study the sample, which was composed of 87 women and 70 men considered to have “obvious schizophrenia.” Using data from all sources, the results, which were published primarily in German, revealed that 50% of these patients were “released from treatment,” but 33% remained enrolled in continued full-time care. In measures of psychopathology, 29.2% of the sample were reportedly “cured” of their schizophrenia, with another 45.6% improved and 30.5% still ill. Work functioning had remarkably resumed, with 77% working full-time, 20% working part-time, and the remaining 8% in family care. Subjects who had incurred injuries prior to illness (34.6%) remained mostly in the “severe final stages” of illness, with only 21% falling into the “cured” category. Course modifiers leading to poorer outcomes included psychological trauma, genetic loadings, and interestingly, later onset (after age 40 years).

Switzerland #2—The Lausanne Investigations

The “Lausanne Investigations” were conducted by Ciompi and Müller (1976), who undertook the longest follow-up study reported in the world literature. They conducted assessments of 92 men and 197 women across a median length of 36.9 years (SD=13.3 years), with a range of up to 64 years after first admission to the University Psychiatric Clinic. Of the sample, 20% had catamnestic histories of more than 50 years’ duration. Thus, Ciompi and Müller’s findings might be considered closer to E. Bleuler’s concept of *Reichung Prognose* (“final prognosis”). The average age of males at follow-up was 75.2 years; females averaged 75.8 years. This sample was considered to be representative of the 1,642 patients admitted to the clinic who were 64 years of age or younger at their first admission and who were 65 years of age or older at the beginning of the study in 1963 (Ciompi and Müller 1976). The initial large group ($N=1,642$) was targeted to study mortality and causes of death.

These investigators used a combination of Kraepelinian and Bleulerian criteria. Inclusion symptoms for schizophrenia included “disturbance of psychotic proportions...marked by manifold and alternating combinations of the so-called primary disorders of thought and emotion, autism, ambivalence, loss of contact, and experience of depersonalization or derealization” (Ciompi 1980, p. 607). Patients with questionable diagnoses of schizophrenia were excluded. The research team conducted 2-hour semi-structured interviews in the probands’ homes, and more data were collected through records, correspondence, and interviews of family, friends, and others in care systems (agencies and clinicians). Because of the complexities of human beings and schizophrenia, outcome domains were measured separately before being combined into a “recovered,” “improved,” or “deteriorated” status.

Results were quite varied. Highlights revealed that the average mortality rate for those in the sample was 173%, versus 100% for the Swiss population (Ciompi 1980), with women suffering the most, at 185% (vs. males at 161%). Twenty percent of subjects had been hospitalized for more than 20 years. Ciompi pointed out that hospitalization rates were also influenced by many social and economic factors (e.g., system, family, social structures).

Symptoms among the patients changed considerably over time. For example, 62% of all individual symptom profiles had “vanished” in old age,...and [an] additional 11% were clearly improved, with just 20% who remained unchanged in old age or had intensified” (Ciompi 1980, p. 611). However, only about a third of these patients were doing exceptionally well in social relationships. Classical predictors, including “good premorbid social, familial, and professional adaptation, few premorbid personality dis-

orders; a marriage, completion of vocational training, and a higher premorbid occupational level,” held into old age. Furthermore, it was found that “the disease tends to run a more favorable course, the more acute, the more lively, and the more mobile the onset of the illness.” Finally, Ciompi (1980) noted that “treatment factors were much less important for the long-term course than the above-described personality and disease factors” (p. 615).

Sex similarities were found, with 66.3% of the women in the “recovered” or “mild” categories compared with 61% of the men; whereas 7.1% of the men became worse, only 3.3% of the women did so (Ciompi 1980). Five patients demonstrated very late improvement. Using composite ratings, the team found “59% recovered or mild end states” (p. 616). Ciompi (1980) later concluded that “the long-term evolution of schizophrenia is much better than hitherto admitted,” which was in keeping with the conclusions of “Bleuler and Huber, [who] both concluded that schizophrenia is in no way ‘basically’ or even ‘predominately’ [an] unfavorable ‘disease process’ running an inexorably deteriorating course” (Ciompi 1980, p. 616).

