

**Overcoming  
Barriers to  
Community  
Integration for  
People with  
Mental Illnesses**



**SAMHSA**



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**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Substance Abuse and Mental Health Services Administration  
Center for Mental Health Services**



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***Foreword by Joyce T. Berry, Ph.D., J.D.  
Center for Mental Health Services***

Editors:

**Carol Bianco • Susan Milstrey Wells**

Advocates for Human Potential, Inc. • Delmar, New York

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Center for Mental Health Services

Substance Abuse and Mental Health Services Administration

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## **Disclaimer**

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## Foreword

Today we are at a critical juncture in the evolution of federal and state policies that affect people with serious mental illnesses. Events over the past two years summon us to sharpen our focus on what helps and what hinders efforts to promote true community integration. The *Olmstead* decision galvanized the entire disability community, and challenged each of us to identify what it will take to ensure that people do not remain in isolated and segregated institutional settings.

Throughout the United States diverse coalitions have formed to develop plans and implementation strategies to carry out this mission. In many cases, coalition members are sitting at the table together for the first time, stepping out of the boxes created by history and habit.

As they begin to work together, coalition members are discovering two very important things. First, they have much more in common than they realized. Most important, they are learning that by joining together, they create synergy and strength. Many barriers cut across all disabilities and age groups. By identifying these barriers together, communities are much more likely to find effective, long-term solutions for all people. Indeed, in these coalitions, planning groups, and task forces, true integration is being modeled by people who are crafting new, shared visions.

These efforts have received significant support from the new Administration. Early this year, President Bush's *New Freedom Initiative* affirmed our nation's commitment to help people live and work in the most integrated settings. Also, through Executive Order Number 13217, President Bush instructed the Departments of Justice, Health and Human Services, Education, Labor, and Housing and Urban Development, along with the Social Security Administration, to examine their programs, policies, statutes, and regulations to identify barriers to providing services in the most integrated settings. In addition, this process has involved extensive stakeholder input from throughout the country.

Within this dynamic environment, I am pleased to provide the enclosed briefing paper. It is intended to help readers, whatever their background or perspective, to more clearly understand the issues we must confront to realize the vision of the *Olmstead* decision and the President's *New Freedom Initiative*.

The Center for Mental Health Services remains committed to providing timely and pertinent resources and materials to people in the field. We hope that this paper will strengthen your efforts to overcome barriers to community integration for all individuals with serious mental illnesses.

Joyce T. Berry, Ph.D., J.D.

September 2001

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# Executive Summary

The landmark 1999 U.S. Supreme Court decision in *Olmstead v. L.C.* held that unnecessary segregation of people with disabilities in institutions is a form of discrimination that violates the 1990 Americans with Disabilities Act (ADA). The decision highlighted the need for states to provide community-based services to meet the needs of all individuals who can benefit from living in the community.

To this end, the Substance Abuse and Mental Health Services Administration (SAMHSA) of the U.S. Department of Health and Human Services has created a National Coalition to Promote Community-Based Care for people with a history or a diagnosis of serious mental illness (hereafter referred to as “people with serious mental illnesses”). SAMHSA’s National Coalition will promote the development of statewide coalitions and will provide technical assistance and training to the state groups.

In particular, the National Coalition has been charged with examining the characteristics and service needs of those individuals with serious mental illnesses who are inappropriately hospitalized or at risk of psychiatric hospitalization; delineating the barriers to serving these individuals in the community; and exploring strategies to ensure their successful transition to community living. This report outlines some of the barriers and strategies that National Coalition members will review.

## The Changing Face of Mental Health Care

Federal research and service interventions have shown that, given the right combination of housing, treatment, and supports, people with serious mental illnesses can live successfully in the community. The advent of atypical antipsychotic medications that have fewer side effects, psychosocial rehabilitation programs, the mental health recovery movement, and consumer-run services have empowered many individuals with serious mental illnesses to reclaim valued roles in their communities.

However, in part due to persistent clinical, service system, and financial barriers, some 58,000 people with serious mental illnesses remain in state psychiatric hospitals. SAMHSA’s National Coalition and its state counterparts will play a key role in addressing the barriers that remain to full community integration for people with serious mental illnesses.

## Individual Barriers to Community Treatment

**The Nature of Serious Mental Illness.** According to a recent report by the U.S. Surgeon General, one in every five adults, or about 40 million Americans, experiences some type of mental disorder every year, and of this number, 5 percent have a serious mental illness—generally defined as schizophrenia and schizoaffective disorders, major depression, and bi-polar disorder (manic-depressive illness). Serious mental illness can strike at any age. Nearly 20 percent of those who are 55 years and older experience mental disorders that are not a part of normal aging, according to the U.S. Administration on Aging.

For some individuals, though not all, serious mental illness will be severe, persistent, and long-term. The cyclic nature of serious mental illnesses can make it difficult for individuals to retain housing and employment when their symptoms recur or worsen. But the good news is that serious mental illnesses can be treated. Today most mental disorders are considered to be as treatable as general medical conditions.

## Systemic Barriers to Community Treatment

People with serious mental illnesses require a broad range of housing, health and mental health care, and social services, yet they face enormous hurdles in gaining access to this needed support.

**Lack of Income Support and Entitlements.** Though people with serious mental illnesses often are eligible for federal and other targeted benefit programs, such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), many eligible individuals are not currently enrolled. Frequently, they lack the required documentation; they may be unable to negotiate the service system unaided; and they may be reluctant to participate in mainstream benefit programs. Often, physicians are unaware of the Social Security Administration’s strict and complex medical standards for eligibility.

**Lack of Affordable Housing.** Housing is perhaps the first line of treatment for people with psychiatric disabilities. Yet with limited income, many people with serious mental illnesses are forced to live in overcrowded and often substandard living environments that place them at physical and emotional risk. The ongoing stigma surrounding mental illness means that many



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housing providers, funding sources, and neighborhood groups are reluctant to serve people with disabilities, despite such legislation as the Fair Housing Amendments Act.

**Lack of Competitive and Supported Employment.** People with serious mental illnesses want to work, and with appropriate support, many are quite successful on the job. However, the unemployment rate among people with serious mental illnesses hovers at 90 percent. Though today's economy has created significant opportunities for people with serious mental illnesses to gain better, higher paying jobs, the technology and the resources to provide them with necessary long-term support in those jobs are lagging far behind.

**Lack of Access to Appropriate Health Care.** People with serious mental illnesses require appropriate and timely mental health and primary health care services. Yet lack of transportation, lack of coordination between mental health and primary health care services, and lack of access to qualified specialists in rural areas present formidable access barriers. Key clinical barriers include lack of attention to issues of trauma, including childhood and adult physical and sexual abuse; failure to make the newer antipsychotic medications widely available; and lack of integrated treatment for co-occurring mental health and substance use disorders.

## Cross-cutting Barriers to Community Treatment

**Fragmented Services.** The multiple services people with serious mental illnesses require typically are handled by separate agencies. The burden of coordination falls on the consumer, but fragmented services are difficult for individuals with serious mental illnesses to negotiate unaided. This fragmentation is especially evident in the transition from an institution such as a hospital or jail to the community (i.e., discharge planning).

**Fiscal Barriers.** Delivering individualized, flexible services is a challenge in a traditional health care system that favors institution-based services, provided in groups, and that severely limits service choices. Individuals are hampered by limited insurance coverage for mental health care, both by private plans and by Medicare. Medicaid home- and community-based waivers, which provide a significant source of funds for other disability groups, are largely unavailable for people with serious mental illnesses. States, which fund the bulk of services for people with serious mental illnesses, continue to reduce spending on public mental health services.

**Stigma and Discrimination.** Nearly two-thirds of all people with diagnosable disorders do not seek treatment, in part because of the stigma associated with mental illness and the receipt of mental health treatment. These attitudes make it difficult for people with serious mental illnesses to find housing and jobs, maintain social networks, and become accepted in their communities.

**Staffing Shortages.** Low pay and lack of training for community-based mental health staff are significant barriers to the creation of appropriate residential and treatment programs for people with serious mental illnesses. Individuals in the human services fields are seeking higher paying jobs elsewhere, and those staff who remain frequently are not trained to address the special needs of people with the most serious mental disorders.

## Successful Strategies for Community Treatment

Community-based services for people with serious mental illnesses must be based on an underlying set of client-centered core values. These values include a focus on treatment in the least restrictive setting; access, empowerment, and responsibility; diversity and flexibility; peer, family, and other natural supports; and the principles of mental health recovery.

The mental health field has developed a well-established set of practices and services to provide community-based care to people with serious mental illnesses. To be effective, the individual service components must be coordinated in a comprehensive, integrated system of care. As outlined by the Surgeon General, such a system includes the following:

- Case management
- Assertive community treatment
- Psychosocial rehabilitation services
- Community alternatives for crisis care
- Services for co-occurring substance abuse and serious mental illness
- Consumer self-help, consumer-operated programs, consumer advocacy
- Family self-help and advocacy
- Housing
- Income, education, and employment
- Health care
- Integrated service systems

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## Putting the Pieces Together

There is no single, simple solution to addressing the service needs of people with serious mental illnesses, especially those awaiting discharge from a state facility or at risk of hospital admission. Yet, there is little need for new technologies. Meeting this goal requires a commitment and partnership by government (federal, state, and local) and the private sector—including foundations, philanthropists, researchers, businessmen and women, the media, and the general public—to help people with serious mental illnesses achieve full participation in society. They deserve nothing less.

Some specific steps that government and private partners can take to make this vision a reality include, but are not limited to, the following:

- Continue research into both effective clinical treatments for serious mental illnesses and successful program design.
- Increase the supply of affordable housing and housing subsidies, and replicate successful supported housing programs throughout the country.
- Facilitate entry into treatment, and into the full range of services required by people with serious mental illnesses.
- Revise federal program policies to increase work incentives.
- Enhance interagency initiatives to address fragmentation of services, especially around issues of discharge planning.
- Continue to reduce stigma and improve public awareness of effective treatment for serious mental illnesses.
- Create programs and services that are culturally appropriate.



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# Introduction

The landmark 1999 U.S. Supreme Court decision in *Olmstead v. L.C.* held that unnecessary segregation of people with disabilities in institutions is a form of discrimination that violates the 1990 Americans with Disabilities Act (ADA). The decision highlighted the need for states to provide community-based services to meet the needs of all individuals who can benefit from living in the community. Such services must be comprehensive and integrated in order to address effectively the multiple and complex needs of individuals with physical and mental disabilities.

To this end, the Substance Abuse and Mental Health Services Administration (SAMHSA) of the U.S. Department of Health and Human Services has created a National Coalition to Promote Community-Based Care for people with a history or a diagnosis of serious mental illness (hereafter referred to as “people with serious mental illnesses”). SAMHSA is the key federal agency charged with improving the quality and availability of prevention, treatment, and rehabilitation services for adults and children with mental health and substance use disorders.

SAMHSA’s National Coalition to Promote Community-Based Care promotes the development of statewide coalitions and provides technical assistance and training to the state groups. In particular, the National Coalition has been charged with examining the characteristics and service needs of those individuals with serious mental illnesses who are inappropriately hospitalized or at risk of psychiatric hospitalization; delineating the barriers to serving these individuals in the community; and exploring strategies to ensure their successful transition to community living.

National Coalition members will help state coalitions secure resources to help remove barriers to the development of comprehensive, community-based systems of care for adults with serious mental illnesses and for children with severe emotional disturbances. The group includes representatives of key federal agencies whose programs and services promote community integration for people with serious mental illnesses. The Coalition also includes representatives of national mental health consumer, family, and professional stakeholder groups.

## Using This Report

The balance of this report focuses on adults with serious mental illnesses.<sup>1</sup> The first section presents an overview of the barriers to community treatment for people with serious mental illnesses and strategies to address those barriers. The next five sections describe specific barriers in the areas of income and entitlements, housing, employment, mental health care, and primary health care. Each section also highlights recommended strategies to overcome these barriers.

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<sup>1</sup>Service needs and barriers for children with severe emotional disturbances are covered in a separate report.



