Inclusive Livable Communities for People with Psychiatric Disabilities

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Executive Summary

> I thought my life would be sitting at home smoking cigarettes and drinking coffee, and then I saw an ad in the paper that said they were looking for a director, someone who's had an experience with mental illness, and it was like, wow! And I met with the board and I just felt I had come home. I love what I do, I love the people I work with. I think it's karma, serendipitous, that I was supposed to be here.
> —*Doug DeVoe, Executive Director, Ohio Advocates for Mental Health*

The Livable Community Framework

Two reports of the National Council on Disability (NCD), *Livable Communities for Adults with Disabilities*[1] and *Creating Livable Communities*,[2] set forth a livable community framework. These reports propose necessary changes in public policies regarding housing; transportation that is reliable and accessible; environments that are physically accessible, including work, education, and health care; and opportunities for participation in social and recreational activities. The intention of such change is to ensure that people with disabilities have all the opportunities and choices available to people without disabilities. All of these elements of change, with the exception of the accessibility of the physical environment, clearly apply to the estimated 24.6 million people with psychiatric disabilities.[3] There is an additional accessibility need for people with psychiatric disabilities: attitudinal barriers continue to prevent people with psychiatric disabilities from full participation, barriers that provide segregated settings and prevent true community integration. To ensure full participation in the community by people with psychiatric disabilities, this report expands NCD's livable community framework to be fully inclusive.

Major Findings

This section presents summary findings linking elements of the livable community framework to mental health recovery, including descriptions of concrete needs essential to all people with disabilities, such as housing and employment. The summary then

moves to a discussion about stigma and discrimination as a major barrier to full participation in society for people with psychiatric disabilities.

Housing: The Key Need

The findings are linked to the element of a livable community that provides affordable, appropriate, accessible housing. Housing is a major element of the livable communities framework. Like people with physical disabilities, people with psychiatric disabilities want to live in mainstream, integrated housing.

To promote recovery and community integration, people with psychiatric disabilities need safe, affordable housing in noncongregate settings, where they can stay as long as they wish, and where they have access to supports of their choice as needed to maintain their community tenure. This model is known as "supported housing." While most people with psychiatric disabilities no longer live in large state institutions (as a result of the deinstitutionalization movement of the 1960s to 1980s), many are living in congregate housing that often does not meet their housing preferences, and they remain segregated from other people. Other people with psychiatric disabilities are homeless, and some have ended up in jails and prisons.

However, NCD recognizes that different perspectives exist. While some mental health professionals believe that congregate housing linked to mental health services is the best form of housing for people with chronic mental illnesses, the review of available data for this paper revealed other approaches. Not all of the approaches identified in this paper have been widely replicated, yet a growing body of research evidence shows the applicability of several alternative programs, such as supported housing, wherein people choose where they live rather than being required to live in a place because of their disabilities. Supported housing provides information about supports and services available in their communities. The concept of choice involves all segments of the population, including people who have been homeless. For example, a "housing first" approach, which moves people directly from homelessness to their own apartments, is one of the most exciting developments in housing for people with mental illness.

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Employment

Employment is another essential element of the livable communities framework. The belief that people with serious mental illnesses cannot work, coupled with a public benefits system that penalizes efforts to maintain employment, has contributed to disproportionate numbers of people with serious mental illnesses being unemployed (compared not only to the general population, but also to people with other kinds of disabilities). The evidence shows that people with mental illnesses can work when they are provided the right mix of services and supports. For people with psychiatric disabilities, this model is called "supported employment." For many years, the most prevalent kinds of work available to people with psychiatric disabilities has been segregated entry-level work in which they could never earn enough income to live independently. The shift during the 1990s to supported employment for people with psychiatric disabilities has shown that meaningful work must be based on the individual's skills and preferences, that the supports need to continue on a long-term basis (rather than being time limited), and that people with psychiatric disabilities are capable of working at jobs ranging from entry level to professional and managerial.

Among the innovations that have enabled many people to return to work are self-help programs run and controlled by other people who have recovered from mental illnesses. People in such leadership roles, often called "consumers/survivors," provide role models, and the programs offer a wide variety of jobs in a supportive setting. Such programs are growing and have shown their efficacy in states that have provided sufficient funding.

Stigma and Discrimination

Visible barriers to the mainstream environment create the main obstacles facing people with many mobility disabilities and prevent their inclusion in the livable communities framework. Although the majority of people with psychiatric disabilities are not hindered by these visible barriers, another barrier that they face—even within the mental health field itself—is no less real: pervasive stigma and discrimination. This is analogous to the sensory, physical, and intellectual barriers faced by people in the physical disability

population. As recognized by the latest anti-stigma campaign jointly funded by the U.S. Department of Health and Human Services (HHS) and the Advertising Council (Ad Council), regretfully, stigma and discrimination are prevalent throughout society. People who have recovered from mental illnesses and have first-hand knowledge and involvement with consumer/survivor-run self-help programs need to be included in designing future anti-stigma efforts.

Core Recommendations

Through an expansion of the livable communities framework to include people with psychiatric disabilities, NCD builds upon recommendations in its 2004 and 2006 reports. In this paper, by examining a variety of programs that show promise or have proved successful in achieving community integration for people with psychiatric disabilities, NCD recognizes the need for major changes in public policies to support further efforts for full integration and participation. Five core recommendations summarizing some essential federal-level changes follow.

Core Recommendation One: Congress should ensure that HHS appropriations continue to support anti-stigma campaigns and expand efforts to provide a funding base for self-help programs operated and run by mental health consumers and survivors, analogous to the funding provided under the Rehabilitation Act for operation of independent living centers. Consideration should be given to implementation through HHS/Substance Abuse and Mental Health Services Administration (SAMHSA) reauthorization or other federal mechanisms. Consumers/survivors should be included in the evaluation of ongoing anti-stigma campaigns and the design, development, and expansion of self-help program funding.

Core Recommendation Two: Implement changes in federal and state funding and policy to encourage housing models that are integrated, in accordance with individual choice, and delinked from mandatory health services, while providing ongoing flexible supports. Several federal agencies should examine policies and practices through a

partnership effort. The work can begin with congressional action to ensure removal of contradictory or incompatible federal paperwork burdens and policy barriers. Congress should provide the funding needed for initial joint planning and reporting by the Department of Housing and Urban Development (HUD), HHS, and the Social Security Administration (SSA).

Core Recommendation Three: Congress and HUD, HHS, and SSA should work to change federal and state funding and policy to eliminate the "benefits trap," which discourages people with psychiatric and other disabilities from working, and to ensure that work opportunities are available for the full range of jobs, with ongoing flexible supports.

Core Recommendation Four: HHS should be authorized to change Medicaid policy and regulations as implemented by the Centers for Medicare and Medicaid Services (CMS). The agency should examine and consider the merits of existing models; for example, the Michigan state model reframes the definition of "medical necessity" to include "community integration," and shifts funding to services based on "person-centered planning." Such changes would allow a broader variety of recovery-oriented services to be eligible for Medicaid funding than is available currently.

Core Recommendation Five: Congress should ask the Government Accountability Office (GAO) to assess and identify indicators of practices that seem to be working in HHS efforts to address cultural and linguistic issues through initiatives like the National Center on Cultural Competence (NCCC). In addition, Congress should allocate funds to expand the NCCC cultural and linguistic competence training model to ensure that as national demographics change, services to people from diverse racial and ethnic groups are provided in ways that meet their self-defined needs.

By ensuring the expansion of the livable communities framework and recommendations to fully include and integrate people with psychiatric disabilities, American society can provide all citizens the opportunity to become part of the American dream. As one participant in a self-help group found,

For many years I felt no hope. It was getting involved in self-help that changed my life; before that, I never felt like a "usual person." I never had the opportunity to be in an environment where I could feel competent and capable.
—Lenora Kimball, Executive Director, Stepping Stone and the Next Step Peer Support and Crisis Respite Centers, Claremont, New Hampshire

Chapter One: Introduction to Livable Communities for People with Psychiatric Disabilities

In 2004, the National Council on Disability (NCD) issued a comprehensive report, *Livable Communities for Adults with Disabilities,*[4] which contained a number of specific recommendations to promote the full integration of people with disabilities. The follow-up NCD report in 2006 was *Creating Livable Communities.*[5] NCD identified six elements that are integral to improving the quality of life for all citizens—including children, youth, and adults—with disabilities. For the promise of full integration into the community to become a reality, people with disabilities need safe and affordable housing; access to transportation; access to the political process; and the right to enjoy whatever services, programs, and activities are offered to all members of the community by both public and private entities. Although the NCD reports addressed people across the full array of disabilities, a main focus of accessibility was on environmental elements that primarily apply more to the "obvious" disabilities than to "hidden" disabilities like many psychiatric disabilities and mental illnesses. Information about the six identified elements of livable communities, other elements, barriers, and promising practices for people with psychiatric disabilities needs to be broadened to achieve all-inclusive communities.

This paper focuses specifically on expanding the livable communities framework and elements to people with psychiatric disabilities and supports full inclusion that leaves out no one. NCD has previously recognized this need for inclusion in its 2000 report, *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves,*[6] a paper on mental health status, and a letter to Congress.[7]

The 2004 and 2006 NCD reports present a framework for livable communities for adults with disabilities and federal policy and program examples in action that emphasize livable communities. Grounded in the six identified elements, a livable community

1. Provides affordable, appropriate, accessible housing

2. Ensures accessible, affordable, reliable, safe transportation

3. Adjusts the physical environment for inclusiveness and accessibility

4. Provides work, volunteer, and education opportunities

5. Ensures access to key health and support services

6. Encourages participation in civic, cultural, social, and recreational activities

When the focus shifts specifically to people with psychiatric disabilities, it becomes plain that without expansion this framework is insufficient to ensure the full integration of all people who have disabilities. The main barrier that people with psychiatric disabilities face is that a community that eliminates all the physical environment barriers still may not be fully accessible to people with psychiatric disabilities because of ingrained attitudes toward mental illness. Before people with psychiatric disabilities can even begin to take full advantage of the elements of the livable communities framework, they must be able to surmount an attitudinal barrier.

The attitudinal barrier is exemplified by policies, programs, and beliefs about people with psychiatric disabilities as needing to receive all services within segregated settings in which mental health providers deliver housing, work, education, health care, and support services entirely within the mental health system. Abolishing this attitudinal barrier is necessary to ensure that people with psychiatric disabilities have access to the wider community and all that it may offer.

Fortunately, the mental health field is evolving toward a model based on recovery—the belief that every person diagnosed with a mental illness is capable of living a full life in the community.

In 1999, the U.S. surgeon general issued a comprehensive report on mental health[8] that recognized the value of consumer self-help and consumer-operated services in promoting positive outcomes for people diagnosed with serious mental illnesses.

In 2003, the President's New Freedom Commission on Mental Health issued its final report.[9] Goal Two of the report recommended a shift toward a system that is consumer-

and family-driven, community-based, and that ensures that people diagnosed with mental illnesses have access to the supports and services they need to live integrated lives in the community. The commission found that the current mental health system is fragmented and makes it difficult for people to access housing and employment.

Efforts at the federal level in late 2006 were designed to effect the transformation of the public mental health system through comprehensive reform. The efforts focused on recovery and the reduction and eventual elimination of stigma and discrimination. On December 4, 2006, the Substance Abuse and Mental Health Services Administration (SAMHSA) of the U.S. Department of Health and Human Services (HHS), in partnership with the Advertising Council (Ad Council), launched a national awareness public service advertising (PSA) campaign designed to decrease the negative attitudes that surround mental illnesses and encourage young adults to support their friends who are living with mental health needs.[10] Then-Acting Assistant Surgeon General Rear Admiral Kenneth P. Moritsugu, M.D., M.P.H., told a reporter,

> [A] mental illness is not something to be ashamed of. It is an illness that should be treated with the same urgency and compassion as any other illness. And just like any other illness, the support of friends and family members is key to recovery.[11]

Also in December 2006, SAMHSA issued its National Consensus Statement on Mental Health Recovery. The statement defines "recovery" as follows:

> [A] journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.[12]

The Consensus Statement also identified 10 essential elements of recovery, finding that recovery is self-directed, person centered, related to empowerment, holistic, nonlinear, strength-based, involves peer support, requires respect, promotes responsibility, and fosters hope.

Another significant action was the Supreme Court's 1999 decision in *Olmstead v. L.C,*[13] in which the Court decided that institutionalizing people when their treating professionals believed they could live safely in the community was a form of discrimination prohibited by the Americans with Disabilities Act (ADA). Although *Olmstead* has had limited results in actually moving significant numbers of people with mental illnesses out of institutions, it has led to the formation of *Olmstead* implementation plans in most states and is a valuable tool for advocates in promoting community living.