United States #1—The Iowa 500 Study

In the first American study, the Iowa 500 Study assessed 100 patients with mania, 225 patients with depression, and 200 patients with schizophrenia who had been part of the annual admissions to Iowa State Psychopathic Hospital during the 1930s and 1940s. An additional group of 160 nonpsychiatric surgical patients (appendectomy or herniorrhaphy) was selected for a control group (Tsuang et al. 1979). These investigators applied the narrow Feighner criteria and clinical judgment to the comprehensive records available of that era (Feighner et al. 1972). The study concluded that these diagnosis were validated by follow-up information (à la Kraepelin) as well as family studies. Of 3,800 admissions, 874 charts were initially reviewed, with 20%–63% of records rejected depending on the chart diagnosis for schizophrenia (i.e., 63% of those diagnosed with schizophrenia were rejected) (Winokur and Tsuang 1996).

In the schizophrenia sample, 48.5% were females; 20% were married; 50% had poor premorbid psychosocial adjustment; 28% were high school graduates; median age at onset was 25 years; age at admission was 27 years; and only 26% had been discharged to the community (this was an era of custodial care with essentially no treatment [Winokur and Tsuang 1996]). Follow-up data were extracted from letters sent by social workers to the families for several of the early years. No information was available on 4%, only 17% of patients were interviewed, and 25% had information supplied by family or friends, with 53% supplied by physicians or other hospital

admissions (Winokur and Tsuang 1996). The fieldwork of the very-long-term follow-up period (average=37 years) consisted of interviewing those patients still living who could be found ($n=86$ of 200, or 43%) and first-degree relatives and evaluating all available records. The Iowa Structured Psychiatric Interview (ISPI; Tsuang et al. 1980) was administered by non-medical interviewers. Current diagnosis was based on data from the ISPI and on medical records through a consensus of three clinicians. Patients or first-degree relatives who had died or who refused to participate were given an "approximate" diagnosis based on medical records. Twenty screening questions were used for both reliability and validity of all diagnoses with little data reported.

Only four major outcome domains were measured: marital, residential, and occupational status and psychiatric symptoms. The criteria for good outcome were married or widowed, living in one's own home or with a relative, employed, retired, homemaker or student, and no symptoms. A fair rating was defined as divorced or separated, living in a nursing or county home, incapacitated due to physical illness, and some symptoms. A poor rating was considered if the patient was single or never married, living in a mental hospital, not working due to mental illness, and experiencing incapacitating symptoms. At long-term follow-up 30–40 years after the index hospitalization, 39 of 186 (21%) had a good marital outcome and 22 of 186 (12%) were rated as fair. For occupational status, 65 of 186 (35%) had good outcome, with an additional 14 of 186 (8%) with fair levels. For residential status, outcomes for 64 of 186 (34%) were good and another 89 (48%) were fair. For psychiatric status, 38 of 186 (20%) were rated as good, with 48 of 186 (26%) at fair levels. Winokur and Tsuang (1996) noted that disorientation and memory deficit at admission seemed to predict poorer outcome. Sex differences (men=102; women=98) were not reported in the overall outcome variables. Although these investigators focused on the 54% of patients who were rated as doing poorly, they neglected to point out that 46% of the cohort were actually doing much better. Nonetheless, the findings showed that outcomes for schizophrenia were at the end of a sequence ranging from affective disorders having the best outcome to schizoaffective disorders to paranoid-type schizophrenia to disorganized type having the worst outcome.

Lithuania—"Late Catamnesis of Recurrent Schizophrenia With Prolonged Remissions"

In an observational study, Kreditor (1977) studied patients with episodic schizophrenia ($N=115$) over a period of 20 years in five regions of Riga at the National Dispensary. The sample consisted of 38 men and 77 women

with an age range of 35–82 years. Approximately 54% were 50 years or older. Diagnostic criteria for schizophrenia were fairly broad. Ninety-seven (84%) of these patients had long-term remissions that extended 8–40 years. Kreditor identified two types of episodic courses, one with occasional episodes and the other with multiple episodes. Ninety-seven subjects had prolonged remissions (including 39% with 20–40 years remitted), and only 18 became worse. Predictors of long-term remission were "harmony of premorbid personality," lack of or low occurrence of character pathology, late onset (ages 30–40 years), and affective stability. The two course-type groups differed in premorbid personality, age at onset, and illness course. "The data give ground to eliminate the prognostic criteria of the probability of long-term remissions" (Kreditor 1977, pp. 110–113).