## Overview of Barriers and Strategies

Susan Milstrey Wells

While the *Olmstead* decision addressed the needs of two individuals who were receiving inpatient services in a state psychiatric hospital, some legal advocates believe that the findings in the decision can be extended to the following groups of adults with serious mental illnesses who may be able to be served appropriately in the community:<sup>1</sup>

- long-stay patients in state psychiatric hospitals;
- nursing home residents;
- individuals who cycle in and out of psychiatric hospitals;
- individuals at risk of psychiatric hospitalization;
- individuals who are inappropriately incarcerated; and
- any other individuals who are receiving services in unnecessarily segregated settings.

As recently as four decades ago, most of these individuals would have been served in state psychiatric hospitals, some staying their entire lives. Most of these institutions housed thousands of people, were located in remote rural areas with self-contained “campuses,” and offered little, if any, opportunity to overcome the symptoms of mental illness, master new skills, and return to community life.

### The Changing Face of Mental Health Care

The role of the state hospital in the treatment and residential care of long-term patients with chronic mental illnesses had diminished significantly since the mid-1950s. The number of resident patients dropped 86 percent between 1955 and 1996—from 560,000 people to 77,000 people.<sup>2</sup> However, in part due to persistent clinical, service system, and financial barriers, some 58,000 people with serious mental illnesses remain in state psychiatric hospitals.<sup>3</sup> SAMHSA’s National Coalition and its state counterparts will play a key role in addressing the barriers that remain to full community integration for people with serious mental illnesses.

Much of this decrease in the state hospital census can be attributed to the movement called “deinstitutionalization,” an outgrowth of three significant changes in American society. First was the introduction in the mid-1950s of antipsychotic medication that gave rise to hopes that, with their symptoms under control, people with serious mental illnesses would be able to live successfully in the community.

Second, passage of the Community Mental Health Centers (CMHC) Act of 1963, and creation of the Medicaid and Supplemental Security Income (SSI) programs in the mid-1960s, provided financial incentives for community care. Finally, consumer, family, and advocacy groups sought to address well-publicized abuses in state hospitals by seeking treatment in the least restrictive setting for people with serious mental illnesses. As a result of these changes, large numbers of people with serious mental illnesses made the transition to the community.

However, the vast array of services and supports never materialized. Fewer CMHCs than anticipated were created, and those that were offered primarily clinic-based services that were inaccessible or inappropriate for individuals with the most serious disorders. Many individuals became homeless as a result, and others ended up being institutionalized in jails and prisons.

### The Development of Community-Based Systems of Care

By the late 1970s, the National Institute of Mental Health introduced the Community Support Program (CSP), later administered by SAMHSA’s Center for Mental Health Services (CMHS). This model of comprehensive community support was adopted as the framework for developing the necessary range of services that would allow people with serious mental illnesses to live successfully outside of institutions. Some of the elements of the CSP approach included outreach; income and medical assistance benefits; 24-hour crisis assistance; psychosocial rehabilitation, including employment services; long-term supportive services; medical and mental health treatment; family support; residential services; case management; rights protection; and advocacy. Today, these elements remain as the cornerstone of com-

prehensive, community-based systems of care for people with serious mental illnesses.

The CSP program and subsequent SAMHSA initiatives such as the ACCESS (Access to Community Care and Effective Services and Supports) program have shown that, given the right combination of housing, treatment, and supports, people with serious mental illnesses can live successfully in the community. As more adults made the transition to community living, and states sought ways to reduce health care spending, hospital closings continued. Indeed, more than three times as many hospitals were closed or downsized in the 1990s than in the previous two decades combined.<sup>4</sup>

Today, driven in part by the cost containment pressures of managed care, general hospitals have become the leading provider of acute, inpatient psychiatric care. Often individuals whose needs are not being met in the community have a pattern of repeated hospital admissions and discharges and are sometimes referred to as “revolving-door” patients. Some of these individuals become long-stay patients in state psychiatric hospitals, which are still the principal providers of inpatient care beyond crisis stabilization for those individuals who are in grave need of assistance.<sup>5</sup>

## Financing Mental Health Services

The public mental health system is funded by a patchwork of federal, state, and local resources. Services provided by state mental health agencies are financed by state appropriations, private insurance, Medicaid, Medicare, and SAMHSA programs, including the Community Mental Health Services Block Grant. Many states contract with community providers to deliver services at the local level.

Public-sector spending accounts for approximately 53 percent of all spending on mental health and substance abuse treatment. To reduce health care spending and improve coordination of care, most states have turned to some type of managed care arrangement to provide behavioral health care (mental health and substance abuse) treatment.

The cost-saving tools used by managed care companies create the risk that medically necessary health and mental health services will be reduced for budgetary reasons or that funding options will be biased toward institutional care, in an attempt to avoid expanding community-based supports. SAMHSA and several national groups offer technical assistance to help states and providers remain competitive in the emerging health care environment.

Consumers, providers, and mental health policy makers know what works to help people with serious mental illnesses achieve and maintain stable community living. There is a wealth of research and service knowledge available, but too often, communities and individual providers lack the resources to provide the services they know will be effective.

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## Individual Barriers to Community Treatment

### The Nature of Serious Mental Illness

One in every five adults, or about 40 million Americans, experiences some type of mental disorder every year, and of this number, 5 percent have a serious mental illness—generally defined as schizophrenia and schizoaffective disorders, major depression, and bipolar disorder (manic-depressive illness).<sup>6</sup> Though many mental illnesses are diagnosed in young adults, elderly individuals are not immune. Indeed, the U.S. Administration on Aging reports that nearly 20 percent of those who are 55 years and older experience mental disorders that are not a part of normal aging.<sup>7</sup> As the country’s population continues to age, disability due to mental illness in individuals over age 65 will become a major public health problem.<sup>8</sup>

In 1996, according to the U.S. Surgeon General, the United States spent more than \$99 billion for mental, addictive, and dementia disorders. Indirect costs of all mental illness in 1990, the most recent year for which estimates are available, totaled \$79 billion dollars. These costs include those associated with lost productivity and premature death.<sup>9</sup>



Many individuals with serious mental illnesses have a co-occurring substance use disorder. Estimates suggest that up to 10 million people in this country have a combination of at least one co-occurring mental health and substance-related disorder in any given year.<sup>10</sup> Individuals with co-occurring disorders tend to be more symptomatic, to have multiple health and social problems, and to require more costly care,<sup>11</sup> including inpatient hospitalization. Many are at increased risk for homelessness and incarceration. Of an estimated 600,000 people who are homeless on any given day, approximately 39 percent have a mental illness.<sup>12</sup>

But these facts only begin to tell the story. They don't reflect the pain, suffering, and disrupted lives experienced by people with serious mental illnesses, whose multiple needs often go unmet. Though they have the same life goals and dreams as people without mental disorders, people with serious mental illnesses often are deprived of the opportunity to achieve satisfying lives in their own communities.

For some individuals, though not all, serious mental illness will be severe, persistent, and long-term. The cyclic nature of serious mental illnesses can make it hard for individuals to retain housing and employment when their symptoms recur or worsen. Yet during periods of remission, and with the advent of newer medications that have fewer side effects, more and more people can achieve or return to extremely high levels of functioning, including competitive employment.<sup>13</sup>

Indeed, the good news is that serious mental illnesses can be treated. In fact, today most mental disorders are considered to be as treatable as general medical conditions.<sup>14</sup> The advent of atypical antipsychotic medications that have fewer side effects, psychosocial rehabilitation programs, the mental health recovery movement, and consumer-run services have empowered many individuals with serious mental illnesses to move beyond their disabilities and to reclaim what Daniel P. Fisher, M.D. Ph.D., co-director of the National Empowerment Center in Lawrence, Massachusetts, calls a "valued social role."<sup>15</sup>

## **Systemic Barriers to Community Treatment**

### **Lack of Income Support and Entitlements**

People with serious mental illnesses often live in poverty. Because many are unable to work full-time,

they must rely on public benefit programs, such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). For many individuals with serious mental illnesses, such benefits provide their only means of support.

However, though people with serious mental illnesses often are eligible for federal and other targeted benefit programs because of their poverty and their disabilities, many eligible individuals are not currently enrolled.<sup>16</sup> They face significant barriers to gain access to income supports and entitlements.

People with serious mental illnesses frequently lack the required documentation; they may be unable to negotiate the service system unaided; and they may be reluctant to participate in mainstream benefit programs because of previous negative experiences. Often, physicians are unaware of the Social Security Administration's strict and complex medical standards for eligibility, and the fluctuating nature of many mental illnesses makes it difficult to tie symptoms to functional impairments that would preclude an individual from working. Once they become beneficiaries, individuals risk the loss of cash assistance and medical benefits when they try to return to work.

### **Lack of Affordable Housing**

Lack of housing that is appropriate, accessible, and affordable is considered by many to be the number one barrier to successful community integration for people with serious mental illnesses. According to "Priced Out in 1998,"<sup>17</sup> there is not one housing market in the United States in which an individual surviving on SSI can afford even a modest one-bedroom housing unit. Using national averages, the cost of a one-bedroom apartment is 69 percent of the SSI monthly income. This is more than double the standard housing affordability threshold of 30 percent, commonly used by the U.S. Department of Housing and Urban Development (HUD) and the housing industry.

As a result, many people for whom SSI is their only source of income are forced to live in overcrowded and often substandard living environments that place them at physical and emotional risk. Others are living with aging parents or relatives, many of whom are also living on fixed, low incomes.

Further, many mainstream affordable housing providers and funding sources are reluctant to serve people with disabilities because of their low incomes, and because of the perception that people with psychi-



atric disabilities need “supervision” or round-the-clock support. While this may be true for some individuals, the overwhelming majority of people with mental illnesses can live in their own homes if they have access to individualized, flexible supports.

Finally, despite legislation such as the Fair Housing Amendments Act, allegations of housing discrimination based on psychiatric disabilities are common.<sup>18</sup> Stigma can be overt, such as vocal community opposition to group homes, or less obvious, such as steering public funds away from housing initiatives serving controversial populations.

### **Lack of Competitive and Supported Employment**

The unemployment rate among people with serious mental illnesses hovers at 90 percent.<sup>19</sup> Many individuals find themselves unable to work consistently, if at all, in part due to active symptoms. In addition, people with serious mental illnesses frequently experience interruptions of education and employment. Though today’s economy has created significant opportunities for people with serious mental illnesses to gain better, higher paying jobs, the technology and the resources to provide them with necessary long-term support in those jobs are lagging far behind.

Despite both personal and systemic barriers, people with multiple barriers to work can and do find jobs. However, according to the Corporation for Supportive Housing (CSH), the current system of requiring everyone to work full-time “does not reflect the experience of significant numbers of people who struggle to gradually attach themselves to the labor market in small, tentative steps.”<sup>20</sup>

Further, many beneficiaries of federal income support and entitlement programs are reluctant to seek employment because there is either a perceived or actual loss of support benefits—a risk too severe to take. CSH recommends such system-wide changes as a more flexible definition of work and continued medical and income support benefits for those with disabilities who do work.

In addition, because mental illness often manifests itself in late adolescence and early adulthood, individu-

als whose job and career development has been interrupted by psychiatric disability must have opportunities to regain exposure and experience in the world of work. Similarly, people whose education is interrupted need help to reconnect and continue with their educational development. Supported education programs help fill this need.

The federal Ticket to Work and Work Incentives Improvement Act of 1999 is designed to remove economic barriers to employment for people with disabilities. Beginning October 1, 2000, the Act allows states to offer expanded availability of Medicaid and Medicare to Social Security Administration recipients who work. Also, in early 2001, people who receive SSDI and SSI will be issued a “ticket to work” that allows them to obtain vocational rehabilitation, employment, or other support services from a provider of their choice.

However, though these developments seem promising, states are offered little incentive to continue to insure people with disabilities who work, and employment network providers will only be paid when a beneficiary leaves the rolls. Few providers may be willing to gamble on people with serious mental illnesses who are unwilling or unable to relinquish cash benefits.

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### **Lack of Access to Appropriate Health Care**

Despite recent advances in understanding the science of mental illness, some key clinical and access barriers to the successful treatment of individuals with serious mental illnesses remain.