Terminology

There are a number of terms commonly used to refer to the population described in this paper: "people labeled with psychiatric disabilities," "people with mental illnesses," "mental health consumers," "psychiatric survivors," and a number of others. Sometimes diagnoses are included, as in "schizophrenics," "people with bipolar disorder," and so forth. In this paper, NCD has determined that the terminology used in its 2000 report, "people labeled with psychiatric disabilities," best captures the identity and experiences of the population. However, because the field uses such a wide diversity of terms, including terms used by people with psychiatric disabilities themselves, this paper will include a variety of terminology used by people quoted herein. The exceptions are editing choices such as removing terms considered detrimental to the community, NCD's mission, and ensuring the use of "people first" language.

This paper was prepared through an examination of available research and through interviews with 22 key informants. Because the psychiatric research literature often does not include the perspectives of people with psychiatric disabilities themselves, it was deemed necessary to look outside the traditional academic literature and to include organizations of people with psychiatric disabilities and their publications.

Chapter Two: The Recovery Model and Its Implications

> I thought my life would be sitting at home smoking cigarettes and drinking coffee, and then I saw an ad in the paper that said they were looking for a director, someone who's had an experience with mental illness, and it was like, wow! And I met with the board and I just felt I had come home. I love what I do, I love the people I work with. I think it's karma, serendipitous, that I was supposed to be here.
> *—Doug DeVoe, Executive Director, Ohio Mental Health Advocates*

What Is the Recovery Model?

The recovery model marks a fundamental change in the way people diagnosed with psychiatric disabilities are viewed. Unlike the medical model, the recovery model was developed by people who themselves had experienced psychiatric disabilities and mental health treatment. Rather than being an academic construct, the recovery model is based on the *lived experiences* of people who recovered and who recognized that there were valuable lessons to be learned from these experiences—they were not exceptional and could be replicated.

Following are the basic principles of the recovery model:

- Recovery is real and possible for everyone.

- Recovery is the gaining or regaining of valued social roles of the individual's choice.

- Recovery is *not* cure.

- Recovery is *not* symptom reduction as an end in itself.

- Medication may be a tool in people's recovery, but it is not the focus.

- Recovery is an ongoing journey, facilitated by the right mix of services and supports.

- Recovery has an end point, at which point the individual faces only the "normal problems" experienced by people who have never been diagnosed with a mental illness.

The journey to this point was long and arduous for consumers and advocates working for decades to bring about change. An indication of success was the inclusion of recovery in *Transforming Mental Health Care in America, Federal Action Agenda: First Steps* as the "single most important goal" for the mental health service delivery system.[14] Demonstration of a change in thinking was attributed to leadership by HHS in partnership with federal, state, local, consumer, advocacy, service provider, private, and nonprofit entities. Another step toward building a more effective public mental health system was the release of a National Consensus Statement on Mental Health Recovery.[15] Other positive steps include looking at promising practices and examining recovery models that seem to be working across the nation.

An Empowerment Model of Development and Recovery[16]

The empowerment model describes how all people go through cycles of development and healing as part of growth. However, life may be interrupted by common traumas (for example, a death in the family, loss of a job or love relationship, natural disaster, and so forth). The person may then move into a cycle of accommodation and adaptation. Trauma can lead to diminished mental functioning and severe distress, which can develop into post-traumatic stress disorder (PTSD).

Empowering interventions, which can include a variety of natural supports and also medical, psychological, and psychiatric treatment, help the person to heal from trauma and to return to the upward spiral of development and healing. For some people, however, because they lack support, severe distress instead can result in the person receiving a diagnosis of mental illness, leading to a loss of social role. At this point, the person enters the cycle of recovery and independent living. A person with a diagnosis of a mental illness often becomes separated from the rest of society and is viewed as experiencing something qualitatively different from the expected cycles of trauma and healing. Once a person has such a diagnosis, it becomes much more difficult, but not impossible, to return to the cycle of accommodation and adaptation, and eventually to the upward spiral of development and healing.

Empowering interventions can take place when the person is in the cycle of recovery and independent living. The essential features of these interventions and how they can be made available to people who have been diagnosed with mental illnesses will be described throughout this paper. Unfortunately, for many people, once they have received a diagnosis of mental illness, they are often viewed as incapable of healing and recovery, making it more difficult for them to return to mainstream life. This entire process will be described more fully in the chapters that follow.

Because the word "recovery" may be interpreted by some people to imply "cure," it is important to stress that perhaps the closest equivalent terminology in the general disability field is "independent living." A person who has recovered may (or may not) continue to experience "symptoms," but these are better seen as normal problems in living. A person who is recovering or has recovered needs an individualized menu of services and supports that help him or her to achieve and maintain the valued social roles of his or her choice. Such supports, especially when an individual is in the latter stages of recovery or has recovered, may come entirely from outside the formal mental health system.

Fulfilling valued social roles is the key element in the recovery model. Every person fills many social roles, such as worker, student, family member, and so forth. When a person is diagnosed with a mental illness, one common result is the loss of social role—the person may leave school; lose his or her job; or lose family, friends, and love relationships. The only social role left to the individual is that of "mental patient," clearly not a valued role or one that people aspire to attain. The process of recovery, therefore, is one in which the individual is assisted to regain the role(s) he or she has lost, or to move on to new roles of his or her choice.

Recovery and Independent Living

There are powerful parallels between the recovery movement for people with psychiatric disabilities and the independent living movement, which has been primarily for people

with more "visible" disabilities (although, as will be described in Chapter Three, many independent living centers also serve people with psychiatric disabilities). The National Council on Independent Living has described the essential elements of independent living as follows:

> Consumer choice, autonomy and control define the Independent Living Movement. The independent living philosophy holds that individuals with disabilities have the right to live with dignity and with appropriate support in their own homes, fully participate in their communities, and to control and make decisions about their lives.[17]

Whether one speaks of "recovery" or "independent living," the principles are the same—personal autonomy, a mix of supports as defined by the individual to assist in the achievement of personal goals, and the full range of opportunities available to people without disabilities to live a full and satisfying life.

Chapter Three: Housing—The Key Element

Programs or Homes?

It should go without saying that decent, safe, affordable housing is a basic component of successful community living. Yet many people with psychiatric disabilities who are not living integrated lives are housed in programs that restrict their independence. In addition, people with psychiatric disabilities comprise a large segment of the homeless population. Many people with psychiatric disabilities who are poor and living on welfare or disability benefits often cannot afford market-rate housing and have few choices for housing outside of what is offered by the mental health system. Although there are some model programs that provide housing where people are not segregated by disability, the vast majority of mental health housing is congregate and is not the kind of housing people would choose for themselves.

The California Network of Mental Health Clients, a statewide self-help organization, conducted a Board and Care Project and issued a report[18] on that state's extensive network of private, for-profit group housing, which allowed many board-and-care residents to voice their dissatisfaction. As one participant, Elaine, described,

> I lived in two board and cares in the past—the experience was so bad I would do anything—do you understand *anything*?—to stay out of those places. It was not my choice to live in a board and care . . . the abuse could be subtle and hard to put your finger on, or it could be right there.
>
> The food was just awful, awful . . . every night, or almost every night, we ate this horrible pork and rice mixture. The operator had a big white dog, and every night as we were eating that stuff she would cut up a big steak and give it to the dog. It felt so bad to be jealous of a dog. The owner lived across the street. She always had new cars sitting there, but we were never allowed to go over there except when she hired us to clean—she would pay us with cigarettes or desserts, not money, and sometimes she would find a reason not to give you what you had earned—it was like she and her relatives were royalty and we were slaves.
>
> They always bought the cheapest of everything and for a while, we even had to buy our own toilet paper from the operator out of our P&I money, which, of course, the board and care controlled. There were always games over money,

being fined for this, finding out you were always wrong about how much you had. Now, how could they be right all the time and all the residents be always wrong? I'm sure they had money of mine when I left, but I was just so glad to leave, I never asked for it. . . .

There were the times we were locked out sometimes till late at night when they got home from parties and things. They told us to wait at the doughnut shop, but you could not sit at the doughnut shop for hours, so sometimes we just had to walk around in the rain. It made you feel worthless.

I also suspect they gave out medication illegally. One time I was upset and they tried to get me to take pills that I knew were not mine. . . . As far as physical care, colds and toothaches or cuts and things, it was really nonexistent—there was no care. . . .

I finally went into the hospital for a while, and when I came out, lived with a friend—I was determined not to go back to another home. Now I have my own place, have for a while. It's so good to talk about all this and get it out—I hope it helps other people who are still going through stuff like that.[19]

In New York State, there has been an ongoing series of scandals concerning for-profit adult homes, which house an estimated total of 15,000 people in large facilities (averaging 150 beds). Deplorable conditions were found, including rat infestations, inadequate food, untrained people giving out medication, residents being subjected to unnecessary medical procedures for financial gain, and numerous other atrocities. Despite repeated investigations, fines, and even operators being sent to prison, these homes continue to be the only housing available for many people discharged from state hospitals in that state.[20]

Other typical housing arrangements for people with psychiatric disabilities include halfway houses and group homes. In most cases, people are required to share a room with another person they have no role in choosing, and must share bathrooms with multiple people. Meals are served at set times, and residents do not get to choose the foods they want. Personality conflicts and similar difficulties, rather than being attributed to the stresses of living closely with others, often are considered part of the person's symptomatology. Most housing programs run by mental health authorities require participation in treatment programs as a condition of remaining in the housing. Typically,

they require residents to be home at a particular time at night, and many also require that the resident be out of the house during the day. These rules can conflict with a person's attempt to become more independent—for example, when an individual is threatened with losing housing because scheduled work or school interferes with times he or she is required to be at the house.

Although the mental health system would describe the person living in a board-and-care home or a mental health community residence as being "in the community," the examples cited in this paper show that the person is living a segregated life and has very little meaningful interaction with people other than mental health clients or staff. Based on available data, the perceptions of mental health staff and people with psychiatric disabilities concerning the kinds of housing people "need" are very different. A review of 26 studies on consumer preferences in housing found that approximately 60 percent of survey respondents preferred to live in integrated housing, either alone or with a spouse or partner, and did not want to live primarily with other people with psychiatric diagnoses.[21] A different study by the American Academy of Clinical Psychiatrists (AACP) found significant differences between what individuals wanted for their own housing and what clinicians, family members, and the general public thought were most important:

- Consumers stated that they were largely limited to housing provided through the mental health system, which had many programmatic requirements and which they found coercive.

- Consumers preferred to live in independent, integrated housing; many clinicians, family members, and the community at large preferred that they live in group-living environments that are closely supervised and highly structured.

- Consumers tended to think of housing choice as a fundamental right, regardless of whether they chose to participate in recommended treatment or programs, while many clinicians believed that providing housing without linking it with services was clinically inappropriate.[22]

The current prevailing model is "supported housing," in which a combination of flexible supports is used to help individuals find and maintain housing of their choice. However, supportive housing terminology is used to describe a wide variety of programs, not all of which are independent, integrated housing approaches.

For example, the story of Elaine (above), the resident of a California board-and-care home, shows a model of housing that, while it is technically "in the community," retains nearly every feature of institutional living. Sadly, this is the reality of "community" for large numbers of people with psychiatric disabilities who are no longer residing in state hospitals but remain institutionalized in every sense of the word.

Programs that enable people to experience integrated lives are very different. A tenant of Main Street Housing, a subsidiary of On Our Own of Maryland (a program that is described below), is just that—a tenant, living in an apartment. The program executive director, Ken Wireman, describes how Main Street Housing works:

> One of our first tenants was a woman who had lost custody of her daughter, mostly because of her psychiatric label. Obviously, it was very distressing to her, and the main thing in her life became getting her daughter back. But she was caught in a typical bureaucratic "catch-22"—the Department of Social Services said she had to have a two-bedroom apartment in order for them to return her daughter, but no housing authority would rent her a two-bedroom unit as a single person. Main Street Housing was able to meet her need, and when she moved into a two-bedroom apartment she regained custody of her daughter. Obviously, this had a very positive effect on her mental health! She is still living in the apartment and is doing very well.[23]

As these two stories make clear, there are fundamental differences between living in a home of one's own and living in a mental health program dwelling. Among the key elements are choice, integration, tenancy, and length of stay.

Choice: Like other people in society, people with psychiatric disabilities have clear preferences about how they want to live. They want to be able to choose, among other things, the type of housing in which they live, the neighborhood, with whom they live (if they choose not to live alone), what and when to eat, whether or not to participate in

mental health services (and, if they want services, to choose the ones they want), and how to schedule their days.

Integration: Given the choice, people with psychiatric disabilities want to live in ways that make them indistinguishable from everyone else. Also, given the choice, they would not live in housing that is identifiable as a mental health program or associate only with other mental health clients.

Tenancy: Housing provided by programs such as Main Street Housing or Pathways to Housing (described below) view people living in the housing as tenants, rather than clients or patients. They are expected to fulfill the requirements of tenancy: paying the rent on time, maintaining the property, and observing neighborhood practices or expectations. People living in housing identified with the two programs sign leases; people living in programmatic housing often have to sign agreements, for example, to take prescribed psychiatric medication or attend day programs, requirements that have nothing to do with housing desires or choices.[24]

Length of stay: As tenants, people can stay in their housing for as long as they choose to lease. In programmatic housing, there may be prescribed lengths of stay, based on clinical diagnosis or other mental health considerations. The housing is considered a "slot" rather than the person's home, and an individual may lose the "slot" for many reasons, including being hospitalized for a brief period.