Germany—The Bonn Investigations

Huber et al. (1979) followed 502 of 758 admissions to the University Psychiatric Clinic of Bonn, Germany, between 1945 and 1959. Of these patients, 142 died before follow-up (including 7 [4.9%] who were suicides). Of those probands still living, 209 males and 293 females were assessed for 22.4 catamnestic years with personal interviews by the clinical team between 1967 and 1973. This part of the sample was believed to be representative of the usual admission profile for the clinic. Relatives reported on the status of an additional 26 probands (4%); 34 (7%) more were lost to follow-up, and 6 (1%) had brain diseases. Forty-eight (10%) refused interviews; however, the investigators found that this group consisted mainly of persons with good prognostic factors such as above-average intelligence and upper-class status. The investigators used the combination criteria of Schneider (based primarily on Kraepelin) and Eugen Bleuler, which had also been used by Manfred Bleuler (1972/1978). Like Bleuler, Ciompi, Harding, and others, they did not use outcome to define the diagnosis. Furthermore, "no symptoms or syndromes at the time of onset could be used to predict with any certainty whatever, the differentiation between malignant or benign, process or nonprocess, ...schizophrenic...psychoses" (Huber et al. 1980, p. 593). Sixty-seven percent became cohort members at first admission.

The authors reported that 57% of their subjects were improved and/or recovered. Other instruments found that 22.1% had achieved complete remission, with an additional 40.2% demonstrating "noncharacteristic residual syndromes." Thirty-five percent were considered to have "characteristic residual syndromes." Fifty-six percent of the cohort were judged to be socially recovered (meaning that they had returned to their premorbid fully employed status)—"all the more remarkable when only 13% had participated in any outpatient rehabilitation program" (p. 595). Social func-

tioning was highly correlated with outcome of psychopathology (Huber et al. 1980). Sex differences were found in better outcome for females in general and specifically in social outcome. Schizophrenia in first-degree relatives tended to differentiate men with poorer outcomes. Females were more likely to have better outcomes if they had multiple episodes with clear-cut precipitating factors. Females also tended to have more florid symptoms but a later illness onset. Complete remission, more favorable outcomes, and social recovery tended to occur in females. Cerebral atrophies occurred more often in males, who also had more psycho-organic disorders of the elderly. Course was described as "phasic" in 22%, "surges" in 48%, and "sluggish" in 21%. The authors identified 76 course types, which they reduced to 12 categories. They also noted that outcome shifted among some cohort members no matter how long a certain status was in effect. However, they found that "no reasonably reliable prognosis for the individual patient is possible" (p. 604).

Bulgaria—Marinow's Long-Term Follow-Up Study

A two-decade study (mean=20.2 years) conducted in Bulgaria by Marinow (1986) followed 280 male schizophrenia patients who had been discharged from hospitalization between 1946 and 1950. The cross-sectional outcomes for members of this cohort were measured every 5 years. Subjects were assessed on variables such as psychopathology and social and work functioning. Each factor was then combined into a summed total outcome or "prognostic" score. Findings revealed that at least 50% of subjects had a "favorable" outcome, with approximately 25% improved and another 25% with a poor outcome. Marinow found the course picture to be one of mixed signals with conflicting indicators of long-term outcome and concluded that it was impossible to predict future status for individuals. In a later study of persons with schizophrenia ($N=634$) whose illness duration ranged from 2 to 20 years, Marinow (1988) found that long-term outcome had greater correlation with the patient's marital status, ability to work, and with neuroleptic treatment than with illness history, number of readmissions, and length of hospitalizations, but he was unable to "predict prognosis." The diagnostic criteria used in this study appear to have been wider than those used in American, Swiss, and German studies.

