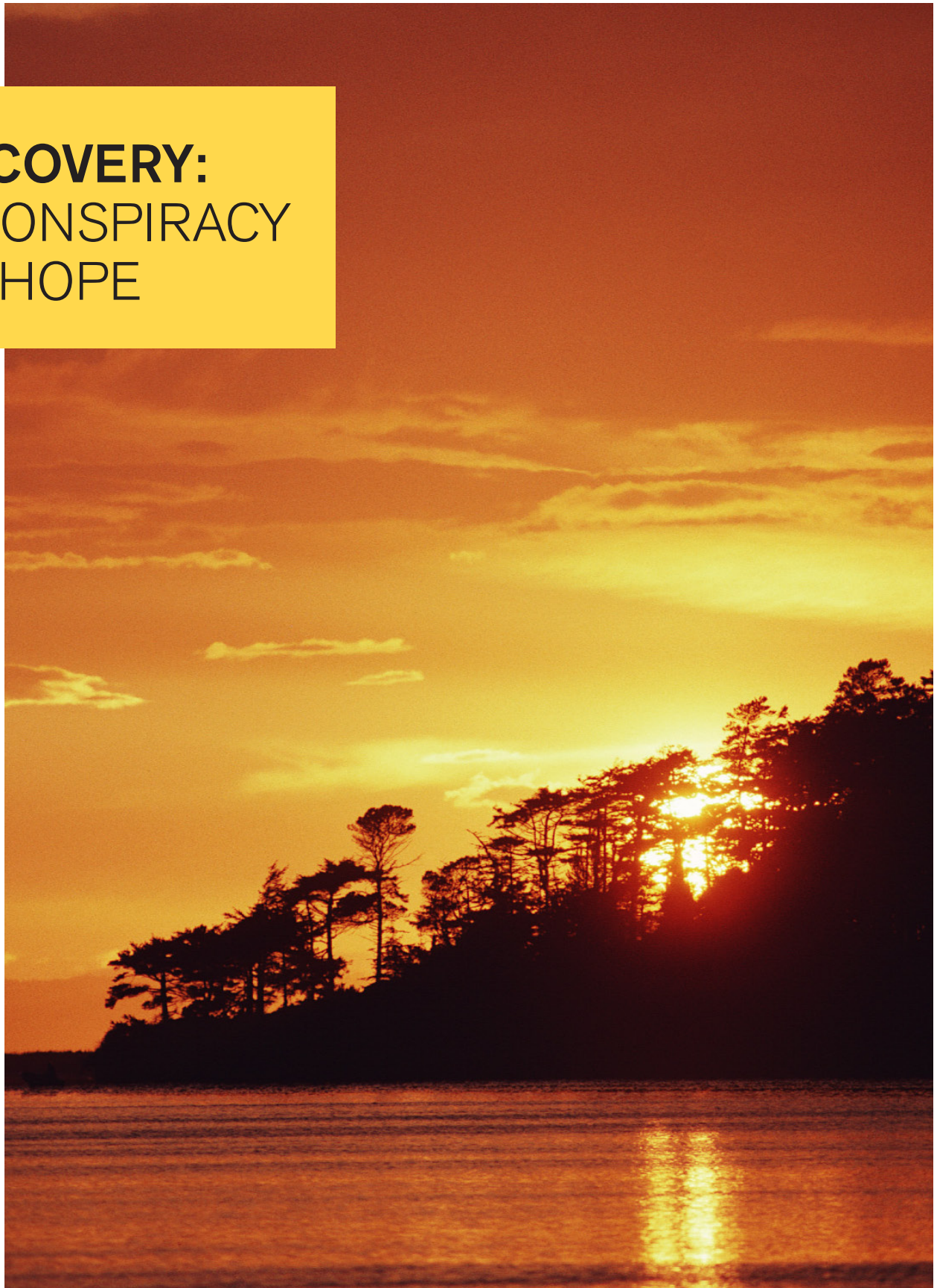


**RECOVERY:**  
A CONSPIRACY  
OF HOPE



*Dreams are renewable. No matter what our age or condition, there are still untapped possibilities within us and new beauty waiting to be born.*

Helen Keller

In 1896, the influential German psychiatrist Emil Kraepelin helped set the tone for a century of psychiatry with his writings on dementia praecox, a condition that would later come to be known as schizophrenia. Kraepelin's work emphasized that even when severe symptoms subsided, there was little hope for the mentally ill to lead meaningful lives. "After the illness has run its course," he wrote, "at best, one can expect to maintain the patient's condition in some degree of stability. It is relatively rare for the patient to be able to return to even a modest degree of mental independence."