Housing is a key element in well-being and recovery. It is difficult to imagine how anyone, particularly a person who may be dealing with the stresses of recovering from a mental illness, can be expected to do well without a secure and safe place to live. Yet the data on housing and mental illnesses shows that homelessness and inadequate housing continue to be major problems.

There is also a strong disconnect between the kinds of housing that are available and consumer preferences, although studies have shown that consumer choice plays a significant role in housing satisfaction and tenure.[25] Therefore, unmet needs include

strengthening the role of consumer choice and increasing the supply of independent, integrated housing, while decreasing the amount of congregate housing. SAMHSA has recognized the importance of consumer choice in housing and the role of housing in promoting recovery.[26]

Two Model Programs

In New York City, a program called Pathways to Housing, in operation since 1992, takes people who are both homeless and have chronic mental illnesses (who also often are substance abusers) and moves them directly into permanent individual apartments, providing support services on site as needed. The "housing first" approach shows promise, as described in a newspaper article:

> Shopping for telephones is what finally drove it home to Tony Bartol that he was reentering that almost-forgotten world where the sidewalk was not his bed. He stood in front of a wall lined with 200 of them in plastic packaging—white phones with speakers, black ones with six lines, red ones with voice mail—and scratched his head, confused.
>
> "I have no idea what to pick here," he said. His hand trembled as he touched one, then another. "The last time I owned a phone was 1977."
>
> A few weeks before, Bartol was sleeping in Manhattan subway stations, so [affected by a mental illness] he could barely pluck reality from the visions of God in his head. He'd been that way for 19 years. On this day in mid-May, the 54-year-old, bushy-bearded string bean of a man was in a department store with two social workers, shopping for a few essentials before moving into his own apartment.
>
> He was still delusional, still without a job, and still not on the medication he needed to address his psychosis. . . . Now, he had one angel over his street-tough shoulder that other homeless people [with mental illnesses] still foraging in alleyways didn't— a program called Pathways to Housing, a New York-minted twist on the "supportive housing" model of tackling chronic homelessness in urban America.
>
> Unlike other cutting-edge supportive housing techniques in New York, Philadelphia, Chicago—and being embraced in San Francisco—in which people who have experienced chronic homelessness are moved en masse into

residential hotels with onsite social services, Pathways to Housing moves them straight off the street and gives them their own, individual apartments apart from other homeless people, alongside average New Yorkers. And unlike virtually any other program in the country, it does this with the hardest core population of them all: the [people with mental illnesses].

"God has a plan for me," said Bartol, as he loaded a $16.95 Coby phone into his shopping basket. "I don't know what it is, but I know this: I've got to move inside, or I'll die." He clenched his teeth, then let a hint of smile creep onto his lips.

"I think these guys can do that for me," he said, gesturing to the Pathways social workers. "They're the only counselor types I ever met who were just straight up with me."[27]

The philosophy behind this "housing first" approach is described by Pathways to Housing as founded on the belief that housing is a basic human right and that all services should be offered with respect, compassion, and in the spirit of hope and recovery.[28] On one hand, among clinicians and the general public, a widely held belief is that people who are homeless and have mental illnesses need to be placed in closely supervised housing. However, a five-year study that compared the housing-first approach with traditional housing continuum models (in which people who are homeless and with mental illnesses are placed in a series of gradually more-independent living situations) found that 88 percent of Pathways to Housing clients were housed at the end of the study, compared with only 47 percent of clients in New York City's residential treatment system.[29] Supportive services are offered to Pathways clients, but the intensity is determined by the client. There also is no requirement that individuals be drug- and alcohol-free before being housed. About half of the program's staff consists of former housing-first program clients.[30] In 2005, Pathways to Housing was awarded an American Psychiatric Association Gold Award for Innovative Mental Health Service Programs.[31]

While the housing-first model has been highly praised and replicated, not all programs that claim to use the model actually follow all of its elements. Some programs, such as Seattle's, that claim to be a housing-first model, use congregate housing. They maintain the program's philosophy of giving housing immediately, but the housing is in a facility

where all the residents are housing-first clients.[32] Therefore, not all "housing first" approaches promote true community integration.

Another housing program that takes an innovative approach to integrated permanent housing is Maryland's Main Street Housing, a subsidiary of On Our Own of Maryland, a consumer-run statewide organization. Main Street Housing purchases buildings in scattered sites, renovates the units, and rents them out to people with psychiatric disabilities. The only program requirements are the traditional requirements of tenancy, and people can stay in the apartments for as long as they like, according to their lease terms. As Ken Wireman, Main Street Housing's executive director, puts it, "A tenant is a normal societal role that has normal responsibilities."[33]

Another innovative aspect of Main Street Housing is the use of community development funds, rather than just mental health sources, thereby expanding the range of funding available for housing people with psychiatric disabilities.

To ensure the availability of safe, secure, integrated housing that meets consumers' housing preferences, coordinated local, state, and federal efforts are necessary. It is important to ensure that people diagnosed with mental illnesses are included in overall housing efforts and are not segregated in special mental health housing with their own funding streams. This approach is supported by the surgeon general's report, which found

> [S]upported housing focuses on consumers having a permanent home that is integrated socially, is self-chosen, and encourages empowerment and skills development. The services and supports offered are individualized, flexible, and responsive to changing consumer needs. Thus, instead of fitting a person into a housing program "slot," consumers choose their housing, where they receive support services. The level of support is expected to fluctuate over time. With residents living in conventional housing, some of the stigma attached to group homes and residential treatment programs is avoided.[34]

Recommendations

The Department of Housing and Urban Development (HUD) should serve as the lead agency for each of these recommendations pertaining to housing needs. However, where changes in federal legislation or policy outside that agency are needed, Congress should provide the necessary supports.

Recommendation One

Housing for people with psychiatric disabilities should be based on consumer choice, provided in integrated settings, and be delinked from mental health programming. Housing needs to be seen as a fundamental element of community integration and recovery. Housing people in the housing of their choice promotes long-term stability and increases successful outcomes. Congress should ensure that funding is designated to appropriate federal agencies for shifting from congregate settings to individual, scattered-site houses and apartments in which people are general tenants, not mental health clients.

Recommendation Two

HHS should work jointly with HUD on a plan to promote integrated housing choices. This plan should include conducting research comparing various housing models, and funds for implementation of effective housing models should be based on the findings of that research. Furthermore, the housing models funded should demonstrate value given to consumer choice and satisfaction based on input from people with psychiatric disabilities.

Recommendation Three

HUD should examine and adjust its programs for the general population. Generic housing programs should include mental health consumers in a nondiscriminatory way. Mental health authorities should not be the sole administrators of housing funds for mental health clients. In addition, including mental health clients in general housing efforts will promote integration and prevent the perpetuation of segregation of mental

health housing—that is, the existence of enclaves in which all residents are people diagnosed with a psychiatric disability.

Chapter Four: Real Jobs at Real Wages

Modern mental health treatment philosophy is based on the premise that people with mental disorders have the right to live and work in the community. To realize these goals, people with mental disorders must be able to access appropriate community-based treatment and rehabilitation services and safe and affordable housing and should have equal access to employment opportunities that are commensurate with their skills, interest, and training.[35]

The Importance of Work

People diagnosed with mental illnesses face high levels of unemployment, which, of course, creates additional barriers to community integration. Without jobs, people are dependent on benefits, which keep them in poverty, and they are also deprived of a meaningful social role. One study found that people with mental disabilities were unemployed at a rate three to five times higher than the rate for people without disability labels; the study reports an unemployment rate for people with a diagnosis of schizophrenia estimated as high as 90 percent.[36] Among the factors that contribute to high unemployment are stigma and discrimination, financial benefits policies that discourage work, the belief by many clinicians that work is "too stressful" and contributes to relapse, and interrupted and spotty work histories. This study found the following:

> Historically, competitive employment has not been a major focus of the mental health system. There has been a tendency to adopt minimal expectations and lower standards of achievement for people with a mental disorder. Sociostructural barriers and disincentives have also made it difficult for people with a mental disorder to get in and stay in the competitive workforce. Modern mental health treatment philosophy is, however, based on the premise that people with mental disorders have the right to live and work in the community. To realize these goals, people with mental disorders must be able to access appropriate community-based treatment and rehabilitation services and safe and affordable housing and should have equal access to employment opportunities that are commensurate with their skills, interest, and training. All too often, stigma, expressed through a lack of political commitment to provide adequate services, community intolerance toward people with [mental illnesses], and

employment inequity, makes this impossible. As stigma is so pervasive and the consequences so profound, international organizations such as the World Health Organization and the World Psychiatric Association have identified stigma related to mental illness as the most significant challenge facing the field of mental health today.[37]

The findings above indicate the difficulty of teasing out the interrelated factors of housing, work, and stigma/discrimination as obstacles faced by people with psychiatric disabilities.

For many years, the prevailing belief among mental health clinicians was that people with severe mental illnesses could not work in competitive employment, and the jobs that were made available were in sheltered workshops, where the work was extremely low skill, wages were far below the minimum, and all employees were people with disabilities. In recent years, there is increasing evidence that people with psychiatric disabilities can work competitively, and the model of supported employment has been used. In this model, the individual with a psychiatric disability works in a competitive job commensurate with his or her abilities and interests and support is provided in individually tailored ways that may include on/offsite job coaching, peer support groups, or whatever else the individual finds useful in maintaining the job.

The Shift to Competitive Employment

The shift from sheltered workshops to competitive employment has been shown to be effective in promoting integration. In one study, a sheltered workshop program that included people with psychiatric disabilities made a gradual conversion, over a 15-year period, to supported employment. When the program was purely a sheltered workshop, less than 5 percent of clients made the transition to competitive employment annually (an unsurprising result, since the program was not geared toward moving clients into the general labor force). The employment rate gradually improved as the program shifted its service model; by the end of 15 years, when a full supported-employment model was utilized, half the clients were able to achieve competitive employment.[38]

The shift in public policy from unemployment and segregation in sheltered settings to promoting competitive employment for people diagnosed with mental illnesses has a growing research base. For example, a SAMHSA-funded, five-year, eight-site study, completed in 2000, found that a supported-employment model, with support services available for as long as people with psychiatric disabilities wanted them, had dramatic results. When compared to traditional vocational programs, more than twice as many people in the experimental (supported-employment) group obtained and kept competitive jobs compared with those in the control group.[39] A review of 11 studies comparing various employment models found that "people in supported employment earned more and worked more hours per month than those who had had prevocational training" and concluded, "Supported employment is more effective than prevocational training at helping people with severe mental illness obtain competitive employment."[40]

The low expectations of the old sheltered workshop and day-treatment models helped produce poor outcomes because they instilled in people the belief that they were unable to work. Edward Knight, Ph.D., vice president for recovery at Value Options in Colorado, a managed care company, saw how the shift affected program participants:

> They dropped their ACT [Assertive Community Treatment] team and their group homes, over a period of time, and ended day treatment, because people were recovering. The executive director [of one of the programs] told me he would be in the mall and would recognize people from the mental health center, and he noticed that in this setting they behaved like other people in society, which they did not do in the mental health center. He made a decision that if they paid less negative attention to people they would start to recover. He found that people were getting better from getting less attention paid to their symptoms and behaviors. He met with the staff and discussed recovery, and then invited me in to do training with the staff over a period of time. At one point, the staff was all upset because the executive director was shutting off day treatment. When they didn't have to go to day treatment every day, one guy, who had been very symptomatic, went out and got a job! So they learned that they could help people to make transitions.[41]

> One of the programs supported by Value Options is Aspen Diversified Industries in Colorado Springs, which is part of Pikes Peak Mental Health Center. Dr. Knight indicates that the program involves people with psychiatric disabilities in starting businesses as their means of employment. He also compares the program with a sheltered workshop environment where the agency double

collects—they collect from the state vocational program or Medicaid program, and they also collect from the companies with whom they subcontract. Sheltered workshops do not always encourage decision making or responsibility. Aspen Diversified Industries is not a sheltered workshop. The [programs include training] for computer skills and train clients or get them training in the kind of work they want to do.[42]

This Aspen program also promotes integration by diversifying its client base:

The workforce is not all mental health clients. They hire people with other disabilities and also poor people going back to work. It's very heterogeneous. They are now very large. The employees are working-class folk—they go to all the meetings and events that Aspen Diversified Industries holds, alongside staff of the mental health center. This serves to change the culture of the mental health center.[43]

Still another model for promoting an integrated workforce is the brokerage model, as exemplified by Empowerment Initiatives of Portland, Oregon. In this model, funds that otherwise would be controlled by a service agency are controlled directly by the client, who can expend the funds for goods or services that promote his or her recovery. The executive director, Adrienne Young, describes how the Empowerment model works:

In one year, we have moved from having 5 people competitively employed to having 13, all doing jobs they want to be doing. Six people were in college or vocational programs, now there are 13. This is out of a total population of 26. We have seen some really amazing stories. One woman was on SSI, she wasn't working . . . her life wasn't going anywhere. Now she has a full time job, she's off benefits, she's doing well. Sometimes it's amazing what a small expenditure can make in a person's life. Using her brokerage plan, she spent $29.99 to buy a sound spa that makes white noise, so she could meditate and calm herself down, and that helped her to do things which she couldn't do before because she was distracted by outside noises. And that was when she began to change her own life. When you're poor, $29.99 on something nonessential is something you just can't do for yourself.[44]

The Problem with Benefits

Unfortunately, one of the biggest barriers to employment is the benefit system itself. Often, this is what people call the "benefits trap." As one study from Cornell University found,

We argue that this discouraging situation will continue unless we can bring disability programs into line with more contemporary understanding of the capabilities of people with disabilities and successfully implement broad, systemic reforms to promote their economic self-sufficiency.[45]

The Cornell researchers also propose a variety of policy changes to promote work and self-sufficiency. They also argue that the benefits system, developed at a time when expectations for people with disabilities were very different from needs and expectations today, contains a variety of perverse disincentives that keep people trapped in poverty while they are collecting benefits. At the same time, the system places numerous obstacles in the way of efforts to achieve self-sufficiency.