**Trauma.** Research reveals that adults in state psychiatric hospitals have experienced extraordinarily high rates of physical and/or sexual abuse, ranging from 43 percent to 81 percent.<sup>21</sup> Severe trauma in childhood, including physical and sexual abuse, may leave an individual more vulnerable to ongoing stresses. In an oft-cited study of female psychiatric inpatients, researchers found a direct relationship between childhood abuse and adult psychiatric symptoms.<sup>22</sup> Patients with a history of abuse had more severe symptoms, more suicidal symptoms, more borderline diagnoses, and were more likely to be given medication.

Trauma is often ignored, or worse perpetuated, in the mental health system. Patients may be retraumatized,

for example, by the use of physical restraints or forced medication, which remind them of the original abuse they suffered.<sup>23</sup> Because such issues often are not acknowledged or addressed, abuse survivors tend to remain in psychiatric hospitals longer than patients who have not been abused.<sup>24</sup>

**Use of New Medications.** The advent in recent years of new atypical antipsychotic medications with fewer side effects raised the hope that many more patients might improve enough to benefit from community living. Though such drugs are not a panacea, these medications may bring symptom relief to some patients. However, they are not universally available. Concerns about cost, and treatment approaches that require patients to “fail” on the older medications first, may keep some patients from receiving the help they need to stabilize their symptoms.<sup>25</sup>

**Treatment for Co-occurring Disorders.** Though current research indicates that integrated treatment is more effective than efforts to treat each disorder separately,<sup>26</sup> mental health and substance abuse services historically have been provided separately by agencies with discrete funding streams, eligibility criteria, and treatment philosophies. Often people with serious mental illnesses are excluded from substance abuse treatment programs because of their mental illness and from mental health treatment programs because of their substance use disorder.

**Lack of Access to Services.** People with serious mental illnesses face significant access barriers to health and mental health care services. These include long waiting lists for free or reduced-price services, clinics that have limited hours for walk-in services, and difficulty scheduling and maintaining appointments.

Individuals with serious mental illnesses enrolled in managed care plans may be assigned to providers who are not conveniently located or who do not have experience in addressing their specific needs. Though outreach is now considered to be a key element in an integrated system of care for people with serious mental illnesses, especially those who are homeless or at risk of homelessness,<sup>27</sup> many community mental health center services are facility-based only.

Older adults may be especially at risk. The U.S. Administration on Aging estimates that only half of older adults who acknowledge mental health problems receive treatment from any health care provider, and only a fraction of those receive specialty mental health services. Though older adults may require such services as elder case management or psychiatric home care

services, only a few states designate older adults as priority clients, and only a minority of states address the mental health needs of elderly people through specialized services designed to meet their needs.<sup>28</sup>

**Lack of Transportation.** Access to health care services is especially problematic for individuals who lack adequate transportation. Many people with serious mental illnesses can't drive because of the symptoms they experience or the medications they take. Others can't afford the costs of purchasing and maintaining a vehicle. Lack of accessible transportation can lead to an individual being almost as isolated in the community as he or she was in an institution. Transportation is also medically necessary because it enables individuals to access community mental health services and supports.

**Lack of Coordination with Primary Health Care** People with serious mental illnesses often have significant co-morbid medical conditions. These include obesity, diabetes, and pulmonary and heart disease, among other chronic disorders. However, health care systems frequently treat behavioral and general health care separately. For example, managed care plans that “carve out” behavioral health care from physical health care make it more difficult for individuals with serious mental illnesses to receive appropriate and timely treatment for their mental and physical health problems. This may complicate treatment for both disorders and lead to higher morbidity and mortality rates.

Lack of coordination with primary care may be especially problematic for older people, many of whom prefer to receive mental health care in primary care settings. But the diagnosis and treatment of older people's mental disorders in these settings are often inadequate, according to the U.S. Administration on Aging. Primary care physicians frequently receive inadequate training in mental health care, and they may attribute psychiatric symptoms to changes expected with age or to co-occurring physical disorders.<sup>29</sup>

**Lack of Access in Rural Areas.** Access barriers are particularly acute for individuals with serious mental illnesses who live in rural areas. Rural and frontier communities may be the last areas to receive advances in mental health care, such as newer antipsychotic medications or specialized treatment programs. Further, psychiatrists typically locate in urban areas, leading to a scarcity of services for people with serious mental illnesses in rural communities.

In response, a number of rural communities around the country have adopted the use of telecommunications technology to provide mental health services at a

distance. Telemedicine has the potential to reduce the disparity of mental health care based on population characteristics by extending scarce resources into geographic areas of need.<sup>30</sup> Yet many rural communities lack the financial resources and technical expertise to put these programs into place.

## Cross-cutting Barriers to Community Treatment

### Fragmented Services

One of the most difficult barriers to community integration for people with serious mental illnesses is a lack of coordination among the many community programs and services designed to meet their multiple and complex needs. People with serious mental illnesses require a broad range of housing, health and mental health care, and social services, all of which typically are handled by separate agencies. The burden of coordination falls on the consumer, but fragmented services are difficult for individuals with serious mental illnesses to negotiate unaided.

This fragmentation is especially evident in the transition from an institution such as a hospital or jail to the community (i.e., discharge planning). The Bazelon Center for Mental Health Law reports that, nationally, only one-third of inmates with mental illnesses in jails and prisons receive any discharge planning services. These individuals frequently are released with bus tokens, a few pills, and the address of a mental health center.<sup>31</sup>

An appropriate discharge plan involves both facility and community staff and addresses such key areas as income support and entitlements, housing, health care, mental health and substance abuse treatment, support services, case management, education and employment, and transportation. When any of these areas are not adequately addressed, especially the need for housing and income support, the result may be medically unnecessary hospitalization, homelessness, or incarceration upon discharge.

**Criminal Justice System Involvement.** Nearly 284,000 prisoners in 1998—16 percent of both state prisoners and local jail inmates, and 7 percent of federal prison inmates—had a mental illness, according to a 1999 U.S. Department of Justice report.<sup>32</sup> This estimate was based on self-reported information about whether a person had a mental illness or had ever stayed overnight in a psychiatric hospital. This number is

nearly five times the number of residents in state psychiatric hospitals. Yet the same Justice Department report reveals that only 61 percent of inmates with a mental illness in state prisons and only 41 percent in local jails reported they had received treatment for a mental condition while incarcerated.

Individuals on probation fare poorly, as well. In 1998, nearly 548,000 people, or 16 percent of all people on probation, were judged to have a mental illness. Just over half (56 percent) reported receiving some type of mental health treatment since their sentence to community supervision.

People with mental illnesses are more likely to be repeat offenders and to have multiple health and social problems, reflecting the lack of appropriate mental health treatment both in the community and in jails and prisons. At the time of arrest, people with mental illnesses are more likely to be unemployed and under the influence of drugs or alcohol. They are also more likely than inmates without a mental illness to have been homeless; to have grown up in foster care, an agency, or an institution; to have been physically or sexually abused while growing up; and to have grown up with a parent who abused alcohol. Among individuals with a mental illness, an estimated 34 percent of state prisoners, 24 percent of federal prisoners, and 38 percent of local jail inmates have a history of alcohol dependence.<sup>33</sup>

**Criminalizing Mental Illness.** People with serious mental illnesses, especially those who are homeless, frequently are arrested for minor offenses or crimes of survival as they attempt to live on the streets. These include trespassing, petty theft, shoplifting, and prostitution. Studies indicate that people with mental illnesses have a 64 percent greater chance of being arrested for committing the same offense as a person who does not have a mental illness.<sup>34</sup> Inmates with mental illnesses serve longer sentences than those without mental health problems, and they are more likely to be involved in a fight or to be hit or punched while incarcerated.<sup>35</sup>

In addition to being arrested themselves, people with serious mental illnesses frequently are victimized, especially if they are living on the streets or in shelters. Poverty and poor survival skills place people with serious mental illnesses in dangerous situations where they are vulnerable to attack.

**The Need for Diversion Programs.** Communities frequently lack appropriate diversion programs designed to keep individuals with serious mental illnesses out of hospitals and jails. A new jail diversion grant program to be administered by the Center for

Mental Health Services was authorized as part of an omnibus child health bill in 2000 (P.L. 106-310), but it has not yet been funded. If funded, the grant program would provide for up to 125 grants to states and localities to develop and implement programs to divert individuals with a mental illness from the criminal justice system to community-based services.

Legislation to establish up to 100 demonstration mental health courts was also passed in 2000 but not yet funded (P.L. 106-515). This program is designed to divert from the criminal justice system to community treatment individuals with a mental illness, mental retardation, or co-occurring mental health and addictive disorder who are charged with misdemeanors or non-violent offenses.<sup>36</sup>

## Fiscal Barriers

Significant fiscal barriers prevent people with serious mental illnesses from receiving the care they need. Delivering individualized, flexible services becomes a challenge under the traditional health care system, one in which funding options favor institution-based services, provided in groups, and which severely limit service choices. In particular, categorical funding—which requires that providers offer only a specific type of service with funds from a particular source (federal, state, local, private, etc.)—makes it difficult to tailor services to individual needs.

**Lack of Health Insurance.** Inadequate health insurance precludes many people with serious mental illnesses from receiving the care they need. More than 44 million Americans have no health insurance at all. Those who do have insurance face limits on coverage for mental health services. Most health plans will cover only a brief hospital stay, and outpatient treatment may be restricted, as well. When patients with private insurance exhaust their resources, they often turn to the public system for help. This further drains state mental health resources, which typically provide for indigent patients.

**The Role of the Medicaid IMD Exclusion.** Medicaid provides important support for community-based services for people with mental illnesses through a series of optional services, including intensive case management and psychiatric rehabilitation. However, Medicaid policy bars from coverage all services provided to adults ages 22 to 64 in an Institution for Mental

Disease (IMD), which includes psychiatric hospitals and community-based residential facilities of 16 or more beds.

Some state-level policy makers, including members of the National Association of State Mental Health Program Directors (NASMHPD),<sup>37</sup> have argued for repeal of the IMD Exclusion. The state directors believe it isolates individuals with mental illnesses from all other Medicaid-eligible populations in its refusal to pay for medically necessary inpatient services. The National Alliance for the Mentally Ill (NAMI), which also advocates repeal of the IMD Exclusion, notes that because the policy bars payment for primary care and substance abuse treatment, as well as for psychiatric services, it complicates the treatment of comorbid conditions for individuals with serious mental illnesses.<sup>38</sup>

Further, proponents of repealing the Medicaid IMD Exclusion believe the policy is a barrier to the development of appropriate community services because it makes the Medicaid home- and community-based waivers program unavailable to help individuals leaving institutions. In order to receive such a waiver from the federal Medicaid program, states must demonstrate that the costs of providing home- and community-based services under the waiver will be offset by savings to the Medicaid program resulting from decreased inpatient use. Because the IMD Exclusion bars Medicaid reimbursement for services provided in psychiatric hospitals, there is no cost offset to justify a waiver.

However, such groups as the International Association of Psychosocial Rehabilitation Services (IAPSRS) and the National Mental Health Association (NMHA) believe that repealing the IMD Exclusion will mean more money for institutional care at the expense of developing community-based services. They argue that because there seems to be no incentive to enact home- and community-based waivers for groups who are currently eligible (only three states have a waiver for children's services and only one for adults age 65 and older), there is little reason to believe states will enact such waivers for other IMD residents if the exclusion is repealed.<sup>39</sup> The groups on both sides of this issue agree, however, that states need additional resources to promote the development of appropriate community-based services for individuals ready to leave institutions or at risk of hospitalization.

**Categorical  
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needs.**



**Medicare Limits.** Though Medicaid does permit states to cover a full array of comprehensive, community-based services, Medicare provides no coverage for services that are critical to individuals with serious mental illnesses, such as case management, psychiatric rehabilitation, and medication. Medicare requires beneficiaries to pay 50 percent of the cost of outpatient mental health treatment, but only 20 percent of other outpatient services, and it imposes a lifetime limit of 190 days on coverage for inpatient care in a psychiatric hospital.<sup>40</sup>

**Provider Reluctance.** Mental health providers may be reluctant to accept patients with either Medicaid or Medicare, since both programs typically pay less for outpatient mental health services than other third-party payers. This is despite the fact that outpatient services, including partial hospitalization, can help individuals with serious mental illnesses avoid unnecessary long-term hospitalization in state psychiatric facilities. The situation may be even less favorable for people with serious mental illnesses served in managed care plans, where Medicaid and Medicare reimbursement may be lower than it is in traditional fee-for-service plans.