United States #2—The Vermont Longitudinal Research Study

A second American long-term catamnestic study was conducted in Vermont for which base reports were published in the 1980s (Harding et al. 1987b, 1987c). This study is the longest study of deinstitutionalized pa-

tients to be conducted in the United States (ranging up to 62 years after first admission) and one of the longest studies of schizophrenia. The sample of 269 patients (144 females and 125 males) with severe and persistent mental illness was selected from the back wards of Vermont State Hospital in the mid-1950s.

Probands were provided with a "rehabilitation unit" after 2 years of only modest responses to long trials of clinically therapeutic dosages of phenothiazine. The patients and their multidisciplinary clinicians jointly created a federally funded, comprehensive model demonstration, biopsychosocial rehabilitation program that targeted self-sufficiency and community integration (Chittick et al. 1961). Their combined effort in the hospital provided training in activities of daily living and social skills; continued medication; vocational assessment, training, placement, and continued supports; patient government; peer support groups; case management; and careful deinstitutionalization.

A substudy of the parametric characteristics of the entire hospital census ($N=1,300$) revealed that the back-ward patients in the cohort had the most chronic course and were the most severely ill and disabled (especially the males) patients compared with the hospital population at large (Harding et al. 1987b). The study cohort had an average of 16 years of illness and 10 years of total disability. Furthermore, these patients were shown to be among 19% who remained in the hospital during the previous 5 years or longer while other patients were admitted and discharged (G.W. Brooks, unpublished study ["Retained Patients With Schizophrenia From 1920s to 1970s"], October 1975). This group is considered to be the most chronic cohort ever studied in the world literature and therefore should have had the worst long-term outcome.

Members of the cohort were carefully deinstitutionalized in the late 1950s into a pioneering community mental health system and were provided rehabilitation for 10 years, until 1965, by the same team from the hospital (Chittick et al. 1961). In the community, all aspects of community care were established, including a range of residential and occupational placements and supports, outpatient clinics, inclusion in natural community organizations, and continuity of care long before community mental health centers were established (Chittick et al. 1961). They were followed for an average of 32 catamnestic years, with a range of 22–62 years after first admission. A major follow-up study funded by the National Institute of Mental Health was initiated in the early 1980s, at which time 97% of the Vermont cohort was located (262 of 269). The average age of the surviving interviewed cohort at follow-up was 61 years. A comprehensive and structured instrument battery was implemented, with all the interrater and interitem concordance testing reported (Harding et al. 1987b, 1987c). The

field interviewers were blinded to the patients' records, and the record abstractors were blinded to outcome. Both cross-sectional and longitudinal measures were assessed. Prospectively gathered records and retrospective data were used to fill in the longitudinal picture, along with vocational rehabilitation records and structured interviews of family, friends, and clinicians. Recalibration of the index-admission diagnosis from the 1950s to the then-new DSM-III (American Psychiatric Association 1980) was performed with interrater trials that achieved a kappa level of .78 ($P < .0007$) (Harding et al. 1987c).

The original cohort was recorded to have 213 of 269 (79%) members with schizophrenia. The rediagnostic effort, done without the previous diagnosis assigned and according to DSM-III criteria, reduced that number to 118 (55%). Although the investigators followed 97% of the total sample of 269 subjects, only the hardest data were reported for outcome of schizophrenia, unlike in other studies. Those probands who were rediagnosed, primarily with schizoaffective disorders, psychosis not otherwise specified, and atypical psychosis, were excluded from the analysis of schizophrenia and outcome, as were those who were deceased.

In a review of North American follow-up studies, McGlashan (1988) mistakenly reported that these patients had very late average onsets, in their 30s. He later corrected that report to a mean onset of 24.2 years for males and of 27.1 years for females (Childers and Harding 1990; McGlashan 1991). McGlashan also originally thought that these patients were the workers of the hospital and were retained by the staff until the rehabilitation study, another misconception that he subsequently corrected (McGlashan 1991).