Work Opportunities in Consumer-Run Programs

One type of program that has been providing a variety of work opportunities for people with psychiatric disabilities is the mental health consumer/survivor self-help movement itself. The experience of Doug DeVoe, the chief executive officer of Ohio Advocates for Mental Health (OAMH) in Columbus, shows how the consumer-run programs can work:

> When I started here as director 16 years ago, I had been unemployed; I was doing jobs like cleaning toilets. When I came to OAMH, I just met this group of people who didn't care about my past history; they just accepted me. I've never been anyplace where I felt accepted just walking in, except for peer support groups.

The Certified Peer Specialist Project in Atlanta, Georgia, provides a similar example. The project trains people who have direct experiences receiving mental health services to work within the mental health system helping their peers toward recovery. Beth Filson, the project manager, is herself a person recovering from mental illness. She recalls,

> This job changed my life. It began with the Georgia Mental Heath Consumer Network. I went to their summer conference; in fact, a friend almost "forced" me into going. Suddenly I realized I wasn't alone. It was a transformative moment— my life can be more than what it was before. I knew I wanted to be part of this.

In my work, I interact daily with people who do not have a disability; in the beginning, some of them saw me as the "crazy person." But now we are colleagues; people … see me as an individual. It's like I have passed some test, that even though I am a person with a mental illness, they see that I can hold down a job with great stress, and that means they respect me.

What do people need in their lives? Employment, employment, employment! Consumers who work within the system as certified peer specialists, they are providing a unique skill set that traditional providers don't have, because we have been there. It's a unique niche for people with disabilities, being a certified peer specialist, but at the same time, it's a competitive employment situation. There are jobs within our mental health system that only certified peer specialists can do—it's required for certain job descriptions. This means that other employees see the person with the disability in a different role, and it changes how they view people. Even the larger society is beginning to see us as "just people." When we tell people what we do, that normalizes what a person with a mental illness is like for other people. I am proud to be part of this program that is changing lives on a profound level.[46]

It is important to ensure that people with psychiatric disabilities can work at jobs that are commensurate with their levels of education and talents. While entry-level jobs may be appropriate for people with little or no work histories or limited education, it is discouraging and demeaning to place people with extensive work histories and advanced education in similar jobs. (Such jobs are widely derided by mental health consumers as "the 3 F's—food, filth, and filing.") A study at Boston University Center for Psychiatric Rehabilitation surveyed close to 500 people who worked at managerial or technical jobs after experiencing psychiatric disability. The sample represented a well-educated segment of the mental health consumer population—83 percent had at least a college degree, a segment of the population that has been served particularly poorly by traditional practices within the mental health system. People in the study reported having a variety of diagnoses, including bipolar disorder, major depression, and schizophrenia; they therefore constitute a population that could be considered to have severe psychiatric disabilities. Nonetheless, 73 percent of respondents were employed full time (an additional 6 percent were self-employed); 62 percent had held their positions for more than two years (29 percent of the sample were employed at the same position for more than five years); and they reported annual incomes ranging from $20,000 (79 percent of the sample), to more than $50,000 (22 percent). An array of

supports were used to maintain the employment, including taking a break (62 percent), use of medication (49 percent), support of spouse/partner (34 percent), and support of therapist/psychiatrist (33 percent).[47]

Federal Policies and Employment

One recent change in federal policy, designed to improve work outcomes for people with disabilities, is the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA). Unfortunately, a recent multisite study on the effects of the act for people with psychiatric disabilities has shown that TWWIIA has had a minimal impact on this population. One problem identified in the study was that many of the employed people did not have health care coverage. They were faced with the cruel choice of remaining on benefits to keep their medical coverage, or increasing their income through work but having to manage without health insurance to meet their needs. Since most people with psychiatric disabilities have high health care expenses, they often had to "choose" not to work.[48]

Given the research evidence showing that people with psychiatric disabilities can work, and want to work, compared with the appalling rate of unemployment among this population, major shifts in policy and practice are necessary to bring people with psychiatric disabilities into the workforce.

Recommendations

Recommendation Six
Congress should ensure that a number of federal agencies collaborate to address the issues affecting the employment of people with psychiatric disabilities, including benefits retention, supported employment, and TWWIIA. The federal agencies that should form the initial partnership are the Social Security Administration and the Departments of Health and Human Services, Labor, and Education. Federal policy on

benefits needs to be restructured to account for changes in the nature of disability and in research evidence.

Recommendation Seven

The Social Security Administration and the Department of Health and Human Services should work together to eliminate the "benefits trap" and encourage work while preserving access to health insurance and gradually reducing income supports for people with psychiatric disabilities.

Recommendation Eight

The U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research should develop and implement evidence-based plans to phase out sheltered workshops and other forms of segregated employment and replace them with more supported work opportunities that provide work commensurate with individual choice, educational level, and interest.

Recommendation Nine

Congress should ask the Government Accountability Office (GAO) to investigate what changes in the TWWIIA would make the program more useful to the population with psychiatric disabilities. The GAO study should include information obtained directly from people with psychiatric disabilities. The research should cover innovative work approaches, including work provided directly by mental health consumer/survivor organizations, and funding should be directed toward such programs with a record of success in providing employment.

Chapter Five: Stigma and Discrimination—The Invisible Barriers

> The biggest and most hurtful obstacle people face is stigma. If you are poor, if you are seen on the streets in town walking around, people identify individuals as being different—and if you're seen going into a mental health center, you're identified. If you are trying to get a job through a case manager, you're identified. And once you have that label, it makes everything more difficult.[49]

Defining Stigma and Discrimination

The barriers created by stigma and discrimination are very real—just as real as the more familiar barriers faced by people with other disabilities. For example, there are stairs that prevent a person who uses a wheelchair from entering a building, printed materials that a person who is blind cannot access and a person with a specific learning disability cannot read, and audible signals and announcements that a person who is deaf or hard of hearing cannot hear. Likewise, the stigma and discrimination surrounding mental illnesses create real obstacles for people with psychiatric disabilities, as they attempt to rent apartments, get jobs, go to school, or engage in many other aspects of community living.

The President's New Freedom Commission on Mental Health defines stigma as follows:

> [A] cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illnesses. Stigma is widespread in the United States and other Western nations. Stigma leads others to avoid living, socializing, or working with, renting to, or employing people with mental disorders—especially severe disorders, such as schizophrenia. It leads to low self-esteem, isolation, and hopelessness.[50]

While stigma focuses on *attitudes*, there is a strong argument to be made that more attention should be paid toward *discrimination*—the way in which stigma is operationalized. Discrimination occurs when a person who is otherwise qualified is not offered a job or an apartment, for example, because he or she belongs to a group about which negative attitudes are held, despite his or her *individual* qualifications. Discrimination can be remedied by legal means, while framing the problem as one of

"stigma" individualizes the concept and requires changing public attitudes. Psychiatrist Graham Thornicroft, M.D., notes,

> The focus upon the core concept of stigma rather than upon prejudice and discrimination has also separated the field of mental illness from the mainstream of disability-related policy, and in particular the stigma idea has offered policymakers and politicians few recommendations for action.[51]

Dr. Thornicroft adds,

> If we deliberately shift focus from stigma to discrimination, there are a number of distinct advantages. First, attention moves from attitudes to actual behavior, not if an employer *would* hire a person with mental illness, but if he or she *does.* Second, interventions can be tried and tested to see if they change behavior toward people with mental illness, without *necessarily* changing knowledge or feelings. Third, people who have a diagnosis of mental illness can expect to benefit from all the relevant anti-discrimination policies and laws in their country or jurisdiction, on a basis of parity with people with [physical] disabilities. Fourth, a discrimination perspective requires us to focus not upon the "stigmatized" but upon the "stigmatizer." In sum, this means sharpening our sights upon human rights, upon injustice, and upon discrimination as actually experienced by people with mental illness.[52]

Lenora Kimball, executive director of Stepping Stone and the Next Step Peer Support and Crisis Respite Centers, Claremont, New Hampshire, is a person who has recovered from a mental illness and describes the reality of stigma this way:

> The biggest and most hurtful obstacle people face is stigma. If you are poor, if you are seen on the streets in town walking around, people identify individuals as being different—and if you're seen going into a mental health center, you're identified. If you are trying to get a job through a case manager, you're identified. And once you have that label, it makes everything more difficult.[53]

Jean Campbell, Ph.D., director, Program in Consumer Studies and Training, Missouri Institute of Mental Health, St. Louis, is another person who has recovered from a mental illness. She describes three levels of stigma. The first occurs within the person:

> This internalized stigma of having a psychiatric disability prevents people from moving on in their lives. They lack a vision of hope. People don't think of having a future or often of being motivated because of what they have been told by family,

neighborhood, doctors, nurses, employers, teachers, etc.—that they have limited possibilities. There is a loss of self, loss of hopes, loss of dreams for the future. People get locked into the past or the present and are not moving forward in their lives.

She identifies the next level as institutional:

The major contributor to stigma is involuntary treatment, because it creates tremendous fear and makes people afraid to seek services that they may need. It makes them think of themselves as second-class citizens. Involuntary treatment and coercion is the biggest barrier in the entire mental health system and in society. People are without full citizenship and rights, which is perpetuated by the mental health system. An albatross around the neck of the traditional mental health system is the biomedical model, because it creates a barrier for initiating the new consumer-directed philosophy and the concept of recovery.

According to Dr. Campbell, the third level is cultural:

There continue to be attitudes throughout society that people with psychiatric problems are hopeless and helpless. There is the additional stigma of poverty that makes people looked down on. People often have lost opportunities for an education, and then they are looked down on because they don't have an education, can't buy a house, go on a vacation, and do things that other people can, and this gets attributed to their mental illness and to being different, rather than just because they are poor.[54]

Stigma and Discrimination Within the Mental Health System

In 1999, the surgeon general urged Americans to take advantage of the tremendous growth of science by seeking treatment and emphasized the importance of bringing this often hidden topic of mental illnesses out into the open. The report notes that mental illnesses are real illnesses that, if untreated, can sometimes be as disabling and serious as cancer and heart disease in terms of premature death and lost productivity. However, quality of life is improved tremendously when diagnosis is early and treatment is appropriate.

NCD's 2000 report, *From Privileges to Rights,*[55] found that pervasive discrimination against people with psychiatric disabilities was built into the structure of the mental

health system itself, which routinely removed decision-making power from people because of their psychiatric diagnosis and subjected them to unwanted treatment that they often found harmful. Unfortunately, most of the anti-stigma campaigns in existence ignore the very real stigma and discrimination practiced by the mental health system. An exception is the Anti-Stigma Project run collaboratively by On Our Own of Maryland (a mental health consumer-run organization) and the Maryland Mental Hygiene Administration, which "fights stigma within the mental health system by raising consciousness, facilitating dialogues, searching for creative solutions, and educating all participants within or connected to the mental health community."[56]

The Maryland project has developed a number of presentations designed specifically to assist mental health providers to recognize stigmatizing practices within their own programs. One is an interactive workshop, "Stigma … In Our Work, In Our Lives." The coordinator, Jennifer Brown, describes the project:

> We basically go in to level the playing field. Through interactive exercises like role playing and group discussion, we ensure that all points of view are heard and that each viewpoint is given equal merit. Many workshop participants have told us that they did not realize how stigmatizing their own actions were until attending the workshop. The process really makes you examine your feelings as well as your actions, and that is true of all who participate, not just consumers or providers.[57]

Stigma and discrimination against people with psychiatric disabilities create barriers that must be removed to ensure that they have equal opportunities to participate fully in livable communities that are welcoming to all.

Recommendations

The surgeon general's report of nearly a decade ago proposed that broad actions were needed to improve the quality of mental health in the nation, including the need to overcome stigma. The report also indicated that stigma and discrimination result in a gap between treatments that research has shown to be optimally effective and what many people actually receive in practice.