Exactly one-hundred years later, Patricia Deegan, a Ph.D. psychologist who had been diagnosed with schizophrenia, announced that a new "conspiracy of hope" was afoot among the mentally ill and their families. "Both individually and collectively," Deegan explained, "we have refused to succumb to the images of despair that so often are associated with mental illness. We are a conspiracy of hope." An inverted image of the picture painted by Kraepelin, the mentally ill individuals Deegan described reflected the need 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 lifeforms." Rather than being sentenced to a lifetime of mediocrity, Deegan and her fellow consumers were testaments to the fact 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."

Kraepelin and Deegan were worlds apart, not just in what they believed the prognosis for mental illness was, but in the outlooks they used as they approached it. While Kraepelin emphasized the despair, disease, and dependency that can emerge because of mental disorders, Deegan highlighted that individuals with mental illness—just like everybody else—have a right to strive for hope, wellness, and self-determination. Both views were very much products of their time, with Kraepelin's being indicative of the deficit-based views of mental illness that were prevalent at the end of the nineteenth century, and Deegan's being a reflection of a more positive viewpoint, which in recent years has come to shape the "recovery model" of mental illness and mental health services.

The goal of the recovery model is help individuals with mental illness to live full, complete, and active lives within the community instead of sheltering them from the outside world. In practice, recovery-oriented mental health treatment focuses on improving consumers' quality of life instead of simple symptom reduction. While recovery has its roots in ideas and approaches towards mental health care that date back to the 1700s, the recovery model of today has evolved over the last two decades. Now, recovery is the driving philosophy behind many public mental health systems throughout the country, especially in California.



Some of the ideas behind recovery go back to the eighteenth century. French psychiatrist Philippe Pinel coined the term “moral treatment” to describe a new way of working with the mentally ill, arguing that by gaining their confidence and instilling hope, physicians could help improve their behavior and their quality of life. Moral treatment focused on kind individualized care for the mentally ill, integrated with activities such as occupational therapy, religious instruction, and recreational pursuits.

Though the goal was to reintegrate individuals into the world outside of the asylum, moral treatment retained strong elements of control. Advocates of the philosophy believed that the mentally ill still needed to be confined in mental institutions, since life among family and friends could be stressful or undermine their treatment. Consequently, they recommended limited freedom for the mentally ill (if they were willing to grant any at all), and it was not uncommon for individuals to be held for an unlimited or undefined period of time, even as late as the 1960s.

After 1860, the emphasis on moral treatment dissipated, due both to new biological understandings of mental illness and the development of drastic, sometimes draconian, physical treatments. The writings of psychiatrists such as Kraepelin painted a dismal picture of many mental illnesses, leaving both the unwell and their families with little hope that they could ever live normal and fulfilling lives. The goal of treatments, therefore, came to be the elimination of disorders and symptoms. Many of these interventions would be considered cruel and barbaric by today's standards. One was hydrotherapy, which involved giving individuals baths or wrapping them in wet packs for extended periods of time. Other strategies included the induction of fevers in hopes that it would reduce symptoms, and the use of physical shocks caused either by insulin or electricity. Perhaps the most notorious of these interventions was the lobotomy, a surgical procedure on the frontal lobe of the brain, which was used from the 1930s to the 1960s.



Few of these treatments resulted in symptom reduction, and it was not uncommon for people who wound up in public mental institutions to remain interned, essentially as wards of the state, for the rest of their lives. By the late 1940s, some professionals in psychiatry recognized that this way of approaching mental illness did little to improve lives. As one psychiatric nurse from Pasadena wrote in a 1949 letter to California Governor Earl Warren, it was clear that changes needed to be made, since the most popular treatments rarely effected a lasting cure. "Cases who have received electric narcosis, electric shock and insulin shock treatment combined with occupational therapy, psychotherapy, hydrotherapy, and physiotherapy have returned to us again for further treatment," she told the Governor. "So many mental cases are just going round the sanitariums and mental hospitals in circles," she concluded, that something needed to change.