With 24% of the cohort deceased, an important methodological balance was introduced. Instead of simply comparing the demographic and illness variables with the surviving cohort, a special protocol was introduced that systematically interviewed the family, friends, and clinicians connected to these patients in one room in order to piece together the life lived by the patients until their deaths. This strategy revealed that instead of the most seriously ill cohort members dying first, leaving the less ill members reporting better outcomes, the subjects mirrored the same proportions of recovered, improved, or unimproved persons found in the live cohort (Harding et al. 1987b). Other long-term studies have combined information for the living and deceased subjects.

The interview instrument battery used in the follow-up study consisted of 15 standard scales and schedules (Harding et al. 1987a, 1987b). Much to their surprise, the Vermont investigators found that nearly two-thirds of the subjects from this chronic, severely ill cohort met stringent objective criteria for recovery and/or significant improvement. Of the

whole, 62%–68% achieved significant improvement or recovery across multiple domains of function, increased work (40%), reestablished social relationships (68%), and self-care (81%) (Harding et al. 1987c). Sixty-eight percent showed no further signs or symptoms of schizophrenia, with 45% of that group having no symptoms at all. All of these areas were predicted in the DSM-III to deteriorate or remain at marginal levels (American Psychiatric Association 1980). Instead, the domains not only reconstituted and improved but also developed further in two-thirds of the cohort.

Recovery criteria included no psychiatric medications, no symptoms, no behaviors that could be construed as those of a "mental patient," being employed, relating well with others, and living outside the hospital. Significant improvement meant that the person had achieved recovery in all but one of these domains. Social functioning was measured by several widely used and standard structured assessments and was another area that showed reconstitution and further development in 62%–68% of subjects (Harding et al. 1987c). Sex differences were also examined in the surviving DSM-III schizophrenia sample, which had 41 men and 41 women. Females, who had had the better premorbid functioning scores (Childers and Harding 1990), were shown to have lost their competitive advantage and ended up at only a trend level better than their male counterparts, who had consistently performed more poorly on all subscales and overall score of the Premorbid Adjustment Scale (PAS). Harding and Hall (1997) suggested that the explanation for the performance decrement seen in women might be the loss of estrogen protection at midlife (see also Seeman 1995). Furthermore, the men appeared to have slowly gained in strength across time (Harding 1994; Harding and Hall 1997; Harding et al. 1987c). Nevertheless, women's scores on the Community Adjustment Scale (Consalvo et al. 1984, cited in Harding 1994) remained slightly higher than those of men, despite the fact that they had longer lengths of stay in the hospital. Women also demonstrated more productivity, had less evidence of psychotic symptomatology, and evidenced higher levels of functioning in social relationships (Harding and Hall 1997).

During the initial data analyses, Strauss and Harding wrote, "we have gathered some evidence that the course of schizophrenia is a more complex, dynamic, and heterogeneous process than has been heretofore appreciated or predicted by diagnostic specificity" (Strauss and Harding 1984, p. 349).

Japan—Gumma University Hospital Study

Ogawa et al. (1987) conducted a 21- to 27-year follow-up of 140 consecutive patients (67 males and 73 females) discharged from the Department of Neuropsychiatry at the Gumma University Hospital in Japan between

1958 and 1962. At entry to the cohort, 81% of these patients were younger than 30 years; 79% were first admissions and resided primarily in the provincial town of Maebashi, northwest of Tokyo. These patients were provided with a program of "neuroleptic drugs, the open-door system, and intensive aftercare" (Ogawa et al. 1987, p. 758). The hospital's rehabilitation model was called *Seikatasu-rinsko* and was described as "clinical work in a patient's everyday life" (p. 750), which was reported as a combination of case management and individual counseling techniques.

At follow-up, 93% of the 140 members of this cohort were assessed, with 105 still living an average of 23.6 years after index hospitalization (range=21–27 years). One hundred subjects were alive and interviewed. In addition to the *International Statistical Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM; World Health Organization 1978) rediagnosis, subjects were also evaluated on social functioning indices with Eguma's Social Adjustment Scale (ESAS; Eguma 1962; Ogawa et al. 1987). Information was acquired from multiple data sources. The data were not analyzed with regard to sex differences.