Recommendation Eight

Recognizing that stigma serves as a deterrent to obtaining appropriate and necessary care, and that stigma and discrimination result in many people not receiving optimal treatment, HHS should ensure that research is conducted on the effects of stigma and discrimination on community integration and within the mental health system itself.

Recommendation Nine

While federal leadership in addressing stigma and discrimination should originate in HHS, the President should establish a governmentwide task force through an Executive Order. Its task would be time limited for reporting outcomes of agency work conducted collaboratively to examine promising practices within individual agencies, as well as joint efforts for combating stigma and discrimination. The Executive Order also should request that the task force report include a plan to ensure broad dissemination of practical findings for possible replication. Ultimately, the outcomes can benefit the people with mental illnesses, their family members, other advocates, and the larger community. Each federal agency that administers programs for the general population should examine antidiscrimination practices toward people with disabilities to ensure equal application to people with psychiatric disabilities/mental illnesses.

Chapter Six: Livable Communities in Action—
Models That Work

> For many years I felt no hope. It was getting involved in self-help that changed my life; before that, I never felt like a "usual person." I never had the opportunity to be in an environment where I could feel competent and capable.[58]

Identifying What Helps

As described earlier, developments in mental health have shown that genuine recovery from serious mental illnesses, once thought of as rare, is possible for everyone, if people are provided with the appropriate mix of services and supports.[59] Practice, however, is lagging far behind the research evidence, since the majority of people diagnosed with mental illnesses are served in programs that do not promote recovery. Carpinello et al. described the lag between the growing research evidence on recovery and the persistence of old practices:

> The challenge in implementing evidence-based practices in routine mental health settings is largely to create a major shift in how the mental health industry defines a high-quality environment. A high-quality system must be based on research evidence and must also be consumer centric, representing a shift in goals from community-based systems of care that treat and shelter or support consumers via community-integrated systems that deliver high-quality services to customers who want to design and manage their own recovery.[60]

Despite these difficulties, there are a number of existing programs that can serve as models and that have integrated recovery into practice, delivering services that enable people diagnosed with serious mental illness to live integrated lives in the community. The programs described here include independent living, personal assistance services, self-help/peer support programs, networking and education for peer support, provider-run programs that promote recovery, innovative uses of Medicaid funding, person-centered planning, and self-determination. These programs and concepts show how a variety of approaches have been successful in delivering services on the local level, and the programs suggest a number of possible directions to guide the redesign of existing programs or the development of new ones.

Independent Living

The independent living (IL) model has been one of the strongest forces in helping to transform the lives of people with disabilities from institutionalization and dependence to self-determination. As documented by NCD in its 2004 report,[61] when people with disabilities have the appropriate supports, community living becomes possible. Unfortunately, this model has never been implemented fully for people with disabilities in general, many of whom continue to languish in nursing homes, group homes, and other facilities; people with psychiatric disabilities specifically have lagged even further behind.

A number of forces have kept progress in psychiatric disability largely separate from the gains made by people with other primary disabilities. The forces affecting segregation include differences in funding streams, negative beliefs about the ability of people with psychiatric disabilities to control their own lives, greater control by professionals over people with psychiatric disabilities than control over people with other disabilities (including the power of involuntary commitment), and general stigmatizing attitudes that have linked psychiatric disability with violence and incapacity.

As one study recognized:

> While it is understood that centers for independent living work with and on behalf of people with all types of disabilities, it must be acknowledged that many centers, especially in the early days of center development, dealt primarily with [people] who had physical and sensory disabilities. Indeed, some refer to mental disability as the "stepchild" of the IL Movement.[62]

Nevertheless, some IL centers have made a deliberate attempt to rectify the neglect of the mental health population; one example is the Westside Center for Independent Living in Los Angeles. Westside developed a peer support project to train mental health consumers as peer supporters, who were then employed by the center.[63]

Another IL center that has conducted outreach to the mental health consumer population is Stavros Independent Living Center in Amherst, Massachusetts. Janet

Shaw, the director of Independent Living Services at Stavros, has found that there are difficulties in serving the mental health consumer population:

> One of the greatest problems is the stigma against people labeled with psychiatric disabilities. They get a bum rap. Society sees them as dangerous. People don't want them in their neighborhood. There is a huge misunderstanding about what it means to have a psychiatric disability.
>
> Another barrier, believe it or not, is the medical model. We're stuck in this model that says that people with psychiatric disabilities will be okay if they just take their medication, and that's basically all they get. For a lot of people, the medications cause some symptoms that are often thought of as being part of their mental illness, like holding their bodies in strange positions or drooling, which makes them look very different. Hospitalization, which is often forced on people, creates many problems. No one is thinking outside the box, about options other than prescribing medicine and putting them in the hospital.
>
> Part of the misunderstanding about having a psychiatric disability, as opposed to some other disabilities, is that there's nothing you can see as far as a disability, nothing that is apparent. For a lot of people with psychiatric disabilities, they would benefit from having, for example, the personal care attendant program [called, in many states, personal assistance services]—at this point, it's incredibly difficult for people with psychiatric disabilities to access this program. For example, we might get someone in here with a label of being bipolar. The nurses who do the eligibility evaluations are trained to look for physical needs, and often it's hard for them to see that the person with this diagnosis could benefit from having personal assistance. This is just one of many difficulties that we find in trying to be helpful to people with psychiatric disabilities.[64]

Mike Oxford, executive director of the Independent Living Resource Center in Topeka, Kansas, has found systemic barriers in his efforts to serve the population of people with psychiatric disabilities:

> A few years ago, our center, working with Kansas's protection and advocacy agency, was able to meet and talk with people in all of the special long-term care facilities for the mental health population in the state, as part of a formal state assessment. We got in the door, we were able to follow up, and some people were able to move out. We asked people, "Why are you here?" It turns out that they end up there because they don't have a support structure—families that either aren't around or aren't supportive. Some people have been there for decades, just forgotten. We've been able to use some pretty low-tech things that every IL center is funded for—advocacy, skills building, helping folks hook up

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with other people and entities they can talk to. Some folks didn't need a whole lot of stuff—physical access wasn't a problem like it might be for people in other kinds of facilities. Sensory accessibility was less of an issue. So it's easier to find housing for people with these disabilities. People may need medical care, but they can get that from medical facilities that are available in the community—it doesn't have to come from an institution. Although concrete physical barriers are less, barriers like bigotry are higher. Extensive waivers and programs may be less necessary if you can find community medical providers and acceptable housing.

One person we were able to help was a man who stayed up all night, making a lot of noise. The facility said that this made him unsuitable for community housing, but we found him a trailer out in the country, where his habits didn't create a problem. The facility's "solution" was to put him on lots of medication and give him a lot of behavioral training to try to change his behavior. This is a clear example of a different kind of mindset—the IL way vs. the traditional provider way. It was no big expense to find this man a cheap place to rent in the country.

We were able to get another person out of the institution by using the brain injury waiver. It's another example of being creative and trying to make the system work for people. But it shows how difficult it can be to serve this population, because you have to make the extra effort.

Our whole theory is to look for what is needed—not what the person's label is—to get the person where they want to go. We can do that, through our regular grant and being creative. The biggest problem is breaking through the professional system.[65]

Personal Assistance Services

Consumer-directed personal assistance services (PAS) is a program offered by many IL centers; it enables people across the severity continuum of disabilities to live independently. In the PAS model, the person with the disability hires and trains an assistant to provide help with activities of daily living that the person has difficulty performing because of disability. In many states, PAS is available with Medicaid funding, through the personal care option. A conference of disability experts, held by the World Institute on Disability in 1999, recommended the expansion of PAS to the psychiatric disability population.[66]

While there have been some instances of providing PAS to people with psychiatric disability, there have also been difficulties in doing so. As one study found,

> [T]here is an evolving recognition that PAS has the potential for becoming a meaningful, efficient, and effective means for serving people with long-term mental illnesses. As it is conceived for people with other disabilities, an individual may provide assistance to people with psychiatric disabilities so that they can achieve greater independence from more intensive or medically oriented services and function more fully as citizens. The actual services provided by the attendant to people with psychiatric disabilities, however, are likely to differ from those provided to people with other disabilities. Help with activities of daily living will less likely require hands-on assistance to transfer from one place to another, but will more likely mean providing the cues, reminders, and encouragement necessary for those with psychiatric disabilities to focus on needed tasks, sequence necessary steps, and initiate effective and concerted actions. Like people with other disabilities, those with psychiatric problems may also require assistance with budgeting, meal preparation, hygiene, and transportation, but again the form of the assistance would likely change from a provider who contributes the physical assistance to one who provides cognitive and emotional assistance. The application of PAS to the psychiatric population is attractive for several reasons. PAS has an established funding base through the Medicaid personal care option, which can be a considerable source of federal revenue for states that wish to serve their Medicaid recipients with psychiatric disabilities in this way. Nonetheless, there are difficulties in a simple expansion of the original concept to those with psychiatric disabilities.[67]

Oregon is an example of a state where PAS has been made widely available to people with psychiatric disabilities; currently, there are over 600 mental health consumers being served in the PAS program, which is funded by Medicaid. Many of the personal care attendants are themselves people diagnosed with mental illness, who are further along in their own recovery than the people they are assisting. In an interview, Michael Moore, Adult Services coordinator for the Oregon Department of Human Services, describes how working as a personal care attendant assists recovery:

> When people go to work, the symptoms of their mental illness actually go down quite a bit, and that makes sense to me, intuitive sense. If you're sitting at home not doing much, you're probably gonna dwell a little bit on yourself. It's probably not too great on the brain.[68]

An Oregon public radio story describing the program interviewed a woman whose severe agoraphobia had kept her housebound until she acquired a personal care attendant. The attendant, herself a person in the process of recovery, receives a salary of $9 an hour to provide 20 hours a month of PAS services, such as assisting with shopping and housekeeping. Moore developed the program based on similar programs that serve people with general medical disabilities, and he believes that it both saves the state money and assists people toward independence.[69] Moore plans to increase the size of the program to serve a thousand recipients by 2008.[70]

Louisiana is another state that has looked at the PAS model for people with psychiatric disabilities. Louisiana has developed a training curriculum to educate personal assistants about the nature of psychiatric disability and how the PAS model applies to people with severe mental illnesses. However, Ann Darling, project director of the Community Integrated Personal Assistance Services and Supports Project (CPASS), Louisiana Office of Mental Health, found that various programs did not interact well, which prevented implementation of CPASS. The agency that makes disability determinations used a purely physical definition of the need for PAS, so only people who had a general medical disability in addition to their psychiatric disability were able to receive PAS services.[71]

Medicaid regulations governing PAS relate the need for these services to the inability of the individual to perform "activities of daily living" (ADL), which are defined as physical activities—bathing, dressing, and transferring from a bed to a wheelchair or feeding oneself, for example. And while available PAS data shows that some states (e.g., Arkansas, Colorado, Kentucky, and New Jersey)[72] already report serving people with mental health needs, national application of the ADL category could assist in the expansion of PAS for people with psychiatric disabilities. The expanded provision of consumer-directed PAS to the psychiatric disability population is one approach that holds enormous potential and is deserving of further study and demonstration projects.

Self-Help/Peer Support Programs

While there are many examples of people with psychiatric disabilities who have received services through IL centers that have enabled them to become independent, the fact is that many or most mental health consumers who receive self-help services access such services through a largely parallel system of programs developed within the mental health consumer movement. Across the United States, there are literally hundreds of drop-in centers, support groups, and other services developed and run by organizations of people with psychiatric disabilities, and these facilities assist people to become more independent and to gain control of their own lives. The mental health consumer movement developed largely separate from, but similar to, the IL movement, based on the same principles of choice and individual control.

Beginning in the late 1970s, former patients began to form groups to promote change in the mental health system and to develop self-help and mutual support.[73] In the beginning these groups operated without outside funding and were, therefore, extremely limited in scope—for example, they met as support groups in people's homes or in church basements, libraries, and similar settings. The first government-funded project was On Our Own of Maryland, which in 1983 received state funding to open a drop-in center. In 1985, with funding from the Community Support Program at the National Institute of Mental Health, On Our Own hosted a national conference for mental health consumers, which helped to spur the development of similar projects around the country.

Unlike IL centers, which have an assured source of federal funding through the amendments to the Rehabilitation Act of 1978 and successor legislation, mental health self-help projects remain dependent on a mixture of federal, state, and private funds. They often face difficulties in assuring a continued source of funding. This makes the existence of even well-established groups more precarious than that of IL centers.