Beyond the testimony of practitioners, statistics gathered in the 1940s and 1950s spoke to the inability of the existing methods to "cure" California's mentally ill and keep them out of state institutions. Reports showed that the state hospital system was becoming extremely overcrowded, with large numbers of patients being forced to sleep on the floor since there was no room for beds. While underfunding was partially to blame for these problems, the fact that individuals were not improving, and rarely left the state hospitals, also contributed to the problem of overcrowding.



*"We were trained to believe that they were crazy, they couldn't think for themselves, we had to take care of them, we had to be very paternalistic with them, (and) that the primary issue is their symptoms, while in fact, the primary issue isn't their symptoms, it's what can they do in spite of their symptoms. We can help control the symptoms, but even if they're quite symptomatic, sometimes people can do quite well...I mean, recovery, the whole recovery movement has evolved from that, or this kind of thinking."*



J.R. Elpers, M.D.

By the late 1940s, even though shock therapy and lobotomies were still being used, many in the mental health field began to advocate for an approach that focused more on improving the lives of the mentally ill than on simple symptom reduction. In its 1949 study of California's mental health system, the United States Public Health Service recommended that the state integrate more psychotherapy, occupational therapy, physical education, vocational training, and schooling into the treatment that the mentally ill received. This reflected part of a broader trend towards recognizing that the old way of trying to "fix" patients through physical interventions was not only difficult, but also ineffective. As presenters at the 1951 meeting of the American Psychiatric Association explained, "the goal of psychiatric treatment is the return of the individual to the community with the ability to utilize community resources for his personal, social, and vocational adjustment. Frequently," they lamented, "these goals are forgotten in our efforts to relieve patients of their symptoms and effect a 'cure.'"

Therapeutic innovations helped change the approach to mental illness in the 1950s and 1960s. Research showed that "therapeutic communities"—which involved multidisciplinary teams, group activities, and giving the mentally ill more of a voice in their own treatment—were more effective than traditional methods in improving outcomes. Even within the confines of state institutions, strengths-based approaches to treatment and respect for patients' rights were integrated into therapeutic practices. The development of new and more effective antipsychotic medications, such as chlorpromazine and haloperidol, also made a significant difference, as they allowed for the more effective management of symptoms without as much clinical supervision.



Thanks in part to these developments, governmental officials began to advocate for more individuals receiving mental health services to be treated in the community, and soon they took action. As early as 1950, a report by the Council of State Governments recommended that community treatment and aftercare programs be expanded; in the 1950s, California began creating a system of outpatient clinics, and also increased the capacity of outpatient departments in the state mental hospitals; California's 1957 Short-Doyle Act and the federal government's 1963 Community Mental Health Centers Act created specific mechanisms for funding mental health services outside of institutions. Alongside a more robust outpatient system, the creation of Medicare and Medicaid in the 1960s, and the institution of Supplemental Security Income and Section 8 voucher programs in the early 1970s, provided the mentally ill with greater means, and consequently more hope for independence, once they were living in the community. Thus by the 1970s, there was good reason to hope that the mentally ill could not only survive, but thrive, outside of institutions if given the opportunity.

Nonetheless, skepticism still prevailed among many in the mental health establishment. As Areta Crowell, the former director of the Los Angeles County Department of Mental Health recalls, “until the late 70s there was the feeling that...mental illnesses were chronic forever, and you were not going to have recovery. Nobody believed in recovery.”

By the 1980s, however, the idea that recovery was possible gained more firm footing. One major reason was the activity of individuals with mental illness themselves. Mental health consumer groups began to form across the United States in the 1970s, demanding more rights, independence, and control over their lives and treatment. Individual consumers began making strong arguments for the mentally ill to have a greater say in the way that mental health services were structured and delivered.



Judi Chamberlin’s 1978 *On Our Own: Patient Controlled Alternatives to the Mental Health System*, made the case for consumer-driven alternatives to traditional treatment methods and philosophies. Deegan, Esso Leete, Sally Zinman, and others both explained and exemplified how individuals could lead independent and fulfilling lives in spite of their diagnoses. Groundbreaking research conducted by Courtenay Harding provided more scientific fodder for the argument, proving that it was possible for the severely mentally ill to improve their quality of life while living in the community.