**The Mental Health Parity Act.** The federal Mental Health Parity Act, which became effective January 1, 1998, requires that health plans provide the same annual and lifetime limits for mental health benefits as they do for other health care benefits. However, the Act does not affect service limits, such as limits on outpatient visits, or cost sharing, such as deductibles. Nor does it apply to substance abuse benefits. Proposed legislation is designed to address these inequities before the earlier legislation expires.

**Declining State Resources.** Finally, despite the aggressive downsizing of state hospitals, hospital budgets still claim significant resources in many state mental health programs. In 1993, for the first time, state spending on community mental health services exceeded spending on state hospital inpatient services.<sup>41</sup> Yet states have reduced their spending on public mental health services (when adjusted for inflation and growth in population) over the past decade and continue to do so.<sup>42</sup>

## Stigma and Discrimination

According to the Surgeon General, nearly two-thirds of all people with diagnosable disorders do not seek

treatment, in part because of the stigma associated with mental illness and the receipt of mental health treatment.<sup>43</sup> Stigma is not new; it has persisted since individuals were locked away in asylums, thought to be suffering from conditions that result from “moral failings or limited will power.”<sup>44</sup>

Though the public’s scientific understanding of mental illness has grown since the 1950s, stigma and fear have increased. In a 1996 survey, the public’s perception of mental illness was frequently associated with the fear of violence, though studies have shown that the absolute risk of violence posed by mental illness is small.<sup>45</sup> Selective media reporting may reinforce negative stereotypes linking mental illness and violence.

Stigma, notes the Surgeon General, is manifested by “bias, distrust, stereotyping, fear, embarrassment, anger, and/or avoidance.”<sup>46</sup> These attitudes make it difficult for people with serious mental illnesses to find housing and jobs, maintain social networks, and become accepted in their communities. In addition, stigma surrounding serious mental illnesses negatively affects the public’s willingness to pay for treatment.

Respondents in public opinion polls rank coverage for mental disorders below that for physical disorders.

*Nearly two-thirds of people with diagnosable mental disorders do not seek treatment, in part because of the stigma associated with mental illness.*

## Staffing Shortages

Low pay and lack of training for community-based mental health staff are significant barriers to the creation of appropriate residential and treatment programs for people with serious mental illnesses. Traditionally, salaries in public behavioral health care programs have been lower than those in the private sector. With today’s booming economy, individuals in the human services fields are seeking higher paying jobs elsewhere. Those staff who remain frequently are not trained to deal with the special needs of people with the most serious mental disorders.

## Successful Strategies for Community Treatment

The mental health field has developed a well-established set of practices and services to provide community-based care to people with serious mental illnesses. To be effective, these services must be integrated, col-

laborative, and based on an underlying set of core values. Key values and services are discussed below.

## Core Values

The values that underlie development of appropriate community-based services for people with serious mental illnesses are as important as the individual service components themselves. In its 1992 report, the Federal Task Force on Homelessness and Severe Mental Illness outlined the following principles, drawn from years of research and practice, that should serve as the cornerstone for all aspects of service delivery to people with serious mental illnesses.<sup>47</sup>

- **Access, Empowerment, and Responsibility.** People with serious mental illnesses require access to appropriate housing, treatment, and supports; they should be empowered to gain access to mainstream resources for which they are eligible; and their dignity must be respected.
- **Diversity and Flexibility.** Services for people with serious mental illnesses should be culturally competent, individualized to meet their needs, and flexible enough to respond to their changing needs and preferences.
- **Peer, Family, and Other Natural Supports.** Consumers, family members, and community members must be involved in ongoing efforts to plan, deliver, monitor, and evaluate services for people with serious mental illnesses. Further, services should be offered in the least restrictive setting possible to take advantage of natural community and peer supports.
- **Local, State, and Federal Participation.** Services for people with serious mental illnesses should be determined at the local level, coordinated at the state level, and supported with strong leadership and financial incentives at the federal level. Mental health planning councils, private businesses, faith-based organizations, foundations, and individual citizens also play an important role in the development of community services for people with serious mental illnesses.

**Mental Health Recovery.** In addition, recent research has pointed to the importance of services and practices that support the concepts of mental health recovery. Research and practice have shown that *people with serious mental illnesses can and do recover*. William A. Anthony, Ph.D., executive director of the Center for Psychiatric Rehabilitation, calls this the “simple yet

powerful vision”<sup>48</sup> of mental health recovery. This vision is backed by research which contradicts the popular notion that serious mental illness is a lifelong condition.<sup>49</sup>

Many advocates believe that recovery involves, at its core, the development of both key relationships with supportive individuals and core beliefs about mental illness.<sup>50</sup> According to these principles, an individual can be considered to be recovered regardless of whether he or she takes medication.

**Treatment in the Least Restrictive Setting.** As the *Olmstead* ruling reinforces, people with serious mental illnesses have a right to be served in the least restrictive setting possible. Both communities and the individuals they serve have much to gain. Closing and consolidating psychiatric facilities allows states to reinvest the resources in community-based programs. They can also take advantage of more flexible funding options, such as Medicaid home- and community-based waivers. Care in the community is less stigmatizing for people with serious mental illnesses, and it allows them to be closer to family, peer, and other natural supports.

## Key Service Components

Both individual services and the way they are delivered are critical to the development of appropriate community-based care for people with serious mental illnesses. In his 1999 report on mental health, the Surgeon General outlined key elements of an effective service delivery system for people with serious mental illnesses.<sup>51</sup>

- **Case Management.** Case managers coordinate service delivery and ensure continuity and integration of services. Case management models range from less intense, in which case managers facilitate their clients’ access to a wide range of services, to more intense, in which case managers are involved in rehabilitation and clinical care. Several studies have shown that consumer case managers may be especially effective.
- **Assertive Community Treatment (ACT).** Begun in the late 1970s with the Program of Assertive Community Treatment in Madison, WI, ACT is acknowledged to be a successful approach to providing a full range of community-based services to people with serious mental illnesses. ACT teams feature a multidisciplinary group of mental health, substance abuse, and social service specialists who provide, or arrange for, each individual’s clinical, housing, and rehabilitation needs. Client/staff

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ratios are low (typically 10 to 1), and services are available 24 hours a day, 7 days a week. Randomized, clinical trials have shown that ACT and similar models of intensive case management reduce inpatient hospitalization, promote continuity of outpatient care, and increase community tenure and stability for people with serious mental illnesses. Consumer outreach workers may increase positive outcomes.

- **Psychosocial Rehabilitation Services.** Psychosocial rehabilitation programs combine pharmacologic treatment, independent living and social skills training, psychological support to clients and their families, housing, vocational rehabilitation, social support, and access to leisure activities. Randomized clinical trials have shown that participants have fewer and shorter hospital stays and are more likely to be employed.
- **Community Alternatives for Crisis Care.** At various times during the course of their illness, some individuals may require inpatient hospitalization to stabilize their symptoms and reconnect them to community services. Increasingly, however, mobile crisis services have been developed in the community to help prevent unnecessary hospitalization. Interdisciplinary mobile crisis teams provide immediate assistance and may link individuals to community-based, respite programs.
- **Services for Substance Abuse and Serious Mental Illness.** Decades of treating co-occurring disorders through separate mental health and substance use services have proven ineffective. Instead, research over the past 10 years supports provision of mental health and substance abuse treatment services offered simultaneously by the same group of providers. Most successful models of combined treatment include assertive outreach to bring people into treatment, case management, and group interventions.
- **Consumer Self-Help, Consumer-Operated Programs, and Consumer Advocacy.** Mental health consumers continue to play an increasingly important role in helping empower their peers to recover from serious mental illnesses. Participants in self-help groups report greater self-esteem, fewer hospitalizations, and better community adjustment. Consumer-operated programs—including drop-in centers, case management programs, outreach programs, businesses, employment and housing programs, and crisis services—provide meaningful work for consumers who serve as posi-

tive role models for their peers. Consumer staff also enhance the sensitivity of the system to the needs of people with mental disorders. Finally, consumer members of such groups as state mental health planning councils and local mental health advisory boards are actively involved in the design, implementation, and evaluation of community mental health services.

- **Family Self-Help and Advocacy.** Because family members of people with serious mental illnesses also experience ignorance and stigma, as well as the difficulties of caring for a loved one, self-help groups are a key resource to help them cope. The largest organization that offers these services, the National Alliance for the Mentally Ill, now has more than 1,200 self-help groups in all 50 states. Family members are also successful advocates for improved treatment, increased funding, and ongoing research and education initiatives designed to improve the lives of all people with serious mental illnesses.
- **Housing.** Most individuals with serious mental illnesses express a preference for living in their own home or apartment. An increasingly popular approach known as supported housing focuses on consumers having a permanent home that is self-chosen, integrated in the community, and that encourages empowerment and skills development. The services and supports offered are flexible, individualized, and responsive to changing consumer needs. [Research on homeless people with serious mental illnesses indicates that supported housing helps individuals with even the most serious disorders maintain both residential and psychiatric stability over time.<sup>52</sup> In addition, housing subsidies are key to helping people with serious mental illnesses maintain residential stability.<sup>53</sup>]
- **Income, Education, and Employment.** People with serious mental illnesses require adequate income, opportunities to begin or resume their education, and meaningful, gainful employment. Adequate standards of living and employment are associated with better clinical outcomes. Some individuals find well-paying positions through a formal rehabilitation program, a community-based educational or vocational training program, or a supportive employer. [Specific approaches cited elsewhere include individual placement and support (IPS), supported employment, and vocational case management.<sup>54</sup>]

- **Health Care.** Because of their low incomes, the high cost of health care, and inadequate private health insurance, most people with serious mental illnesses rely on Medicaid, Medicare, and other government programs to provide mental health treatment, medications, and general medical care. Reduction or loss of these benefits may result in declining health and increasing use of emergency services.
- **Integrated Service Systems.** Finally, and perhaps most important, the individual service components must be coordinated in a comprehensive, integrated system of care for people with serious mental illnesses. The CMHS ACCESS program was

specifically designed to test the hypothesis that integrated systems would improve clients' functioning, quality of life, and housing outcomes. Begun in 1993, the five-year demonstration program includes an extensive, cross-site evaluation of both system-level and client-level outcomes. Preliminary data from these evaluations has revealed that systems integration has a positive impact on housing outcomes for people with serious mental illnesses who are homeless. [Additional findings indicate that systems integration is both possible and measurable and that systems integration reduces service system fragmentation.<sup>55</sup>]

## A Model Approach

The Village Integrated Service Agency in Long Beach, CA, is recognized by SAMHSA as an exemplary practice model for the innovative way in which it provides coordinated, comprehensive services to people with serious mental illnesses who are moderate to high "utilizers" of the mental health system. The model was established in 1989 through a statewide competition to design and implement an integrated service delivery system that uses capitated, or case-rated, funding. In 1996, funding for the Village became a permanent part of the Los Angeles County Department of Mental Health budget.<sup>56</sup>

The Village's program is grounded in the psychosocial rehabilitation/recovery philosophy. Collaborative case management teams encourage program members to choose, pursue, and achieve quality of life goals in the areas of finances, housing, employment, social activities, education, legal assistance, substance abuse treatment, and medical care. Each team, which includes both medical and paraprofessional staff, has a budget with which to purchase services for members. This allows the teams to design services around the needs of individuals and to focus on community-based services rather than institutional care.

The case management teams are supported by a variety of rehabilitation specialists, including community integration/outreach specialists who work with members to create a "menu" of social activities. A full-time substance abuse/recovery specialist supports members' recovery efforts. Because employment is a cornerstone of the Village philosophy, all members have access to the Village employment staff, which includes job developers who help create opportunities for competitive jobs in the community. Members are also paid employees in several Village businesses that serve as preparation for competitive, community employment. Financial services include money managers/payees and a Village bank.