The results revealed that 57% of the subjects were considered to be "fully self-supportive" (i.e., fully productive, living in own home and often also married, psychologically recovered, with a return to premorbid levels of functioning and independent social life without clinical interventions as well as maintenance of a normal family life). "Semi-self-supportive" ratings were given to another 19%, and 34% were considered to be "hospitalized and maladjusted cases." The Japanese team concluded that social recovery was greater than improvement in psychiatric status. They conducted monthly assessments of social adjustment and reported patterns of adjustment across time. These patterns showed multiple fluctuations early in the illness course, with later differentiation between the self-supporting and chronically institutionalized groups (Ogawa et al. 1987).

United States #3—The Maine–Vermont Longitudinal Comparison Study

The most recent American study was conducted in Maine (DeSisto et al. 1995a, 1995b) and, to my knowledge, is the only matched comparison study of very long outcome ever reported in the world literature. In this study, patients from the Vermont Longitudinal Research Study ($N=269$) were matched by age, sex, diagnosis, and length of hospitalization with patients in Augusta State Hospital who were treated during the same era and in similar catchment areas as defined by health and census data. The Maine study employed the same research protocols as the earlier Vermont study and incorporated the careful rediagnostic workups that the Vermont Lon-

gitudinal Project had used (DeSisto et al. 1995a, 1995b). The study also used the same treatment era and intraproject reliability testing. Of the Vermont patients, 97% were tracked for an average of 32 years after first admission; 94% of Maine patients were tracked across an average of 36 years. The major difference between the two study cohorts was that whereas subjects in the Vermont cohort had been part of a comprehensive model rehabilitation demonstration program, the Maine patients had experienced primarily traditional custodial care.

The Maine–Vermont study had an average of 36 catamnestic (time since first admission) years. Following the rediagnostic work, the sample comprised 102 subjects with DSM-III schizophrenia (57 males and 45 females). Comparisons of the two matched cohorts revealed significant differences. After covarying out several variables that could not be matched (e.g., urban vs. rural residence, level of education), three very strong findings held: Vermont patients 1) had much stronger community functioning ($P<.001$), 2) much stronger work functioning ($P<.009$), and 3) substantially reduced symptoms ($P<.002$). Overall, global functioning results found Vermont patients at 68% and Maine patients at 49% ($P<.0001$). Sex differences were found in the Maine cohort, with women rated better in premorbid social functioning.

What Have We Learned From These Studies?

In the following sections I assess the combined findings described above to determine what we might learn about the domains of diagnosis and time, symptom course, social functioning, ability to work again, psychopharmacology and side effects, predictors of long-term outcome, and reconstitution of lives.

Diagnosis and Time: Not as Strong a Predictor as Once Thought

In the field of psychiatry, diagnosis has long been reified and conceived of as a "lifetime" label (American Psychiatric Association 1980, 1994). In the United States, psychiatry tended to be ethnocentric, especially after an analysis showed that American clinicians overdiagnosed schizophrenia based on DSM-II criteria (American Psychiatric Association 1968) in comparison with clinicians in the United Kingdom (Cooper et al. 1972). Thus, although the Swiss and German studies used criteria narrower than those of Eugen Bleuler but wider than the Kraepelinian-based DSM-III (American Psychiatric Association 1980), American investigators discounted the European findings and proceeded to make criteria narrower and narrower.

However, the narrowness of the criteria used does not predict uniformly poor outcome, as was once thought (Harding et al. 1979, 1987c). The narrow Feighner criteria employed by the Iowa 500 study identified such a poor-outcome group with more efficiency (Tsuang et al. 1979, 1981). This approach was a trade-off, because it made the cohort findings less generalizable to the entire population with schizophrenia. However, much to everyone's surprise, even the sample identified in this manner has found heterogeneity in outcome. With one exception, these long-term studies revealed that diagnoses could be reconceived as "cross-sectional working hypotheses" (Harding 1998, p. 321) that need to be reviewed and revised over time and in many cases eventually discarded. There is evidence that patients with schizophrenia have more difficulty in achieving good long-term outcome than do many patients coping with affective and schizoaffective disorders, as found by the Iowa 500 group and others. However, the Vermont sample and others have demonstrated that even this effect is reduced to a trend level across decades. In an opposite approach, Vaillant (1975) also found heterogeneity when he attempted to follow up the other end of the continuum, the so-called good-prognosis patients. Discovering heterogeneity after 10 years, he concluded that "prognosis and diagnosis are two different dimensions of psychosis," in direct contradiction to Kraepelin (1902).