The 1989 publication of *In Pursuit of Wellness* – a study conducted by Jean Campbell, Ron Schraiber, and the California Network of Mental Health Clients – brought a new perspective to the issues facing the mentally ill by elucidating what consumers felt improved their quality of life. Among other findings, Campbell and Schraiber’s research showed that validation of personhood, recognition of humanity, and tolerance of individual differences were critical for recovery, and that when consumers were denied a voice in treatment or disrespected, they were less likely to improve. As they wrote:

*“Clients are all too human, with basic needs, despair, and dreams of the future. Clients surveyed reported that well-being comes from having good health, good food, and a decent place to live, supported by an adequate income earned through meaningful work...Through individual and group self-help, clients can and do take control of their everyday lives if they are validated and supported materially and socially as human beings living with an understanding and respectful community.”*

In spite of this growing body of knowledge, some of the supports needed to help the mentally ill thrive in the community were still lacking. Around the mid-1980s, policymakers, professionals, and advocates began working to create a more comprehensive array of services. Research at this time showed that the mentally ill needed more than basic mental health care, financial support, and shelter; services designed to enhance their personal safety, opportunities for growth, and empowerment were also essential.

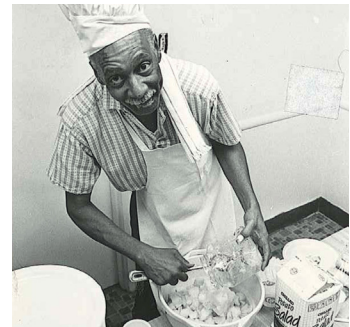
Thus a more holistic approach to care, one that helped consumers in all areas of their lives – not just with their mental illnesses – was needed. This treatment philosophy, which eventually would develop into the recovery model, began to be more clearly articulated by the end of the 1980s. As Boston University researcher William Anthony, one of the pioneers of recovery, summed up in 1993, recovery would come to be defined as:

*“...a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness...Treatment, case management, and rehabilitation are what helpers do to facilitate recovery.”*

Putting the principles of recovery into practice, however, was no small task for mental health policymakers in California. Successful programs elsewhere had shown that intensive case management and assertive community treatment programs could help the mentally ill thrive in the community, and served as a model for what recovery-oriented services could look like. Research sponsored by the California Alliance for the Mentally Ill also helped lead the way, demonstrating that the public mental health system needed to do more to offer consumers quality housing, help finding work, and socialization activities. By the end of the 1980s, staff at the Los Angeles County Department of Mental Health took notice, and began to integrate these services into their plans for the public mental health system.



*“I think recovery for me is a state of being where a person is able to interact with others, they are able to work, if they so choose, they are able to function in the community and take care of themselves and they have inner peace. That for me would be recovery from mental illness and maybe substance abuse too. The best way to do that, or to help a person reach that state of being, if they come in for treatment is to talk about that recovery from the first day you meet them. Everything you do for a person who is mentally ill has to be aimed at recovery and you have to keep helping them focus in on that as the goal of what’s going to happen... we’ve had people where we stabilize them but we also, we give them a crutch and they do real well as long as they have that crutch, but none of us have a crutch all the time and instead of a crutch we ought to give them a phone number or teach them the minute you start to feel this way you call whoever, or you reach out to whoever it is who you can reach out to and have them, you know, talk with them about what’s going on with you because you know then that’s a danger signal. But, we also need places for clients to... have socialization.”*



*Cora Fullmore, L.C.S.W.*

At the California State level, major changes were brewing around the same time. In the mid-1980s, Lieutenant Governor Leo McCarthy convened a special task force on mental illness, which was led by advocates Rose King and Dan Weisburd. The group's work eventually led to the passage of State Assembly Bill 3777, which funded the creation of three intensive case management programs called Integrated Service Agencies (ISAs). One of them would be housed at The Village, in Long Beach. The Village marked a departure from the normal mental health services offered in Los Angeles at the time. First of all, The Village devoted a significant amount of resources – over 77% of its funding – towards helping consumers build skills and expand on their strengths, instead of just trying to treat their symptoms. They were also given a voice in determining what kind of services they would receive, and activities were tailored to what consumers requested. The approach was a novel one, as the focus of services shifted from treating mental illness itself towards treating the person as a whole.