Village members are intimately involved in the management and evaluation of the program, and each service plan incorporates self-help, peer support, family support, and community involvement. The program's success is measured in part by fewer hospitalizations and shorter lengths of stay for Village members. Overall, the program spends 7 percent of its budget on hospitals and other 24-hour institutional care, compared to a county-wide baseline of 42 percent. Village members spend an average of 7 days in the hospital.

Despite the fact that Village members include those who were formerly long-stay hospital patients, homeless, or incarcerated, 95 percent continue to live in the community. A significant number work or attend school.

For more information on the Village's program and services, visit its Web site at [www.village-isa.org](http://www.village-isa.org), or contact Director Martha Long at (562) 437-6717.



## Recent Federal Initiatives

In support of both the *Olmstead* decision and President George W. Bush's New Freedom Initiative, which pledges to help remove barriers to equality for the 54 million Americans living with some type of disability, several federal agencies recently announced new grant programs to help both children and adults with disabilities live successfully in the community. These are outlined in brief below.

**Real Choice Systems Change Grants.** Congress and the Administration have made \$50 million available to help states improve home- and community-based services available to children and adults with disabilities. Initial awards of \$50,000 were made to all states and territories that requested one. These start-up funds will help pay for the development of public-private partnerships, including consumer task forces, to advise each state on the use of federal funds that will increase services and supports to people with disabilities. The Center for Medicare and Medicaid Services (CMS) of the U.S. Department of Health and Human Services will administer this grant program.

Real Choice grants are designed to help states partner with their disability and aging communities to help people of all ages who have a disability or a chronic illness, including a serious mental illness, to 1) live in the most integrated community setting appropriate to their needs and strengths; 2) exercise meaningful choices about their supports; and 3) have quality services arranged in a manner as consistent as possible with their community living preferences or priorities. The grants will fund activities that promote system improvements designed to make these goals possible.

**Nursing Facility Transition Grants and Access Housing.** CMS has teamed with the U.S. Department of Housing and Urban Development (HUD) to help people of all ages who live in nursing homes, including those with serious mental illnesses, make the successful transition to community living. CMS is providing approximately \$12 million to \$15 million in state program grants to help states design, implement, and/or provide outreach and ongoing support for identified individuals leaving nursing homes. HUD will make up to 400 Section 8 vouchers available for use by eligible non-elderly individuals with a disability who make the transition from a nursing facility to the community. The agency's goal is to fund 2,000 vouchers depending on future appropriations.

States may apply for both the state program grant and the Section 8 rent vouchers as part of a single appli-

cation, or they may apply for just one of the two programs. CMS expects states that receive grant awards to partner with state and local housing authorities to make full use of all applicable HUD programs that benefit low-income elderly individuals and those with disabilities (see the Housing section of this briefing paper for an overview of such programs).

**Community-Based Attendant Services with Individual Control.** To help states develop or improve community-based attendant service systems that offer individuals with disabilities maximum control, CMS is awarding \$5 million to \$8 million in state infrastructure grants. The goal of this program is to create systems that support self-determination for people with disabilities. Eligible activities, for example, will include training consumers to recruit and supervise personal care attendants and to understand their fiscal and legal responsibilities as employers.

## Putting the Pieces Together

There is no single, simple solution to addressing the service needs of people with serious mental illnesses, especially those awaiting discharge from a state facility or at risk of hospital admission. Yet, there is little need for new technologies—the mental health field has developed a well-established set of practices and services to provide community-based care for people with serious mental illnesses. What is required is a commitment and partnership by government (federal, state, and local) and the private sector—including foundations, philanthropists, researchers, businessmen and women, the media, and the general public—to help people with serious mental illnesses achieve full participation in society. They deserve nothing less.

Some specific steps that government and private partners can take to make this vision a reality include, but are not limited to, those that follow.

### Individual Barriers

- Continue research into both effective clinical treatments for serious mental illnesses and successful program design.

### Systemic Barriers

- Increase the supply of affordable housing and housing subsidies, and replicate successful supported housing programs throughout the country.

- Facilitate entry into treatment, and into the full range of services required by people with serious mental illnesses, especially income support and entitlements, job training and employment programs, education programs (including programs to make higher education possible), and health care.
- Establish Medicaid funding options for home- and community-based, long-term care services for people with psychiatric disabilities.
- Reduce financial barriers to treatment.
- Revise Social Security policies to increase work incentives.

## Cross-cutting Barriers

- Enhance interagency initiatives to address fragmentation of services, especially around issues of discharge planning.
- Reinvest resources from facility closing and consolidation into community-based services.
- Continue to reduce stigma and improve public awareness of effective treatment for serious mental illnesses.
- Invest in human resources—provide adequate salaries, training, and professional education for behavioral health care staff.
- Create programs and services that are culturally appropriate.

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<sup>27</sup>Federal Task Force on Homelessness and Severe Mental Illness. *Outcasts on Main Street*. Washington, DC: Interagency Council on the Homeless, 1992.

<sup>28</sup>*Older Adults and Mental Health: Issues and Opportunities*. Washington, DC. Administration on Aging, 2001.

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<sup>30</sup>Smith, H. and Allison, R. *Telemental Health: Delivering Mental Health Care at a Distance*. Rockville, MD: Center for Mental Health Services and Office of Rural Health Policy, submitted for publication, 1998.

<sup>31</sup>*Discharge Planning for Inmates Being Released from Jail or Prison*. Washington, DC: Bazelon Center for Mental Health Law, 2000. Available at [www.bazelon.org/dischargeplanning.html](http://www.bazelon.org/dischargeplanning.html).

<sup>32</sup>Ditton, P. *Mental Health and Treatment of Inmates and Probationers*. Washington, DC: U.S. Department of Justice Bureau of Justice Statistics, July 1999 (NCJ 174463).

<sup>33</sup>Ibid.

<sup>34</sup>Teplin, L. "Criminalizing Mental Disorder: The Comparative Arrest Rate of the Mentally Ill." *American Psychologist* 39:794-803, 1984.

<sup>35</sup>Ditton, P. *Mental Health and Treatment of Inmates and Probationers*. Washington, DC: U.S. Department of Justice Bureau of Justice Statistics, July 1999 (NCJ 174463).

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<sup>37</sup>National Association of State Mental Health Program Directors. *Position Statement on Repeal of the Medicaid IMD Exclusion*. Approved June 6, 2000. Available at [www.nasmhpd.org/exclusion.htm](http://www.nasmhpd.org/exclusion.htm).

<sup>38</sup>National Alliance for the Mentally Ill. *IMD Exclusion: Implications of Repeal*. Available at [www.nami.org/update/imd2.html](http://www.nami.org/update/imd2.html).

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<sup>40</sup>*Funding Sources and Expenditures of State Mental Health Agencies: 1993*. Alexandria, VA: NASMHPD Research Institute.

<sup>41</sup>*Funding Sources and Expenditures of State Mental Health Agencies, Fiscal Year 1997, Final Report*. Alexandria, VA: National Association of State Mental Health Program Directors, 1999.

<sup>42</sup>*Mental Health Policy: Campaign 2000 Briefing Paper*. Washington, DC: Bazelon Center for Mental Health Law, 2000.

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<sup>44</sup>Ibid.

<sup>45</sup>Mulvey, E. "Assessing the Evidence of a Link Between Mental Illness and Violence." *Hospital and Community Psychiatry* 45:663-668, 1994.

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<sup>50</sup>Ahern, L. and Fisher, D. *Personal Assistance in Community Existence*. Lawrence, MA: National Empowerment Center, 1999.

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<sup>52</sup>Tsemberis, S. and Eisenberg, R. "Pathways to Housing: Supported Housing for Street-Dwelling Homeless Individuals with Psychiatric Disabilities." *Psychiatric Services* 51(4):487-493, 2000. Also, Shern, D., et al. "Housing Outcomes for Homeless Adults with Mental Illnesses: Results from the Second-Round McKinney Program." *Psychiatric Services* 48(2):239-241, 1997.

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<sup>54</sup>Shaheen, G. *Work as a Priority: A Guidebook for Employing People with Mental Illness Who Are Homeless*. In press.

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# Income Supports and Entitlements

Edward L. Knight, Ph.D.

Rick Kugler

Susan Milstrey Wells

## Overview

People with serious mental illnesses often are eligible for federal and other targeted benefit programs because of their poverty and their disabilities. However, they face significant individual and systemic barriers gaining access to income supports and entitlements.

In particular, at many steps along the way, people with psychiatric disabilities find themselves in a “Catch-22” situation, caught between multiple bureaucratic barriers and the complex nature of their illnesses. For example:

- People with serious mental illnesses exiting institutions who do not receive any type of income support may become homeless. Once homeless, their chances of successfully completing a benefits application are significantly reduced.
- To receive benefits, people with psychiatric disabilities must prove they are too sick to work. To improve their economic situation and regain a useful role in society, they must prove they are healthy enough to hold a job.
- The traditional design of most benefit systems—such as Social Security, welfare, and medical assistance—seems to be based on an all-or-nothing principle. Either a person is totally incapacitated and/or impoverished thereby needing to be supported, or he or she should be completely self-supporting.
- Because of the nature of their illness and the complexity of the benefits process, people with psychiatric disabilities have a difficult time qualifying for benefits. As a benefits recipient, they may have a difficult time reducing their dependence on income support.
- Those individuals whose disabilities are severe enough to qualify for disability benefits may be too ill to successfully complete the application process.<sup>1</sup>

## Income Support and Entitlement Programs

The most common income support benefits for which people with psychiatric disabilities qualify are Social Security Disability Insurance (SSDI), which is outlined in Title II of the Social Security Act, and Supplemental Security Income (SSI), which is outlined under Title XVI. Both benefits are administered by the Social Security Administration (SSA).

SSDI pays an average monthly benefit of \$786 to 5 million workers with disabilities. In addition, some 1.6 million family members receive monthly benefits. Nationwide, 6.6 million people receive SSI benefits, including 900,000 children with disabilities.<sup>2</sup> Nearly one-third (31 percent) of individuals who receive SSDI or SSI have a psychiatric disability.<sup>3</sup>

**Social Security Disability Insurance.** The SSDI program is an entitlement program. SSDI benefits are paid to individuals and their dependents who have been employed and have paid Social Security taxes. When individuals work, both employees and employers contribute Social Security taxes that are reflected on employees’ paychecks as Federal Insurance Contributions Act (FICA) deductions. SSDI provides disability benefits to those who cannot perform substantial work and who meet SSA disability criteria.

Adults with disabilities who do not have sufficient Social Security covered work history for insured status may receive Social Security benefits based on a parent’s insured status. To be eligible for Social Security Child’s Insurance Benefits, commonly known as Social Security for the Disabled Adult Child (SSDAC), individuals must be:

- 18 years of age or older;
- disabled by SSA’s definition before age 22; and
- the child of insured workers who are either disabled, retired, or deceased.

**Supplemental Security Income.** The SSI program is an economic need-based program. SSI was established in 1974 to provide benefits assistance to individuals who demonstrate economic need and who are age 65 or older or have a disability. Unlike the SSDI program, SSI was funded through the general revenues of the Federal Treasury. As a result, to be eligible for an SSI cash bene-



fit, it is not necessary that a person have a past history of employment and payroll tax contributions.

Eligibility for SSI is, instead, based solely on meeting specific income, resource, and disability criteria. For people over age 18, the criteria and process used to establish an individual's disability status for initial eligibility is the same for SSI and SSDI. Section 223(d) of the Social Security Act defines the disability requirements in the following manner:

- “the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.
- “an individual shall be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work.”

To receive SSI, individuals must also meet the income and resource test. Income includes both earned income (monthly gross earnings) and unearned income, such as Social Security and any other type of benefits, monetary support, or in-kind support received. A standard formula that accounts for earned and unearned income is used by SSA to compute the dollar amount of SSI cash benefits for which individuals qualify. Some states supplement SSI, though supplement values range from several dollars to several hundred dollars a month.

The SSI benefit program has specific resource limitations set by statute that include real or personal property (including cash). This must not exceed the specified amount at the beginning of each month. The resource limits are not subject to regular cost-of-living increases, and the current limit is \$2,000 for individuals and \$3,000 for couples.