Peer support is the key service of both IL centers and mental health self-help programs. The basis of peer support is the belief that a person who has experienced a particular

problem has a special expertise in providing help to others with similar problems. Peer support grew out of the negative experiences that people with disabilities faced in dealing with professionals who, themselves, often held limited and stigmatizing beliefs about the very people they were supposed to be helping. An example is Ed Roberts, often called the "father of independent living," who was told by a counselor that he was "too disabled" to benefit from the college education he wanted. He not only obtained his college education, but later became the director of the same agency that had turned him down.[74]

Peer support has become a key component of many mental health programs, spurred by the growing recognition of the value that people who share the same experiences can bring to mental health services. In Georgia and a few other states, peer support is a Medicaid-funded service, provided either in a freestanding peer support center or as part of an existing clinical program. Beth Filson, the project manager of the Georgia Certified Peer Specialist Project, sees the value of the project as

> Restoring a person's belief in themselves, so that they can face the problems that all individuals deal with on a daily basis. We teach them skills to problem solve, and then link them to natural supports in the community. Then, if people feel empowered, they feel that they are the masters of their own destiny.[75]

The expansion of Medicaid funding to peer support services is a milestone that needs to be studied and replicated. However, essential to extending Medicaid funding to cover the services of peer support specialists is an accompanying ongoing transformation of the mental health system to a recovery-based model, so that the peer specialist expertise is utilized to its full extent. Without such an understanding, there is a risk that peer support specialists could be seen as "junior clinicians" within a medical model paradigm, rather than as bringing a new kind of expertise that promotes recovery.

When people with psychiatric disabilities become involved with self-help programs, often that is the first time they have heard about the possibilities of recovery and self-determination. Emily Hoffman, the state network coordinator of On Our Own of Maryland, describes the differences in approach:

Psychosocial rehabilitation and residential programs have a tendency to keep people dependent on those programs. They can make it hard for people to move on in their recovery process. Some are better than others, but folks in those programs are separate from the community. For example, they get transported by vans in groups to do their shopping, which is not the way most people shop. The programs don't seem to help people move ahead to truly integrated living. When people come to one of the On Our Own drop-in centers, on the other hand, many of them say that they've been told in the programs that they're not capable of truly integrated living. For example, a person may talk to a counselor in a traditional program about getting a job, but will often be told "you're not ready" or "you might want to think twice." It comes down to respect—they don't seem to respect individual choices.

When On Our Own presents workshops on recovery and we tell people, for example, that there are ways to continue to get benefits while getting a job, the reaction is often "this is the first time anyone has listened to me and respected my opinions and choices," because some of these programs actively discourage people stretching themselves and taking risks. Some people have been in these programs for years and years, which is a form of mini-institutionalization.[76]

The Freedom Center in Northampton, Massachusetts, is an example of a grassroots, independent program run by psychiatric survivors that receives only minimal funding, yet has developed a number of alternative programs to assist people to achieve their self-determined goals. The Freedom Center offers innovative approaches such as yoga classes and acupuncture, provides peer-run programs, helps people to find housing, and advocates for a noncoercive mental health system in which people are free to make their own choices about the kinds of treatment they want.

Oryx Cohen, one of the founders of Freedom Center, describes how the project started:

There were a few of us who were not getting what we needed out of the traditional mental health system. We didn't know what we were doing when we started, but we knew we wanted something different. It started with me, Will Hall, and a few others. We wanted to combine support and activism. The movement had been pretty strong with activism from back in the '70s, but we really wanted to combine the support aspect. A lot of people we ran into wanted to do activism, but others just wanted emotional support. So we tried to do a combination. We started a monthly support group in the fall of 2001. The group was run by peers. Now it's every week—it's been weekly for a few years now. Anywhere between 6 and 30 people come to the group—an average of 12 to 15. There are some core people and "veterans," but the membership changes. We met

in a church. Now we meet in the Quaker Center; we've been there for a few years. We rent the space.

Everything the Freedom Center does comes from the membership. There are no paid employees: all volunteers. We have a collective set up that makes the key decisions. To join the collective a person has to be a member for at least six months, attend the monthly organizing meetings, and then get voted in by the rest of the members.

There was a slow transition to other activities besides the support group. The first thing was yoga; a lot of people were looking for alternatives to day treatment or medications. We decided to start a yoga class, because people couldn't afford commercial classes. We've been doing that for about four and a half years. We raised some money (private foundations and individual donations) to hire a teacher. We get some money from the City of Northampton. Our total budget is about $10,000 per year. We are hoping to start another class because the current class is so big.

Then we started an acupuncture clinic. We offer these programs to everyone in the community, not just our members. We're trying to break down labels and promote community integration. The person who does the acupuncture is a licensed acupuncturist who does ear acupuncture. We have gotten a lot of publicity—a big article in the local paper on our acupuncture clinic. About 20–25 people come each week—we've had as many as 50! At the start of each class we announce what the Freedom Center is and the work we do. We don't ask people whether they are people with the "lived experience" or not.

We also do events—we've invited speakers on various mental health issues. We've had as many as 200 people show up for those events. We also get new people through these events who are interested in getting more involved. Because we don't have paid staff, sometimes we can't respond to all the inquiries and e-mails. We also have a weekly radio show on a local grassroots community radio station. We've been doing that for about two years.[77]

New Hampshire is an example of a state that has provided significant funding for peer self-help programs for mental health consumers. Lenora Kimball, executive director of Stepping Stone and Next Step Peer Support and Crisis Respite Centers, which has offices in Claremont and Lebanon, New Hampshire, describes the program:

New Hampshire's peer support program is based on a nonmedical model. Individuals behave very differently here in the Center in their relationships than they do when they are with their case managers or other people who have authority over them. In the Center, they are more dynamic, more expressive,

the conversations are about more everyday things (not just focused on mental illness or problems). People are less critical of themselves in the Center with their peers.[78]

Kimball, like many people who work in the consumer movement, has her own story of personal success through self-help:

> . . . In the Center I was treated as if I could make my own decisions, and that helped me to be able to make them. I got a lot of support, to the point where I began working for the Center, and eventually was hired as the director.[79]

People in self-help programs are allowed to proceed at their own pace and to take as much time as they need to develop trust. Kimball describes one member:

> One of our employees is a woman in her fifties. She was institutionalized as a teenager and was in the system for many years. Eventually she got out, and about five years ago she came to Next Step. She wasn't sure what to think about us, and it was very gradual—at first, she would just come into the parking lot, before ever coming inside. Eventually she became involved and, after awhile, got a job in the Center. In the year before she became involved, the state spent over a million dollars on her care because of multiple hospitalizations and other services. Her involvement in the Center totally changed that—now she uses a very small amount of mental health services. She has responsibilities at the Center, is getting an education, has a place to live, friends, and feels good about herself.

> The environment is key—it's an educational, nonjudgmental environment, where people can risk new behavior. They can do things badly, but then say, "I will try again." We hold people accountable for their actions. Conflicts sometimes arise, and they are addressed and dealt with. People are endlessly surprised that when they respectfully communicate something about other's behavior that they don't like, it is received in a nonjudgmental way. This teaches people, often for the first time, that they can change their behavior, and gives them the motivation to do so. The peer support sites are the "practice fields" for people to try new things. We teach people skills and give them an arena to practice.[80]

The program also includes a crisis respite program, which provides services to people who might otherwise have to go into hospitals, based completely on peer support. One component is a "warm line"—a telephone line staffed by peers that people can call just to talk, if they are feeling lonely or if they think they need some extra support. This is a different model from a "hot line," which is usually operated by mental health service

agencies and is focused on crisis. While hot lines discourage people calling just to chat, warm lines are set up for precisely this purpose, since loneliness and isolation are some of the major problems people face as they attempt to live in the community. People use the warm line not only when they are facing difficulties, but also when good things are happening in their lives. The warm line is confidential, with no records kept except for utilization statistics.

Another component of New Hampshire's program serves people in crisis, who might otherwise be hospitalized:

> Our crisis respite program is amazing. We have two locations—each is in a house in the community. It's not an institutional setting. There are two rooms, each with one bed (one is handicapped accessible). Any New Hampshire resident is eligible, at no cost to them; out-of-state people can use the service for the actual cost, which is approximately $200 a day. People can stay in the house for up to seven days. It's an alternative to hospitalization for people when they're in crisis. It's not a place as much as it is a philosophy: crisis is seen as an opportunity for change. It's not a time to be nurtured and pampered, but a place where, with support, you can discover things about yourself so that you can change your life. There is a crisis respite team that provides support. Most people, when they come into the program, say that they want to stay for the full seven days, but in fact people stay, on average, three to four days. Sometimes when people come in they are suicidal, but they are assisted to develop a self-care plan—even in these difficult situations many people may leave in a day or two. Some people used to come cyclically, every month or six weeks, but they get challenged: "What can you do differently?" And they have changed and don't come back as often. The cost to the state is much less than it would be to stay in a hospital unit, and, for many people, we are helping them to break the cycle of repeated hospitalizations. It saves the state money, and it helps people to have different and much more satisfying lives.

> Eligibility is determined by a crisis respite interview. This is a meaningful, deep conversation with one of the crisis workers, which builds a personal connection. It's very different from when a person comes into a hospital, where they are often not asked very much about themselves—and not listened to. Our focus is on what the person's life is like when they are feeling good, what they like, what their experiences are in crisis, what they need, what they don't want, and what is meaningful to them. The membership rights and responsibilities are made clear—they can come and go as they please; they are not allowed to come back under the influence of alcohol or street drugs (they will be told to leave if they do); they can go to work during the day, or take care of their kids, or anything else

they need to do; but they come back to spend the night and get the support then. If they have a pet at home, they can bring the animal with them. This is a major issue for a lot of people who are very attached to their pets and face additional stress when they are hospitalized because they don't know who is taking care of their animal.

The program is not about "protecting" people and "controlling symptoms." If a person takes medication, it is their choice and their responsibility. We have a locked cabinet where people can keep their medications, to which they have the key. If they want, staff will remind them to take their medication, but it's their choice.

It's amazing how many people who have been in the system for a long time don't have the most simple skills, like how to do laundry. (A lot of people don't know how to do this because their case managers do it for them.) So we teach them how to do it, and other things they need to take care of themselves. Cooking is another thing—we don't serve them meals, but instead the respite workers cook and eat with the guests.[81]

Networking and Education for Peer Support

Each year since 1985, with funding from the Community Support Program, a conference called Alternatives brings together hundreds of mental health consumers from all over the country involved in self-help projects. The program for Alternatives 2006, held October 25–29 in Portland, Oregon, featured dozens of workshops, presented by self-help participants, on such varied topics as "Life Beyond Recovery: Programs and Services Are Just Not Enough!" "Valuing Our Diversities at Self-Help Centers," "Understanding Barriers for Latinos in Recovery," "From Relief to Recovery: Role of Peers in Disaster Relief," "A State Hospital's Journey to Recovery," "Teamwork and Collaboration: A Project for the Peer Specialist Certification Program in New Mexico," "Consumer Operated Programs and Evidence-Based Practices: A SAMHSA-Funded Implementation Resource Kit," "Using the Arts for Healing and Personal Transformation," "Achieving Recovery: Peer-Run Programs That Leave No One Behind," "Working While Maintaining Social Security and/or Medicaid Benefits," and many others. The Alternatives conferences have been a valuable tool in the growth and development of peer-operated programs and have provided opportunities both for individual growth and for organizations to increase their levels of competence

and sophistication. Alternatives 2007 is scheduled to be held October 10–14 in St. Louis, Missouri.

Attending an Alternatives conference has been a mind-changing experience for hundreds, if not thousands, of participants over the years. Many have gone home to educate their peers about what they have learned and to found new support groups and self-help projects. The opportunity to learn from others who have experienced recovery and have improved their own lives is a dramatic example of self-help and peer support in action.

Organization of the annual Alternatives conference is rotated among the three consumer technical assistance centers funded by SAMHSA: the Consumer Organization and Networking Technical Assistance Center (Charleston, West Virginia), the National Empowerment Center (Lawrence, Massachusetts), and the National Mental Health Consumers' Self-Help Clearinghouse (Philadelphia, Pennsylvania). These centers provide valuable information and assistance to individuals and organizations concerning self-help, empowerment, and recovery. The centers are operated and controlled by people who have experienced psychiatric disability.

Provider-Run Programs That Promote Recovery

In Colorado, state-funded mental health services are provided through a managed care company, Value Options, which has changed from programming that promoted maintenance to recovery-oriented services. Dr. Edward Knight, vice president for recovery at Value Options (himself a person who has recovered from mental illness), oversees eight programs funded by Value Options across the state, some of which have been described in Chapter Four.