The success of this approach was striking. Consumers and families reported higher satisfaction with services at The Village than they did in other programs; Village consumers were more likely to live independently, more likely to get a job, and less likely to be institutionalized than those receiving traditional services; perhaps most importantly, individuals at The Village reported having greater feelings of hope and optimism, and researchers also found that they experienced more symptom improvement than others in the public mental health system.



Optimistic about the success of the Assembly Bill 3777 programs, California passed legislation to create more ISA-type services with Assembly Bill 34 in 1999, and Assembly Bill 2034 in 2000. When expanded, these programs again demonstrated that the recovery model could produce positive outcomes for consumers, both in Los Angeles County and throughout California.

Formally trained providers and government officials were not alone in their work to transform the vision of recovery into a reality in the 1980s and 1990s. Consumers began to play an integral role on the policy level, particularly by embodying the principles of empowerment and self-help with their actions. Both as individuals and in organized groups and coalitions, the mentally ill began working to make their voices heard in Los Angeles and throughout California. When officials in Sacramento made decisions that affected the provision of mental health services, consumers were consistently there to let them know what they wanted, and that they would not be ignored.



In Los Angeles County in particular, consumer empowerment began to reach new heights in the 1990s. Under the leadership of directors Areta Crowell and Marvin Southard, the Los Angeles County Department of Mental Health established the county's client coalition to give consumers a unified, effective voice in shaping how decisions concerning their services were made. Community-based organizations, such as the Mental Health Association of Los Angeles (now Mental Health America of Los Angeles) and Pacific Clinics also made a point to give consumers an opportunity to have a say in programmatic decision-making and engage in self-help activities. In 1992, Project Return, a network of self-help organizations, became client run, and thanks to the leadership of consumers such as Bill Compton, it continued to grow and work to "help people to help themselves." With the subsequent development of Wellness Centers, mental health providers in Los Angeles County began to provide a new type of recovery-driven services, with a focus on peer support and improving consumers' overall quality of life.



By 2000, recovery was becoming the standard in public mental health care systems across the country, and gaining support from both governmental and professional organizations. In 1999, the Surgeon General issued a report on mental health that recommended a recovery orientation for the nation's mental health care system. In 2003, the President's New Freedom Commission on Mental Health issued its final report, and citing The Village as an example, recommended that recovery become a guiding principle as mental health systems across the country transformed. In 2004, the American Psychological Association issued its best practices for recovery-oriented treatments, and the following year, the American Psychiatric Association followed suit.



California, and Los Angeles County in particular, have become national leaders in the move towards the recovery model in the last decade. In 2000, the Los Angeles County Department of Mental Health, together with community partners and stakeholders including consumers, family members, and representatives from other agencies, completed a plan for a Comprehensive Community Care system. In 2004, the County announced that it would adopt the recovery model as the official orientation of its service delivery system, and that it would establish guidelines to help providers shift their services towards recovery. According to the County, recovery was to be "based on self-determination and partnership of mental health clients in the system of care itself and community life including meaningful activity and gainful employment." That same year, voters in California approved the Mental Health Services Act (MHSA), a piece of legislation that was designed to create a recovery-based system of care.

"I would define the recovery model first as it is defined in the Mental Health Services Act, which means that you have a totally voluntary system of services – totally voluntary – that is committed to the belief that people can get well and that affirms people's rights to self-determination and to make choices about – within their limits and within their abilities to pay – where they want to live, what they want to do, do they want to go back to school, do they want to get a job, do they want to be an artist? You know, what will be a meaningful way for them to contribute their core gift to society? It's the notion that everybody has something to give and that if we are willing to affirm that, we can find a way to help people do that."

Catherine Bond, M.F.T.

From the individual who has just received a diagnosis to the psychiatrist charged with his or her care to the policymaker who designs mental health systems, recovery has had a significant impact on what it means to receive and to give mental health services in the past few decades. Yet in spite of the changes it has brought about, the meaning of recovery-oriented mental health care is strikingly simple. As Dr. Susan Mandel, the President and Chief Executive Officer of Pacific Clinics says, a recovery-oriented approach to mental health services revolves around providers asking consumers one question, and sticking to one service philosophy:

"What do you want to go do, and how can I help you do it?...You don't focus on only the problem, you focus on what you want to do and how I can help you do it."