**State General Assistance/TANF.** Many people with mental disabilities rely on state General Assistance funds while waiting for approval for SSI and/or SSDI. Generally, these funds are lower than those provided by federal benefit programs. Though most individuals exiting institutions will not have children with them, people with psychiatric disabilities who do live with

children under age 18 may receive financial assistance from the Temporary Assistance to Needy Families (TANF) program. TANF is need-based and may provide a bridge for individuals who have applied for SSI and/or SSDI. This may be enough to help them remain in the community and avoid hospitalization or homelessness.

**Medicare and Medicaid.** When people who are disabled qualify for SSI and/or SSDI, they may also receive health care benefits. Individuals who receive SSDI for 2 years become eligible for Medicare, a federal health insurance program for people who are elderly or disabled. In most states, an individual who receives SSI automatically becomes eligible for Medicaid, a joint federal/state health insurance program that covers people with low-incomes who are elderly or disabled, among other groups. Some individuals who have worked in the past but whose income is low enough may receive both SSDI and SSI, and Medicare and Medicaid, at the same time.

## Barriers to Income Supports and Entitlements

Many individuals with psychiatric disabilities who are eligible for SSI and/or SSDI are not currently enrolled. They face significant barriers to qualify for income supports and entitlements, to maintain those benefits once found eligible, and to reduce their dependence on benefits as they transition to employment. Key barriers include the following:

- access to information and ongoing assistance with the complex application, eligibility, and appeals process;
- fragmented service systems; and
- disincentives for work, including possible loss of health care and other benefits.

## Access to the Application, Eligibility, and Appeals Process

Many people with psychiatric disabilities have limited work history and low income. For these individuals in particular, SSI benefits may be the only source of support that helps them remain in the community. Yet people with disabilities of all types, including those with serious mental illnesses, have the greatest difficulty gaining access to the SSI program, according to a survey by the U.S. Conference of Mayors.<sup>4</sup> Cities respond-

ing to the survey listed the following barriers to participation, in order of importance:

- Difficulties in obtaining requirement documentation
- Misinformation/lack of information about the program
- Lack of an address
- Stigma
- Lack of outreach efforts
- Complexity of the application process
- Excessive paperwork requirements
- Inadequate staffing in SSA offices
- Lack of transportation
- Language barriers
- Literacy level required to complete the application

In addition, survey respondents cited strict and complex medical standards for eligibility, physicians' lack of knowledge about the definable medical listings for disabilities, and lack of advocates to help eligible people gain access to benefits as further barriers to SSI participation for people with disabilities. For individuals who do complete the application, failure to meet disability guidelines was the most common reason why individuals with disabilities were deemed ineligible for benefits, the mayors said.

**The Application Process.** Individuals with serious mental illnesses, especially those who have been homeless, may be reluctant or unable to provide the required documentation to complete a disability benefits application. Even with the right information, the application itself poses a significant barrier. According to the Social Security Administration, as reported by the National Law Center on Homelessness and Poverty, the application process for Social Security benefits poses enormous barriers for all applicants.<sup>5</sup> "The application form was not designed to be filled out by the applicant; rather, assistance by SSA staff was assumed," an SSI official said (page 9). Extensive documentation is required, particularly medical evidence that supports the individual's claim of disability.

**The Disability Determination Process.** As noted earlier, SSA defines disability as *the inability of an individual to engage in substantial gainful activity by reason of a*

*medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.* To determine whether or not a person meets this definition, SSA uses a five-step sequential evaluation process that includes the following questions:<sup>6</sup>

- Is the person working at a substantial gainful activity level? (As currently defined, substantial gainful activity or SGA is \$740 a month.)
  - Is the individual's medically determinable impairment or combination of impairments "severe"?
  - If the impairment is determined to be severe, does it meet or medically equal the severity of a listing in SSA's List of Impairments?<sup>7</sup>
- If the impairment is severe but does not meet or equal the severity of the listing, does the individual retain the capacity to do past relevant work considering his or her residual functional capacity?
- If past work is precluded, does the person retain the capacity to do any other kind of work in the national economy?

People with serious mental illnesses face enormous hurdles when confronted with this disability determination process. One of the most significant barriers is finding a qualified medical professional who understands the SSA definition of disability, and who can relate an individual's functional impairments to his or her inability to work. "Determination of disability for those with mental disorders is particularly difficult, given that the effect of the symptoms on work ability is often not clear," says Samuel O. Okpaku, MD, of Vanderbilt University.<sup>8</sup>

In particular, note Diane C. Piagesi, MA, CRC, and William A. Anthony, PhD:

The areas of functioning limited by the impairment must be linked to the specific clinical signs. In and of themselves, signs or limitations have little impact on the [SSA] reviewers' assessment. Describing the two without establishing the link is a common mistake in presenting evidence.<sup>9</sup>

There is sufficient reason to question the reliability of SSA determinations for mental disorders, according to

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Dr. Okpaku.<sup>10</sup> Indeed, in 1997, the U.S. General Accounting Office (GAO) reported that 39 percent of applicants with mental illnesses were approved for benefits by state Disability Determination Service staff. However, this compares with an 87 percent approval rate for individuals who appeal their case to an Administrative Law Judge.<sup>11</sup>

The GAO found that differences in assessing functional capacity explained the inconsistent decisions between Disability Determination Service staff and Administrative Law Judges. In particular, the report noted, SSA staff tend to rely on objective medical findings, while judges often rely on a claimant's testimony and the treating physicians' opinions. Especially for people with psychiatric disabilities, objective medical evidence may be inconclusive and difficult to interpret relative to work ability.

#### **Continuing Disability Reviews.**

Individuals who qualify for SSI and/or SSDI will have their case reviewed periodically by SSA staff. The continuing disability review (CDR), a process begun in 1981, is a way for SSA to determine whether or not the individual still meets the agency's definition of disability. When people return to work, SSA looks for evidence of medical improvement.

This can be a problematic and stressful experience for people with psychiatric disabilities. In particular, because of the cyclic nature of serious mental illnesses, individuals whose symptoms wax and wane may be doing well at the time their case is reviewed. An SSA examiner who is not familiar with the nature of psychiatric disorders may see this as evidence of medical improvement and a possible cause for stopping benefits.

**The Appeals Process.** SSA provides four levels of appeal for individuals who are denied benefits on their first application. They can have their case reconsidered by a different group of SSA reviewers; appeal the case to an Administrative Law Judge; ask an Appeals Counsel to review the decision; or take the case to Federal Court. Appeals can add an average of 378 days to the length of time a claimant must wait for a final decision, according to the GAO.<sup>12</sup> A case that goes to Federal Court may not be decided for several years.

Individual with psychiatric disabilities, especially those ready for discharge from inpatient facilities, don't

have years to wait before they begin collecting benefits. Many of these individuals have no other means of support. They might continue to wait in hospitals contrary to the *Olmstead* decision or end up homeless and ill equipped to negotiate the streets. Case managers report that it is difficult to reconnect to the service system those people with psychiatric disabilities who become homeless. These individuals may be especially reluctant to begin the benefits application process again.

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#### **Fragmented Service Systems**

Another significant barrier for people with serious mental illnesses seeking benefits is fragmentation and lack of integration among systems on which beneficiaries depend. In 1996, the GAO reported that federal assistance to people with disabilities is provided through 130 programs in 19 federal agencies, with many of the services offered by public and private agencies at the state and local level.<sup>13</sup>

Different federal programs use different operational definitions of disability and have different eligibility criteria, which makes the system especially difficult for people with psychiatric disabilities to navigate, notes the National Council on Disability.<sup>14</sup> Applicants for Social Security benefits must submit their application to the local SSA office; have their case reviewed by the state Disability Determination Service; provide required documentation from psychiatrists, psychosocial rehabilitation specialists, and other health care providers; consult with an attorney to submit an appeal; and coordinate the receipt of benefits with employment opportunities.

The coordination between benefits and work is an especially difficult area for individuals with psychiatric disabilities to negotiate. Case managers may advise them to limit their income to maintain their eligibility for benefits, while employment specialists may encourage them to work to increase their independence. If the two providers aren't communicating directly, the individual may inadvertently jeopardize his or her benefit status by not taking advantage of work incentive programs that may allow benefits to continue even as income increases.

## Disincentives for Work

Consumers, advocates, and providers agree that work can be an important adjunct to mental health recovery, allowing individuals to regain valued roles in their communities. Income from work also helps them raise their standard of living.

Yet despite the fact that many individuals with disabilities want to work and are able to so with appropriate supports, only a small percentage of SSDI and/or SSI beneficiaries leave the rolls because of work. In 1998, the GAO reported that not more than 1 in 500 SSDI beneficiaries left the rolls by returning to work, and that receipt of SSDI benefits may be associated with lower success in return-to-work interventions.<sup>15</sup>

People with psychiatric disabilities who receive federal benefits may find it difficult to return to work for several reasons. Fear of losing health care benefits is the single largest impediment, according to SSA. In addition, though SSDI, SSI, Medicare, and Medicaid all contain work incentive programs, SSA acknowledges these programs are “underused and, often, are poorly understood by beneficiaries and professionals alike.”<sup>16</sup> Finally, increases in income may jeopardize additional benefits for which individuals qualify, SSA notes.

For example, many people with disabilities rely on a patchwork of financial supports that have different eligibility criteria and application procedures. The benefits derived from a number of these programs are means-tested. Increases in income can also cause rent increases in Section 8 housing, loss of food stamps or public assistance payments. Many individuals who may be willing to risk the loss of cash benefits from TANF, SSDI or SSI cannot absorb the loss of housing subsidies and other supports.<sup>17</sup>

Even new incentive programs that look promising may be problematic for people with psychiatric disabilities. For example, the “ticket to work” employment vouchers for people receiving SSDI and SSI—authorized under the 1999 Ticket to Work and Work Incentives Improvement Act—allow individuals to obtain vocational rehabilitation, employment, or other support services from a provider of their choice. However, the employment network with which a beneficiary uses his or her voucher isn’t paid until that person leaves the SSA rolls.

Notes Michael Walling, principal associate of Service Enhancement Associates of West Chester, PA:

Previously most professionals cautioned a person to limit income to protect benefits. To assist a person in

using the Ticket to Work program, these same professionals must now encourage the person to earn significant income and forego cash benefits. Service providers that have the potential to be Employment Networks do not have the fiscal resources to gamble with for people who are indecisive about the cash benefit ceasing.<sup>18</sup>

## Strategies to Address Barriers

### Provide Access to the Application, Eligibility, and Appeals Process

**Conduct Outreach.** Outreach to individuals with psychiatric disabilities who are eligible to receive benefits is the number one recommendation of providers, consumers, advocates, and policy makers. Outreach is labor-intensive and time-consuming work, but most observers agree it is absolutely essential for individuals with psychiatric disabilities to have help negotiating the benefits application, eligibility, and appeals process. The goals of outreach include the following:

- providing accurate information about disability benefits and work incentive programs;
- helping individuals gather the required personal, financial, and medical documentation or referring them to programs that provide this assistance; and
- helping individuals file an application and mount an appeal, if necessary.

SSA recognized the importance of having a knowledgeable advocate to help individuals navigate complex program requirements when it created its Benefits Planning, Assistance, and Outreach program, which is authorized to fund community-based outreach projects in every state. Outreach providers, who will be trained by SSA, must be knowledgeable about other benefit programs, as well, including TANF, Medicaid, and Department of Housing and Urban Development programs.

**The Role of Case Managers.** Knowledgeable case managers and clinicians can make an enormous difference in their clients’ ability to obtain and maintain disability benefits. For example, the Projects for Assistance in Transition from Homelessness (PATH) project in Oklahoma City, OK, received an SSA grant to conduct outreach to people with serious mental illnesses who are homeless. Project staff were able to obtain benefits on initial application for about 50 percent of the clients with whom they worked, a significant increase over the state average.<sup>19</sup> Providers developed relationships with



individuals and with SSA staff, collected necessary documentation, helped physicians provide relevant disability information, and accompanied clients to appointments.