Another Colorado program is the Pikes Peak Mental Health Center in Colorado Springs. This mental health center shifted from employing clients in a traditional sheltered workshop program to providing competitive employment through Aspen Diversified Industries. As Dr. Knight describes:

They do competitive employment by starting businesses. Each business has to make a profit, or at least break even. A construction company, for example, competes with other construction companies in Colorado Springs. They also operate a maintenance company, a catering company, and some others are economically viable. In a sheltered workshop environment, the agency double collects—they collect from the state vocational program or Medicaid program, and they also collect from the companies they subcontract with. They never encourage individual decision making or responsibility. Aspen Diversified Industries is not a sheltered workshop. They have a training program so people can learn skills, a computer program, for example. They will train the client, or get training for a client in a skill that the client wants to learn, rather than just assigning people to a "slot." The workforce is not all mental health clients; they also hire people with other disabilities, and also poor people going back to work. It's very heterogeneous, and promotes integration. The employees are working-class folk—they go to all the meetings and events that Aspen Diversified Industries holds, alongside staff of the mental health center. This serves to change the culture of the mental health center.[82]

This approach has even been successful with a segment of the population considered difficult to treat—people with both mental health histories and involvement with the criminal justice system, where an Assertive Community Treatment (ACT) model has been adapted to promote choice and recovery. ACT is defined as "a team treatment approach designed to provide comprehensive, community-based psychiatric treatment, rehabilitation, and support to people with serious and persistent mental illnesses such as schizophrenia."[83] While proponents of ACT speak of it as a voluntary program, some researchers and many program participants find it to be coercive.[84]

As Dr. Knight describes the program,

There's a criminal justice ACT team in Alamosa, Colorado. Dave Hayden, the man who runs it, doesn't believe in force. Instead, he runs the ACT team by helping people get what they want out of life. They work together with a recovery center and a case management unit, all in Alamosa, which all share this philosophy. This ACT team is one of three criminal justice teams in Colorado, but it's very different. We have found that for people served by the teams in Boulder and Denver, their employment level goes down. In Alamosa, it goes up. This is dealing with a difficult population, but about 35–55 percent are working, and about 80–85 percent are living independently. Dave has to do this balancing act, between preventing people from being yanked back into prison, on the one hand, and intervening without force, on the other, to help people get what they want. He is constantly problem solving and is great to work with.[85]

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Dr. Knight has found that Value Options has made a real commitment to funding approaches based on recovery and empowerment:

> I get more support working here, in a private profit-making company, than I ever got working for the New York Office of Mental Health. The owner of the company really believes in empowerment and recovery, and takes personal risks to support it. He's willing to make decisions that could cost him money to back consumer empowerment. My boss is a psychiatrist, but he is the rare one who believes in recovery. So I work in an extremely supportive atmosphere.[86]

Another example of a program that has implemented a comprehensive approach is the Life Link in Santa Fe, New Mexico. Raymond Anderson, the director of operations and training, describes how different services work together to address clients' multiple problems:

> It takes good wrap-around services, not just treating the client as if they are just one particular thing. We help people with housing, employment, or getting a GED or other forms of education. We have a psychiatrist, therapists, peer supporters, and case managers. Case management is the glue that holds everything together. When you have a team approach, when you have an agency that works together on all fronts, it helps the clients move forward, because they are being looked at from so many different angles.
>
> We have a psychosocial rehabilitation program. Our psych rehab counselor draws up schedules for different classes the clients can take, like money management or ways toward healthier living. If someone wants to get a GED, she helps with that. It's very individualized, based on what the person's goals are.
>
> We have peer supporters—mental health clients who learn how to take care of other mental health clients. It's different from case management in that it involves giving support from people who have shared the same experiences. We have peer support training so that people can learn the skills needed.
>
> It dovetails with our therapy programs. We do mental health and substance abuse counseling together; our counselors are trained to do both. This way, the client isn't caught in the middle between programs. We see the client as one person and help them whatever way we can, addressing both problems. That's what we find works.

Case management is really important. Our therapists have time to do therapy, because the case management component is really strong. The case managers take folks around to help them get benefits, jobs, housing, medications—whatever they may need. That undergirds therapy. Folks can get just case management if that's what they want. Dealing with government agencies and paperwork can be really daunting, more so if you're depressed or hearing voices. So it's good to have a case manager to get you through all of that.

We have an employment specialist who helps clients to do job searches, teaches them how to interview for a job, [and] walks through the beginning rungs with them. It's important for anyone, for self-esteem, to be able to earn a buck. Even if it's not a whole lot, that buck is yours. For some folks, it's very embarrassing not to have any kind of work. Even if it's part time, at least that's something.[87]

Innovative Uses of Medicaid Funding

A number of states have developed innovative models for using Medicaid funding to provide recovery-oriented services. These models are important because Medicaid, as a federal program, can be used in all states to implement and fund these approaches. Oregon's use of Medicaid funding to provide personal assistance services has been described above. Another innovative use of Medicaid funding is provided by Michigan, which has redefined "medical necessity" as including "community integration," making Medicaid funding available for a wide variety of recovery-oriented services that would not otherwise be Medicaid eligible. Under the Deficit Reduction Act of 2005, there are increased opportunities for innovative uses of Medicaid funding.

Another example of an innovative use of Medicaid funding by Oregon is individualized budgeting, which allows people diagnosed with mental illness to control a budget to purchase their own services. Individualized budgeting is a funding methodology that has been used for people with other disabilities to give them greater control over the services they receive. Its use has been promoted for people with developmental disabilities, as a tool toward community integration and independence. As Agosta has found,

Adults with developmental disabilities want control over their lives. They also want to live in the community, work, have friends, be healthy, and stay safe. They

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want to live life just like any other citizen. Expectations like these are fueling a steady shift in service systems. Community systems are increasingly offering services that promote integration and self-direction. These approaches also provide greater opportunity for service recipients to have extensive control over managing their own services.[88]

This approach, while widely utilized in the developmental disability field, has not been used as widely in psychiatric disability. However, some models exist that illustrate its applicability to this population. Oregon provides a model for providing individual budgets. Empowerment Initiatives, Inc. (EI), in Portland, Oregon, is an agency run by mental health consumers that assists people with psychiatric disabilities in purchasing services. Adrienne Young, the EI executive director, describes the program as

> [A] brokerage model, providing up to $3,000 for each individual in our program, combined with person-directed planning and community resources. We help the person work toward their dream and life goals and help them in their mental health recovery. We also run a 10-week, 6-hour-a-day training program for people to learn about their own recovery and how to help others recover. This program is called SPIRIT–Service Provider Individual Recovery Intensive Training. We do a two-month support group follow-up to help people get jobs in the community, mostly within the program but also in the wider community.[89]

Person-Centered Planning

Person-centered planning is a key tool in reframing services so that they are under the individual's control and meet the individual's self-defined needs. Agosta defines person-centered planning as "a process that is directed by the individual (and with the individual's consent, family and support network members as well) to assess his or her strengths, preferences, capacities, and needs, and to specify the supports that must be offered to address those needs."[90] Once again, this is a tool that has been more widely used to address the needs of people with general medical and cognitive disabilities rather than psychiatric; however, Michigan has made person-centered planning and community integration the focus of its mental health delivery system.

As described by the Community Mental Health Services (CMH) of Muskegon County, Michigan,

Person-centered planning is all about your hopes and dreams. You and the people who are important to you talk about your life: Where do you want to live? How do you want to spend your day? How do you express your spirituality? Where do you want to work, volunteer, or go to school? Do you want supports (i.e., guardianships, financial payee) in areas of your life? Person-centered planning respects and honors cultural differences and targets your strengths.

Person-centered planning puts the consumer in charge, is about making choices, builds on your strengths, identifies resources at CMH and in the community, lets you choose who will help you build your plan, and addresses health and safety issues.

CMH lists five elements of person-centered planning:

1. Pre-planning activities: this is when you choose who will facilitate your meeting, if you will use a self-determination plan or not, who you want to be at the meeting, the topics you wish to talk about, where the meeting will be held, and what time is best to hold the meeting. Planning for your needs right now and for things you will need in the future.

2. Changing your plan when your wants or needs change.

3. Making sure all of the people you count on work together.

4. Asking for your opinions so the plan is about your dreams and goals.

5. Changing your plan when your wants or needs change.[91]

Self-Determination

The basic unifying principle of all the programs described in this chapter is self-determination. Tom Nerney, executive director of the Center for Self-Determination, defines this concept as having five basic components:[92]

- Freedom: to choose a meaningful life in the community

- Authority: over a targeted amount of dollars

- Support: to organize resources in ways that are life enhancing and meaningful to the individual with a disability

- Responsibility: for the wise use of public dollars and recognition of the contribution individuals with disabilities can make to their communities

- Confirmation: of the important leadership role that individuals with disabilities and their families must play in a newly redesigned system and support for the self-advocacy movement

Specifically, Nerney has recognized the applicability of the self-determination model, originally developed for people with developmental disabilities, to the mental health field:

> Self-direction shifts the power in treatment and recovery plans from providers and professionals directly to the individual who experiences mental illness or the family of a child with serious emotional disturbance. Self-direction facilitates the development of personal goals and objectives that allow the individual or family to control the public and private resources necessary to purchase those supports and services central to the success of the plan. The individual's goals and objectives are used to design a plan to recovery. In this paradigm shift, professionals and providers become helpers and resources for the person, rather than the ones who narrowly define treatment options and press individuals with disabilities to select those options. Ideally, this fundamental change in power recognizes the primacy of the person who experiences the disability and changes the role of providers to a more respectful role that honors personal plans of recovery. Peer support can become another resource for individuals who need assistance in formulating and purchasing their unique plans of recovery.[93]

Bringing together the concepts of self-determination and recovery, the mental health field is in the process of transformation to a truly consumer-directed field, as the President's New Freedom Commission on Mental Health strongly recommended. This transformation will not be easy; changes may contradict many long-standing practices and beliefs in the mental health field. However, if redesigned and implemented effectively, changes will lead to a mental health service system that truly meets the self-defined needs of people with psychiatric disabilities.

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Recommendations

Recommendation Ten

Congress should provide sufficient appropriations to the Department of Education's Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration (RSA), for the expansion of IL services, rather than the decrease in funding that has occurred. With adequate funding, RSA can be tasked to explore, plan, and implement expansion of IL services to people with psychiatric disabilities. A part of the IL program goals at the federal level should focus on supporting and monitoring state-level collaboration that includes IL staff and mental health consumer leadership. Program objectives and indicators should be developed and tracked to ensure that otherwise-qualified individuals are not excluded from IL programs because of the nature of their disability.

Recommendation Eleven

Congress should provide a secure funding stream, analogous to that provided for IL centers through the Rehabilitation Act of 1973, as amended, that supports self-help programs for mental health consumers, the annual Alternatives conference, and the consumer technical assistance centers.

Recommendation Twelve

Through the Centers for Medicare and Medicaid Services, HHS should develop methodologies and funding streams to expand the availability and applicability of consumer-controlled personal assistance services to people with psychiatric disabilities. Oregon, which has made PAS available to people with psychiatric disabilities on the same basis as people with other disabilities, should serve as a model.

Recommendation Thirteen

Congress should authorize and HHS should implement changes in Medicaid policy and regulations to allow a much wider variety of recovery-oriented services to be eligible for Medicaid funding than is currently available. The agency should examine and consider the merits of existing models, for example, the Michigan state model of reframing the

definition of "medical necessity" to include "community integration," and shift funding to services based on "person-centered planning."

Recommendation Fourteen

Congress should enact legislative and/or policy changes that enable adoption of promising practices demonstrated at the state and tribal levels and authorize

- Medicaid administrators to use person-centered approaches. HHS should examine Michigan's state model of shifting to funding services based on person-centered planning, incorporating the consumer's goals into Medicaid-eligible services.

- Medicaid and vocational rehabilitation changes in budget practices. HHS should investigate the state models in Oregon and Florida that make individual budgeting available for people diagnosed with mental illnesses, as the federal provisions already allow for people with other disabilities.

- Medicaid changes in clinical supervision requirements. HHS should study models established by several states—including Georgia, South Carolina, Hawaii, Pennsylvania, and Michigan—to fund peer specialists, i.e., change the clinical supervision requirements to enable peer specialists to perform their unique services, so that peer support is available to people with psychiatric disabilities in all states.

Chapter Seven: Other Barriers to Inclusion in Livable Communities

As has been described, people with psychiatric disabilities face numerous difficulties as they attempt to live self-directed lives. This chapter will present some of the barriers that have not been addressed in earlier chapters, including special problems of people in rural areas, and access to general medical care.

People Living in Rural Areas

Having a psychiatric disability presents a number of problems for people living in rural areas that are not faced by people in urban areas. Services may not be readily available, both those provided by professionals and peer support. Getting to any kind of service may require traveling long distances, which can be especially difficult because of the lack of public transportation in rural areas, and the fact that many mental health clients don't have their own cars.

There is some evidence that stigma is even more of a problem for people with mental health difficulties living in rural areas than it is in cities, which offer a far larger degree of anonymity. An issue paper prepared by the National Rural Health Association[94] found that although the prevalence of psychiatric disorders is similar in rural and urban areas, a complex web of factors makes it more difficult for people in rural areas to receive appropriate services. Among the factors cited were high stress levels attributed to endemic economic difficulties for rural populations; inadequate numbers of treatment personnel at all levels; ingrained cultural beliefs that make people reluctant to seek help; and the fact that, even when they do, they usually frame their distress in general medical terms and seek out general medical practitioners who are often unequipped to deal with psychiatric issues.

Isolation, which is a problem for many people with psychiatric disabilities, may be especially acute in rural areas. In fact, the National Rural Health Association paper found that many rural people actually prefer to travel to cities when they seek mental

health services, taking advantage of the anonymity offered by cities to avoid their problems becoming known to neighbors and friends. The paper also highlighted a complex set of cultural beliefs among rural populations that require practitioners to become culturally competent to serve this population, just as cultural/linguistic competence is necessary for people from diverse racial and ethnic groups.