Symptom Course—Ever-Widening Heterogeneity With Early Fluctuations and Later Decrease of Virulence

Eugen Bleuler (1911/1950) called the disorder "a group of schizophrenias," and follow-up investigators are aware of the wide variation of individual histories, which supports Kendler's complex model of gene-person-environment interaction (Kendler and Eaves 1986). Huber et al. (1975) suggested 76 course types, indicating the wide heterogeneity found, but eventually reduced these to 12. Ciompi (1980) also published a diagram of 8 course types. His chart, with accompanying percentages, has been perceived as *the* standard by which course and outcome regularly proceed. However, Childers and Harding (1990) found evidence in the Burghölzli Hospital reports and the Vermont findings that these percentages are not written in stone but rather depend on the composition of the cohort. This observation means that predicting a probable long-term course for individuals is difficult if not impossible.

Predictors of Long-Term Outcome Weaken Over Time

Although some studies, such as the Lausanne Investigations, found that the classical predictors held across time, an unpublished manuscript by Harding

and colleagues showed that the classical predictors of outcome in schizophrenia research can also fade in power to trend levels across decades. Such predictors include gender, type of onset, early versus late onset, symptom profile, and age at onset. The predictive power of sex, which has classically shown strong evidence in favor of females, weakens across time, perhaps as the protective effects of estrogen wear off with menopause (see Seeman [Chapter 8] in this volume). Menopausal women in the Vermont cohort lost their edge to the trend level, whereas the men grew increasingly stronger (improved in functioning and had fewer symptoms) across time. The only predictors that showed resistance to weakening over time were certain types of negative symptoms.

Restoration of Social Functioning

Harding et al. (1987a) and Harding and Keller (1998) analyzed the literature on social functioning and schizophrenia, which describes poor pre-morbid adjustment, deterioration during illness, feelings of isolation and estrangement, disordered emotional responsivity, bizarre behavior and speech that can drive friends and family away, and the symptom of blunted affect, which increases social isolation. The long-term studies revealed that social functioning most often is restored and even undergoes further development after a schizophrenic psychosis. Many of the studies found that this effect happened with greater frequency or was highly correlated with improvement in psychological functioning.

Regaining the Ability to Work Again

The assumption that once-psychotic persons are unable to work has been challenged repeatedly by a number of investigators (e.g., Anthony et al. 1984; Drake et al. 1999). Strauss and Carpenter (1974) showed that the best predictor of working is past work experience. Furthermore, diagnosis and symptoms did not predict work or social functioning or outcome across 5 years of follow-up. Previous social functioning did cross over to help predict work functioning. In the Maine-Vermont comparison, the subjects were matched and also happened to have had similar work histories prior to being hospitalized. The Vermont patients, who had participated in an intensive vocational rehabilitation program, continued working throughout the follow-up period at a rate of 30%–40%, with an additional 20% engaging in volunteer work within their communities. The Maine patients who did not receive vocational rehabilitation struggled to regain their employment status. The Vermont model focused on rehabilitation, self-sufficiency, and community integration; by contrast, the Maine model emphasized stabilization, maintenance, and entitlements (DeSisto et al. 1995a; 1995b).

Psychopharmacology and the Assumption of Lifetime Use Not Supported

There is an assumption—albeit one not supported in the literature—that most persons with schizophrenia need to remain on antipsychotic medication all of their lives. However, the Vermont study revealed that 20% were no longer receiving prescriptions for medication; 30% had drawers full of medications never taken; 25% had invented targeted strategies before Herz et al. (1991) and Carpenter et al. (1988); and the remaining 25% were taking their medications religiously, having been so threatened with recurring psychosis by past clinicians that their current clinicians were unable to taper their dosage. Harding (1998) concluded that perhaps only a small group of patients really needed continuing medications across a lifetime and recommended that the findings be investigated further. The idea of lifetime use of antipsychotics has been assumed because of the myth “once a schizophrenic, always a schizophrenic” or nowadays reframed as “once a broken brain, always a broken brain.”