With the client's approval, case managers may also request duplicate copies of SSA mailings, which can ensure that individuals won't miss a deadline for submitting required information or filing an appeal. People with psychiatric disorders who receive notices about a possible loss of benefits may become discouraged and confused and need extra support at this time.

Case managers may also serve as representative payees for clients who need help managing their benefit checks. About 25 percent of individuals who receive SSI have a representative payee, according to SSA. The agency requires that individuals with psychiatric disabilities who have a past or current substance abuse problem have a representative payee to receive their benefit checks.

**The Role of Peer Advocates.** Peer advocates can fill a similar role. For example, the Brooklyn Peer Advocacy Program of the Baltic Street Mental Health Board, Inc. provides information, referrals, and hands-on assistance to individuals with serious mental illnesses seeking benefits and other community resources. Peer advocates speak from personal experience and professional expertise. They help individuals gain access to the benefits and services they need and connect them to organizations that can help them overcome the personal and systemic barriers they face.

**Provide Discharge Planning.** Appropriate discharge planning may be seen as a type of "inreach" to people with psychiatric disabilities ready to leave inpatient facilities. Notes the Bazelon Center for Mental Health Law:

States can improve access to SSI for unnecessarily institutionalized people by facilitating applications for benefits as individuals are discharged from a hospital. By entering into agreements with local Social Security offices, state institutions can arrange for SSI applications to be filed prior to discharge so that benefits may begin immediately upon release from the hospital.<sup>20</sup>

Receipt of benefits on discharge can help people with psychiatric disabilities avoid homelessness or inappropriate rehospitalization. For those individuals who cycle in and out of hospitals, the Bazelon Center points

out that SSI permits continued payment of benefits for up to three months of hospitalization. Benefits can be continued if a physician certifies that the individual is expected to be discharged within three months and needs the continued cash benefit to keep his or her living arrangement in the community.

**Train Providers.** Psychiatrists and case managers who are not familiar with SSA disability criteria have a difficult time helping clients prepare successful applications and appeals. A number of organizations around the country provide training for providers who work with SSA applicants. In addition, as part of its Benefits Planning, Assistance, and Outreach projects, SSA has contracted with Cornell University to provide 5-day, face-to-face training sessions for benefits planning specialists.

**Improve the Process.** The process of applying for disability benefits should be simplified and streamlined, according to mayors who participated in a 38-city survey.<sup>21</sup> Among their recommendations was a series of suggestions aimed at making SSI more accessible to all individuals, especially those with disabilities. These include the following:

- Reduce the complexity of the program. Simplify the review process.
- Simplify the eligibility requirements for disabled applicants.
- Develop practical techniques for determining disabled applicants' psychological and behavioral ability to work.
- Take steps to decrease the length of time needed to approve or deny applications.
- Increase staff at SSA field offices to enable them to serve clients better. Mandate lower caseloads and increase staff training at SSA offices.
- Increase number of SSA field offices, especially in less populated cities.
- Expand legal assistance available to SSI applicants.

## **Integrate Service Systems**

**Offer One-Stop Shopping.** Social Security applicants and beneficiaries need one place they can go to gather all the information they need about eligibility, the application and appeals process, and work incentive

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programs. The SSA outreach program mentioned earlier is expected to be effective in this capacity.

In addition, 12 states have State Partnership Initiative cooperative agreements with SSA to develop innovative projects to increase employment of people with disabilities who want to work. A number of the participating states agreed to promote education about benefits and employment through a seamless or “one-stop” approach. California, New Hampshire, Vermont, and Wisconsin are among the states using this approach to focus on people with serious mental illnesses.

**Integrate Services.** Services for people with disabilities may be coordinated in one of three areas, notes the GAO. Programs and agencies may share basic program information (informational), establish compatible eligibility criteria (eligibility), or cooperate in service provision (service).<sup>22</sup> Any of these types of coordination can be difficult to achieve but highly successful.

In 1991, SSA and the U.S. Department of Veterans Affairs (VA) implemented a Joint Outreach Initiative to improve access to disability benefits among homeless veterans with mental illnesses. Both a Social Security claims representative and a state disability determination analyst were co-located with VA clinical staff at four of the VA’s Health Care for Homeless Veterans programs. During the 2 years after the initiative began, higher proportions of veterans applied for disability and were awarded benefits, according to investigators who evaluated this approach.<sup>23</sup>

## Improve Incentives for Work

Disability beneficiaries’ fears about returning to work center on the loss of income and health care benefits. A number of new and ongoing programs administered by SSA and by the Center for Medicare and Medicaid Services (CMS), several of which were authorized by the 1999 Ticket to Work and Work Incentives Improvement Act, are designed to address some of these barriers.

**New SSA Rules.** Several new SSA rules that took effect January 1, 2001, will allow more people with disabilities to test their ability to work without fear of losing cash benefits and health care coverage. They include:

- *An increase in the amount that constitutes substantial gainful activity or SGA* Beginning January 1, Social Security beneficiaries can earn \$740 a month and still remain eligible for benefits, the first increase since July 1999, when SGA was set at \$700. Further, the SGA amount will automatically be adjusted

annually based on increases in the national average wage index.

- *An increase in the amount that constitutes a trial work month from \$200 to \$530.* This amount will also be adjusted based on increases in the national average wage index. SSDI beneficiaries may work for 9 trial months before the SGA level is used to determine continued eligibility.
- *An increase in the amount of income exclusion for students receiving SSI who return to work.* Previously, when a student under the age of 22 worked, up to \$400 of earned income (wages or self-employment) per month was excluded when determining SSI eligibility. The maximum yearly exclusion was \$1,620. On January 1, 2001, those amounts increased to \$1,290 per month and \$5,200 a year, which correspond to what a student may realistically earn in part-time or summer employment.

**Benefits Planning, Assistance, and Outreach.** The goal of the Benefits Planning, Assistance, and Outreach program, mentioned earlier, is to increase SSA beneficiaries’ understanding of various work options. The program is required by the Ticket to Work Act and is part of SSA’s Employment Strategy for People with Disabilities.

**Employment Support Representatives.** Also in 2000, SSA created a position of Employment Support Representative (ESR) at 32 sites across the country to help beneficiaries who have questions regarding income from work and continuing eligibility for benefits. The ESR replaces the work incentives liaison each office was supposed to have. In fact, many SSA staff had no formal training on work incentives counseling. The agency hopes to expand the ESR program this year.

**Expanded Availability of Health Care Services.** Beginning October 1, 2000, several health care provisions of the Ticket to Work Act took effect.<sup>24</sup> In particular, the Act created two new Medicaid eligible groups. States now have the option to offer Medicaid to working individuals between the ages of 16 and 65 who, except for their income and resource levels, are eligible to receive SSI. They may also offer Medicaid to employed individuals with a medically improved disability who lose Medicaid eligibility under the first option because they no longer meet the SSI definition of disability.

In addition, the Ticket to Work Act extends to 8 1/2 years premium-free Medicare Part A coverage to SSDI beneficiaries who lose cash assistance because they return to work. Previously, SSDI beneficiaries received continuing Medicare coverage for 39 months following

a trial work period as long as their medical disability continued.

Also beginning October 1, 2000, states were eligible to receive monies under two new CMS grant programs designed to support working individuals with disabilities. The Medicaid Infrastructure Grant Program provides \$150 million in the first 5 years for states to design, establish, and operate health care delivery systems to support the employment of people with disabilities.

Funded at \$250 million for 6 years, the Medicaid Demonstration to Increase Independence and Employment allows states to provide Medicaid services to workers with potentially severe impairments that are likely to lead to disability or blindness. This demonstration is designed to evaluate whether early Medicaid intervention delays the onset of disability.

**Existing Medicaid Provisions.** There are also two previously enacted programs to help SSI beneficiaries retain their Medicaid coverage as their earnings increase. One is Section 1619(b) of the Social Security Act, which provides continuing Medicaid coverage to individuals with increased incomes who still meet the disability requirements, who need Medicaid benefits to continue to work, and who have gross earnings insufficient to replace SSI, Medicaid, and publicly funded attendant care services. Each state establishes a threshold amount beyond which a beneficiary is no longer eligible for 1619(b) protection.<sup>25</sup>

In addition, the Balanced Budget Act of 1997 permits states to allow certain SSI beneficiaries who are disabled

and who would lose eligibility because their earnings exceed the allowable limit to buy into Medicaid. Section 201 of the Ticket to Work Act includes several key provisions to make this program more attractive. For example, it allows states to offer a buy-in to people with earnings greater than 250 percent of the poverty level. States can set income limits and require cost-sharing and premiums.

As part of the State Partnership Initiative demonstrations mentioned earlier, some states have sought waivers from SSA and CMS to enhance current work incentives and to create Medicaid buy-in and other health care initiatives. Some states partnerships that emphasize people with serious mental illnesses include California, Illinois, Minnesota, New Hampshire, New York, Ohio, Vermont, and Wisconsin.

**Support Benefits Disregard.** Some advocates have suggested that beneficiaries may have more to gain by working if the loss of entitlements from one system are offset by the ability to maintain benefits in another. For example, if someone loses \$25 in food stamps or \$100 in a housing subsidy because of earnings, these amounts would be deducted from countable income when calculating an SSI adjustment or determining SGA. This type of "support benefits disregard" program would benefit individuals and might reduce administrative efforts among several government agencies, because each program would have less of a demand to generate and implement its own work incentive programs.

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## Endnotes

<sup>1</sup>SSA Disability Programs: the Eligibility and Appeals Process, Part I. A transcript of the PATH National Teleconference, November 9, 2000. Delmar, NY: Advocates for Human Potential, Inc.

<sup>2</sup>"Social Security Administration Increase in SGA Level." Social Security Administration press release, January 3, 2001. Available at [www.ssa.gov/pressoffice/sga2001.htm](http://www.ssa.gov/pressoffice/sga2001.htm).

<sup>3</sup>Personal conversation with Ron Manderscheid, PhD, Chief, Center for Mental Health Services Survey and Analysis Branch, January 11, 2001.

<sup>4</sup>*Barriers to Participation in Benefit Programs: A 38-City Survey*. Washington, DC: U.S. Conference of Mayors, 1988.

<sup>5</sup>*Social Security: Broken Promise to America's Homeless*. Washington, DC: National Law Center on Homelessness and Poverty, 1990.

<sup>6</sup>Golden, T. *SSA Disability Programs: The Eligibility and Appeals Process*. Background material for PATH National Teleconference, November 9 and 21, 2000. Ithaca, NY: Cornell University Program on Employment and Disability.

<sup>7</sup>The List of Impairments provides a description of medical conditions that are considered severe enough to prevent an individual from performing work at a substantial gainful activity level. The list is included in *Disability Evaluation Under Social Security* (SSA Pub. No. 64-039) and is available from the SSA Public Information Distribution Center, PO Box 17743, Baltimore, MD 21235, (410) 965-0945.

<sup>8</sup>Okpaku, et al. "Disability Determinations for Adults with Mental Disorders: Social Security Administration vs Independent Judgments." *American Journal of Public Health* 84(11): 1791-1795, 1994.

<sup>9</sup>Piagesi, D. and Anthony, W. "Social Security and Psychiatric Disability: What a Practitioner Must Know and Do." *Psychosocial Rehabilitation Journal* IX(1):31-44, 1985.

<sup>10</sup>Okpaku, et al.

<sup>11</sup>*Social Security Disability: SSA Must Hold Itself Accountable for Continued Improvement in Decision-making*. Washington, DC: U.S. General Accounting Office, 1997. GAO/HEHS-97-102.

<sup>12</sup>Ibid.

<sup>13</sup>*People with Disabilities: Federal Programs Could Work Together More Efficiently to Promote Employment*. Washington, DC: U.S. General Accounting Office, 1996. GAO/HEHS-96-126.

<sup>14</sup>*From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves*. Washington, DC: National Council on Disability, 2000.

<sup>15</sup>*Social Security Disability Insurance: Multiple Factors Affect Beneficiaries' Ability to Return to Work*. Washington, DC: U.S. General Accounting Office, 1998. GAO-HEHS-98-39.