The association also recognized the value of self-help groups and urged that funding be made available to support the availability of consumer-run services. Such programs can be especially valuable in rural areas because of the general unavailability of professional services, as well as people's reluctance to identify themselves as needing mental health services.

Many self-help organizations in states with large rural populations have been actively involved in trying to bring self-help into rural areas. For example, Linda Corey, the executive director of Vermont Psychiatric Survivors (VPS), points out many efforts that VPS makes to reach people who live in the countryside:

> The number one problem facing people in rural areas is transportation—getting people around. There is not much public transportation, and a lot of people don't have cars, so we try to provide peer-to-peer transportation. We will reimburse mileage, so if one person has a car, we link them up with other people who don't, so they can get to meetings and events. We convinced the state to pay for transportation reimbursements, explaining that people needed to get to meetings. When there is a meeting that involves both professionals and consumers, we ask the professionals to provide the transportation.

> Mental health clinics are not as skillful as we are at linking up people with transportation. We try to get people to events, meetings, to visit their friends in hospitals, as well as just to get out into the community, to go have coffee with others, and similar social opportunities. Some people say these kinds of support have helped to keep them out of the hospital. We take people to visit their friends who are still hospitalized. Recently, a bunch of people got together, loaded up their cars, took them all to the state hospital to celebrate the birthday of a person in the hospital. So the person knows that they're not forgotten, which helps to build their sense of hope.

> Isolation is another major problem. Services, both professional and peer, are usually in the towns and cities, so they're not very accessible. So, again, we are

trying to link people with cars to those without, and reimburse the cost of mileage. For those who have Internet access, this is a good way to provide peer support, but a lot of people don't have computers or don't know how to use them, so we do a lot of phone conferences. The state pays the cost. Also, our warm line is very well utilized.

Stigma is higher in rural areas—small towns where everyone knows everyone else's business. This can work both ways: sometimes it helps because the townspeople know the person and see them as an individual, not as a mental health client, but sometimes it cuts the other way. Three communities have rejected having any kind of peer programs set up, claiming it will hurt tourism, or other excuses are given.[95]

Doug DeVoe, executive director of Ohio Advocates for Mental Health, finds similar difficulties in his state:

A lot of Ohio is in Appalachia. There's a lot of poverty. There is no public transportation. A peer center could be 60 or 100 miles away, so without a car people can't get there. Even when people have cars, the cars tend to be older, less reliable cars that may not run in the winter. The price of gas is also a factor that makes it difficult to travel long distances.

Health care in general is hard to find. Doctors are few and far between. In rural areas, the doctors often don't speak English as their primary language. So there is often a language barrier between doctor and patient. So trying to describe symptoms regarding stress or depression, for example, is quite difficult. It may be just a rural legend, but the story is told of one doctor who tried to commit someone because she described being nervous as having "butterflies in her stomach" and he thought she was having delusions!

It's also been hard to set up peer centers in rural areas. When we do find a building that's available, it's usually an old house that's not physically accessible, is hard to heat, has poor plumbing, and other problems. A lot of our clients have accessibility issues—many people are obese, they have movement disorders caused by the drugs, and problems like that, so buildings with steps and nonaccessible bathrooms aren't very useful for us.[96]

Transportation presents problems not only for people in rural areas, but for many other people with health service needs as well. However, the issues are compounded by geographical location and other factors. For example, because so many people with psychiatric disabilities are poor, car ownership is low, and except for large cities, public transportation is often inadequate if it exists. So getting to a doctor's appointment, a

self-help group, or any other service becomes complicated. When a person is dealing, for example, with depression or other emotional difficulties, any obstacle—including transportation barriers—can seem insurmountable.

Even when public transportation is available, there are often barriers to its use. Workers at advocacy programs frequently hear from people with psychiatric disabilities who face discrimination when they apply for reduced rate passes because their disabilities are not visible. One individual successfully obtained a pass, but told of being harassed and ridiculed by a bus driver when she tried to use her pass. The bus driver said loudly, "There's nothing wrong with you—you're just cheating the system." She was so humiliated that she seldom tried again.[97]

Accessing General Medical Care

A number of barriers make it difficult for people with psychiatric disabilities to get help with their general medical needs. Many people with low income or living near and at the poverty level are dependent on Medicare and Medicaid, and they face all the widely publicized difficulties of these public benefit programs compounded by having mental illnesses. As an example, one study found the following:

> New Mexico implemented Medicaid managed care for both physical and mental health services in 1997. The reform led to administrative burdens, payment problems, and stress and high turnover among providers. Restrictions on inpatient and residential treatment exacerbated access problems for Medicaid recipients. These facts indicate that in rural, medically underserved states, the advantages of managed care for cost control, access, and quality assurance may be diminished.[98]

It is quite common for people with psychiatric disabilities who seek care for general medical problems to receive disparate treatment. Sometimes providers attribute symptoms to people's mental illnesses, rather than investigating their complaints.

> People come to mental health professionals with the expectation that the cause of their problem will be identified. An underlying medical illness that is unrecognized and treated with only psychological interventions will likely

contribute to a downward spiral of the person's health. Being aware of the most common masked medical illnesses that present with psychological or behavioral symptoms should be the responsibility of all who work in the field of mental health care. Indeed, our patients have a right to expect nothing less.[99]

The available data also shows that people diagnosed with mental illnesses die prematurely from multiple causes. People with psychiatric disabilities experience heart disease, diabetes, obesity, high blood pressure, and other severe medical problems in disproportionate numbers compared to the general population. Coupled with the difficulties experienced in accessing general medical care, it is not surprising to find high rates of morbidity and mortality, which present a crisis requiring multiple approaches.

Many medical providers present the same sorts of stigmatizing attitudes as the general population. The providers often treat people with psychiatric disabilities as people who are unable to articulate their needs, to follow medical instructions, or to practice basic self-care. Coupled with the limitations on access to care because of lack of health insurance and the inadequacies of Medicaid funding, there is a pressing need for all providers and consumers to open lines of communication in order to improve access to services and to address mutual misunderstandings.

One of the ways that people with mental illnesses are segregated from their communities is in health care. The Institute of Medicine's (IOM) 2006 report, *Improving the Quality of Care for Mental and Substance-Use Conditions,* calls for integration of the mental health system and the general medical system.[100] The IOM says this is necessary to improve the quality of health care for all Americans. Such an approach would offer some hope of changing the dismal fact that people with mental illnesses who are served by our public systems die an average of 25 years younger than the general population. It would also be a big step in the direction of community integration. And while the IOM did not suggest this course of action to reduce stigma, integration would automatically remove the stigma of being served in a mental health system. A recommendation could be for SAMHSA (or the National Institute of Mental Health) to provide grants to develop pilot sites that fully integrate mental health and general medical care.

Recommendations

Recommendation Sixteen

Further research is needed to identify the special problems of people living in rural areas and to promote best practices that address these needs, with a particular focus on self-help and peer support. Within HHS, the Services Research Branch of the National Institute of Mental Health should initiate a dialogue with other federal agencies with rural area programs, such as the U.S. Department of Education's Office of Special Education and Rehabilitative Services and the Department of Labor, regarding data available through existing programs.

Recommendation Seventeen

The transportation needs of people with psychiatric disabilities must be met in ways that recognize their particular problems, address stigma and discrimination, and focus on innovative self-help approaches. The Department of Transportation should make public a plan that ensures that its programs directed to people with disabilities are inclusive of people with psychiatric disabilities who live in the rural areas of this nation.

Recommendation Eighteen

The provision of appropriate general medical services to meet the complex needs of people with psychiatric disabilities calls for a coordinated system. Such a system would bring together the diverse expertise of medical providers, mental heath providers, and consumers, with particular attention to the high rates of mortality and morbidity among this population. Within HHS, SAMHSA should take a leading role in this effort.

Recommendation Nineteen

SAMHSA and/or the National Institute of Mental Health should provide grants to promote the development of pilot sites that fully integrate mental health and general medical care policies, practices, and programs.

Chapter Eight: Envisioning an Ideal Future

> There is no single antidote for the current dysfunction of the public mental health system. Clearly, visionary leadership, adequate funding, and expansion of proven models (including consumer-directed programs) are essential ingredients. More than these, however, there needs to be a dramatic shift in aspirations for people with psychiatric disabilities.[101]

NCD's contention in its paper *The Well-Being of a Nation: An Inter-Generational Vision of Effective Mental Health Services and Supports*[102] was that public mental health systems must be driven by a value system that sees recovery as achievable and desirable for every person who has experienced a mental illness. Systems also must commit to serving the whole person, and not merely the most obvious symptoms. In other words, mental health systems will have to do more than just develop the expertise to deliver medication and counseling: they must coordinate with other entities that address needs for housing, transportation, employment, and other supports as well.

In an ideal world, a diagnosis of mental illness would not lead to isolation and hopelessness, but instead would provide every diagnosed individual with multiple pathways to recovery, based on individual choice, self-determination, the full range of supportive services, and all the elements of community integration described in this paper. The vignette that closes this paper envisions how life could unfold for a person diagnosed with a mental illness if all components were in place.

Karen is a 45-year-old woman who was diagnosed with schizophrenia in her early twenties. The first 10 years after her diagnosis were difficult ones—multiple hospitalizations, periods of homelessness, a loss of hope, no vision for the future. Even when she was out of the hospital, she was placed in a group home where no one was ever expected to get better. She was told that she would never hold down a job or live in her own apartment.

Things began to change when Karen started to attend a drop-in center run by an organization of former mental health patients. For the first time, Karen saw people who had similar histories and diagnoses, but who were making a success of their lives. She had role models. She began to believe she could succeed as they had done.

Karen became a volunteer at the drop-in center. This led, eventually, to a paid part-time position. She also took part in support groups in which people talked about their plans for the future. Slowly, Karen began to develop her own life plan. She wanted to go back to college (she had dropped out when she was first hospitalized) and to become a pharmacist.

Fortunately, Karen had access to a helpful vocational rehabilitation counselor, through her state Department of Vocational Rehabilitation. Her counselor supported her in her career goals and helped her to get the financial aid she needed to complete her education.

The mission of the state Department of Mental Health was to help each individual to define and then realize his or her own goals, with supports of the person's choosing. The mental health service workers who worked with Karen were also helpful and supportive. When Karen had setbacks, rather than telling her she was trying something "too stressful," they encouraged her to stick to her life plan, even when she had to drop out of college for a semester.

Her psychiatrist was helpful, also, working with her to find the right combination of medications that controlled her symptoms without causing her to be drowsy or have other side effects that interfered with her studying. When her symptoms were well under control, Karen decided to try to go off medication, and her psychiatrist worked with her to slowly reduce the dose. Eventually, Karen decided to remain on a very low level of one medication that she found helpful. After several years, she was able to stop taking even this medication, and now takes another medication occasionally when she experiences an increased level of symptoms. Her psychiatrist is always available to support her in her choices.

Her participation in the self-help group was also a big part of her continuing success. She could always count on the group members for help when she felt discouraged or overwhelmed. And a big contribution to her own growing sense of empowerment and recovery was when other group members began to point to her as a success story, as a role model for newer members of the group.

Karen was assisted to make the transition from benefits to work through helpful programs that gradually decreased her cash benefits as she increased her income. She also was able to purchase health insurance at an affordable rate, without being discriminated against because of her past psychiatric history.

Karen was able to move into her own apartment through a program that provided a subsidy while she was still in school, which was gradually reduced as she became a wage earner. When Karen graduated and applied for pharmacy jobs, strong antidiscrimination laws assured that her past psychiatric history was not held against her.

Karen continued to have difficulties from time to time, but through a combination of professional and self-help supports, and the occasional use of medication, she learned to manage so that the difficulties did not interfere with her life goals. She found it extremely helpful when she stopped thinking of the problems she encountered from time to time as "symptoms," and instead saw them as the same kinds of problems other people, who had never been diagnosed with a mental illness, faced in their own lives.

As she made various transitions—going back to school, moving into her own apartment, getting a job—she was able to use her support system whenever she began to doubt her own ability to succeed. She felt a growing sense of self-confidence and empowerment and began to see herself as a person capable of living her dreams.

Through friends she made in the self-help program, Karen also had a good social life. She began to take part in various aspects of her "livable community": she joined a local church and became active in several committees. One of her hobbies, knitting, led her

to a group of knitters who met weekly for friendship while they worked on their crafts projects. In both her church and the knitting group, at first Karen concealed her psychiatric history, but at a point when she felt comfortable talking about it, she did so— and was met with understanding and a deepening of her natural support system.

Appendix

Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities; and to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities in the Federal Government, at the state and local government levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with

disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.

- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.

- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).

- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.

- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.

- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.

- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report.*

International

In 1995, NCD was designated by the Department of State to be the U.S. Government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became ADA. NCD's present list of key issues includes education, transportation, emergency preparedness, international disability rights, employment, foster youth with disabilities, vocational rehabilitation, livable communities, and crime victims with disabilities.

Statutory History

NCD was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

ENDNOTES

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