Many Pathways to Improvement and Recovery

M. Bleuler (1972/1978) observed that “the long-term experience gleaned from my probands revealed one fact most impressively, namely that successful results can be achieved through totally different methods” (p. 441). Furthermore, in the Vermont–Maine comparison, the investigators were startled to find that although significant outcome differences were found between the samples (which may have been attributable to the rehabilitation program in Vermont versus the custodial care in Maine), 49% of Maine patients continued forward toward improvement. At first, DeSisto et al. (1991) thought that the greater forward progress of the Vermont patients was due to decisions made at the top of the system—that is, Vermont appeared clear and consistent in its mission and comprehensive in its programs whereas Maine did not. Although some of this environmental impact may have been operative, Maine patients continued to improve despite the vagaries of their system of care.

After looking at all of the long-term studies across many treatment eras and finding that patients persisted toward recovery and/or improvement, new thoughts began to emerge about the power of human relationships, no matter what services are being delivered. The Vermont patients reported that they received the greatest benefit when they were told that someone believed in them: “Someone believed in me, someone told me I had a chance to get better.” To Harding, this illustrated the importance of hope and showed that hope was connected to the natural self-healing capacities

of people. She began to write about neural plasticity (e.g., Harding 1998). Andreasen (2001, p. 31) stated recently, “brain plasticity...stresses that our brains are in constant dynamic change, which occurs as a consequence of the impact of experience on our mental functions and states.” Strauss and Harding (1990) suggested that treatment providers and research investigations need to target developmental issues and course of disorder as “two interacting systems,” especially in this era of biological psychiatry. They described both positive (amplifying) and negative (limiting) feedback loops within this interaction. Given the arguments of schools fighting for certain models of treatment as more effective than other models, one wonders whether clinicians may need to rethink this stance. An alternative plan calls for clinicians to collaborate with one another and with their patients by employing a range of treatment options—depending on the ever-changing needs of patients—with warmth, encouragement, optimism, and persistence.

Rebalancing the Picture for Schizophrenia

The long-term course of schizophrenia is vastly different than what has been extrapolated from short-term studies as well as from older cohorts of convenience formed by patients still in systems of care for a wide variety of reasons. Such reasons include lack of incentives to get better, self-fulfilling prophecies derived from pessimistic attitudes and continuing severity of symptoms, and the expectation of lifetime diagnostic specificity and need for psychopharmacology.

In regard to treatment, M. Bleuler (1972/1978) suggested that “The inner life of the schizophrenic is never ‘burnt out.’ It always continues on its way. When ceaseless attempts are made to establish contact with him as with a normal person, and he is not left to stand aside like an outsider, a communal relationship is established that means a great deal to both the patient and the doctor” (p. 442). In fact, Bleuler taught us to see “the person behind the disorder” with comments such as “seriously ‘demented’ schizophrenics have not lost touch with a healthy psychic life,...in their case, healthy perception, memory, recall, judgment, and feeling are merely concealed behind their pathological behavior” (M. Bleuler 1972/1978, p. 191).

Summary of Findings

For the past century, the course of schizophrenia has been thought to be a downward course for most if not all patients. In this chapter I presented ev-

idence from the long-term literature that revealed a very different outcome. These studies found wide heterogeneity of course and social and work functioning, significant weakening of traditional predictors, and an interaction of adult development with symptom course. The discussion detailed the possibilities for a more positive outcome emerging from such studies. Explanatory models were proposed of neural plasticity, the change from extreme anxiety and fear arising from the experience of schizophrenia itself, to "active coping" through rehabilitation, hope and optimism, recalibration of neurobiological mechanisms during the aging process, and human endurance and resilience.

The most remarkable finding of these long-term studies is the confluence of results showing that at least 50%–60% of each intact cohort studied across two to three decades significantly reclaimed their lives, even in the face of persisting beliefs that this would be impossible. Reconstructed lives have begun to erode the old beliefs, and new strategies with a recovery vision are beginning to be employed.

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