<sup>16</sup>Cooperative Agreements for Benefits Planning, Assistance, and Outreach Projects; Program Announcement No. SSA-OESP-00-1. Federal Register (65)105, May 31, 2000.

<sup>17</sup>Ibid.

<sup>18</sup>See [www.wallinginc.com/fall00.htm](http://www.wallinginc.com/fall00.htm).

<sup>19</sup>*SSA Disability Programs: The Eligibility and Appeals Process, Part II*. A transcript of the PATH National Teleconference, November 21, 2000. Delmar, NY: Advocates for Human Potential, Inc.

<sup>20</sup>*Under Court Order*. Washington, DC: Bazelon Center for Mental Health Law, 1999.

<sup>21</sup>*Barriers to Participation in Benefit Programs: A 38-City Survey*. Washington, DC: U.S. Conference of Mayors, 1988.

<sup>22</sup>*People with Disabilities: Federal Programs Could Work Together More Efficiently to Promote Employment*. Washington, DC: U.S. General Accounting Office, 1996. GAO/HEHS-96-126.

<sup>23</sup>Rosenheck, et al., "Improving Access to Disability Benefits Among Homeless Persons with Mental Illness: An Agency-Specific Approach to Services Integration." *American Journal of Public Health* 89(4):524-528, 1999.

<sup>24</sup>For details on the information that follows, see the CMS Ticket to Work and Work Incentives Improvement Act Fact Sheet available at [www.hcfa.gov/medicaid/twviia/factsh01.htm](http://www.hcfa.gov/medicaid/twviia/factsh01.htm).

<sup>25</sup>A state's annual income threshold limit can be found on the SSA Office of Employment and Support Programs Web site at [www.ssa.gov/work/ResourcesToolkit/Health/1619b.html](http://www.ssa.gov/work/ResourcesToolkit/Health/1619b.html).





## Housing

Ann Denton

Carol Bianco

*Note: The authors are indebted to the Consortium for Citizens with Disabilities and the Technical Assistance Collaborative, Inc. for their “gold standard” documentation of the housing crisis for people with disabilities. Much of these data are included below. Priced Out In 2000, Priced Out In 1998, and Going It Alone: The Struggle to Expand Housing Opportunities for People with Disabilities, provide important proof regarding housing needs and make intelligent recommendations for needed policy changes. Many of these recommendations are included below.*

### Overview

Housing is perhaps the first line of treatment for people with psychiatric disabilities. Yet America is experiencing an affordable housing crisis of appalling proportions. The lack of affordable housing, especially for households at the lowest levels of income, is a direct causal factor in the growth of homelessness in this country.

In 1990, 23 percent of renters and 7 percent of owners had incomes at or below 30 percent of the median family income (extremely low income). Among the renters, nearly 60 percent have “severe cost burdens,” meaning that they are paying more than half of their income for rent. This translates to 5.9 million renter households and 3.1 million owner households with a “worst case” housing need. Despite the efforts of the government, only about half of the households in need of housing assistance receive it. “Just to have enough units to meet current worst case needs would require more than doubling the present number of 4.8 million HUD-subsidized low income housing units” (p. 6).<sup>1</sup>

Americans living in poverty—with and without disabilities—face a serious housing crisis. This crisis is complicated by the fact that in real dollars, the federal funding for affordable housing has been cut by more than 75 percent in the last 10 years. The reductions are

even more severe in housing programs targeted to people with disabilities, including people with mental illnesses. National estimates reveal that 1.8 million people with disabilities have severe housing problems.<sup>2</sup>

Many individuals with disabilities, including people with mental illnesses, receive Supplemental Security Income (SSI) as their only means of financial support. In 1998, the national average monthly income from SSI was \$515 per month. In that year, there was not even one community in the United States in which a person living on SSI could afford to rent or own a housing unit, using the U.S. Department of Housing and Urban Development’s (HUD) standard of affordability.<sup>3</sup> Some people with serious mental illnesses become homeless because they cannot afford housing, and because stigma and prejudice prevent them from obtaining what little housing is both affordable and otherwise available.

***Housing is perhaps the first line of treatment for people with mental illnesses.***

The U.S. Supreme Court’s *Olmstead* decision offers both an important opportunity and a serious risk. By the end of 2000, 22 states had prepared *Olmstead*-related plans to help them respond to the mandate for community integration, but not a single one mentioned housing.<sup>4</sup> It will be useful to help states create meaningful housing plans for people exiting institutions; however, the need for new housing for people leaving institutions may worsen the existing housing crisis for people with serious mental illnesses. An effective housing strategy for people with serious mental illnesses will include responses to the current crisis, with specific strategies within the plan targeted to people with mental illnesses in the *Olmstead* population.

### A Brief History

Since the Great Depression, the federal government has been involved in housing, with the goal of safe and decent housing for every American. Housing policy has been an eclectic mix of helping the housing industry, supporting home ownership for middle-income Americans, and providing assistance to developers in an effort to provide low-cost units for poor Americans.

The history of public policy regarding housing has been one of extremes, with different strategies of assistance dominant at various times. The basic tension seems to have occurred between the desire for ever increasing production of units (usually championed by the housing industry) and support for different forms of rental assistance. The subtext of this debate concerns targeted recipients of assistance: housing production tends to favor higher income households, and rental assistance “levels the playing field” for poorer households. Over the last decade, federal housing assistance has settled into three key strategies: vouchers (rental assistance), block grants with significant local planning requirements, and low-income housing tax credits.

People with disabilities have been largely ignored in this debate. As federal policy has shifted back and forth, people with disabilities have received only a small share of resources (through the Section 811 Supportive Housing for Persons with Disabilities program, for example). Also, the federal government has allowed housing authorities to designate as “elderly only” occupancy in units formerly available to both populations. The Consortium for Citizens with Disabilities Housing Task Force estimates that 273,000 units of housing have been lost to people with disabilities as a result of this policy.

In general, mental health advocates believe that federal policy has failed to meet the housing needs of people with disabilities. The funding targeted for this population has been inadequate, the number of housing units created with these funds has been reduced by the elderly only policy, and the mainstream housing programs have not been held accountable.

## Federal Housing Programs

**Citizen Involvement in Planning.** Despite the decreasing allocations for affordable housing at the federal level, there have been some promising developments in the past few years. Chief among these are the new HUD requirements for citizen and advocate participation in local planning processes that determine the use of HUD dollars at the local level.

- **The Consolidated Plan.** This plan must include a description of an inclusive planning process, a housing needs assessment and market analysis, and both a five-year strategic plan and a one-year action plan. Many of HUD’s mainstream resources are controlled by the Consolidated Plan.

- **Public Housing Agency (PHA) Plan.** This plan must include a description of the Resident Advisory Board assembled to provide input to the plan, and a description of the housing needs of low and very low-income households in the community. The PHA plan must be consistent with the local Consolidated Plan.
- **The Continuum of Care Planning Process.** The Continuum of Care is HUD’s overall approach to breaking the cycle of homelessness. The Continuum of Care model features a coordinated community-based process of identifying needs and building a system to address these needs, and it prepares communities to make application for McKinney Homeless Assistance funds. It must be consistent with the local Consolidated Plan.

These relatively new planning processes mean that for the first time, advocates, citizens, service providers, city officials, and others have the opportunity to make resource allocation decisions that address the true needs of a community. However, key stakeholders must be certain that the local process is true to the requirements, that it is inclusive of advocates and providers, that it is not dominated by one or another local faction, and that the input of citizens is both solicited and considered.

**HUD Programs/Initiatives Benefitting People with Disabilities.** HUD sponsors a wide range of programs that can be used to serve people with disabilities. These include programs targeted specifically to individuals with disabilities, such as the Section 811 Supportive Housing for Persons with Disabilities program and the McKinney Shelter Plus Care program, as well as such mainstream programs as the Home Investment Partnership Program (HOME), the Community Development Block Grant (CDBG), and Section 8 rental subsidies (see the table that follows this section). Several of these programs are also described below.<sup>5</sup>

**Public Housing.** According to December 2000 data found in HUD’s Multifamily Tenant Characteristics System (MTCS), approximately 1.12 million people live in public housing in the United States. Of this number, approximately 202,000, or 18 percent, are non-elderly people with disabilities, and 359,000, or 32 percent, are elderly people, many of whom have some form of disability.

**Section 8 Housing Vouchers.** According to December 2000 data found in HUD’s MTCS, approximately 1.5 million people use Section 8 housing vouchers to obtain private rental apartments in the United

States. Of this number, approximately 345,000, or 23 percent, are non-elderly people with disabilities, and 255,000, or 17 percent, are elderly people, many of whom have some form of disability.

*HUD's Continuum of Care Programs.*

Approximately 40 percent of all adults served by HUD's Continuum of Care programs have some form of disability. The following Continuum of Care programs serve people with disabilities:

- *The Supportive Housing Program* provides funds to states, local governments, PHAs, Indian tribes, private non-profits, and community mental health associations for transitional housing for homeless people, permanent housing for homeless people with disabilities, and supportive services. Funding is provided for new construction, acquisition and rehabilitation, leasing of structures, operating and administrative costs, and supportive services costs. Special consideration is given to homeless people with disabilities and homeless families with children.
- *The Shelter Plus Care Program* serves homeless people with disabilities (primarily people with serious mental illnesses, AIDS and related diseases, or chronic problems with alcohol or drugs) and their families by providing rental assistance to states, local governments, and PHAs in the form of tenant-based rental assistance, project-based rental assistance, sponsor-based rental assistance, and single-room-occupancy-based rental assistance.

Some of the results of HUD's Continuum of Care Approach include the following:<sup>6</sup>

- Supportive Housing Program funds assist an estimated 189,000 people with disabilities.
- More than 48 percent of all Supportive Housing Program projects awarded funding in FY 1999 helped people with severe mental illnesses, and more than 64 percent of the funded projects helped people with substance abuse problems.
- In 1999, \$151 million was awarded to Shelter Plus Care projects that serve only homeless people with disabilities and their families.

**Public-Private Development Organizations.**

Fannie Mae and Freddie Mac are organizations that ensure a reliable flow of funds to mortgage lenders,

thus bolstering the American housing industry. Fannie Mae was created by Congress in 1938 to help restore the housing industry from the depths of the Great Depression. In 1968, Fannie Mae became a private company, operating under a congressional charter that requires Fannie Mae to work to increase home ownership for low, moderate, and middle-income Americans. Freddie Mac was created in 1970, with a similar mission regarding affordable home ownership for American families.

Fannie Mae has provided critical leadership in the area of home ownership for people with disabilities with the development of the HomeChoice mortgage product. This mortgage product allows lenders to relax standard underwriting criteria and provides a path to home ownership for people with disabilities. The Federal Home Loan Bank has created an Affordable Housing Program that provides an excellent source of funds to non-profit housing developers to encourage the development of affordable housing.

**A Full Range of Housing Options**

Over the past two decades, the mental health system has become more aware of the need for housing for people with serious mental illnesses. As systems have invested time, energy, and resources in the development of real, integrated housing options for people with mental illnesses, the advantages of including these options have become clear. First, preference studies show that people with serious mental illnesses want to live in typical community settings—apartments, houses, townhomes, condominiums, etc.

Second, providing assistance in choosing, getting, and keeping housing is a set of activities within the range of most public mental health systems, often offered as part of intensive case management.

Third, the cost of providing rental assistance often can be the responsibility of the housing system. Even where housing systems (PHAs, city governments, Community Development Corporations, and Community Housing Development Organizations) will not assume this responsibility, the cost of providing rental assistance is much less than the cost of more traditional settings. These factors—consumer preference, feasibility, and cost—have led to increasing interest in creating partnerships between mental health and housing systems.

*People  
with serious  
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typical community  
settings.*



This paradigm shift does not exclude residential treatment or even more custodial care settings from the menu of services that *should* be available. For people with a clinical need for transitional housing, with the goal of a more independent setting in the future, short-term residential treatment may be the answer. For people who choose to live long-term in a group setting, for companionship and support or because of a need for structure and supervision, more custodial group homes might be the answer. The key is **choice**, and a consumer does not have a *real* choice unless regular, integrated housing is one of the options.

This chapter addresses the needs of people with serious mental illnesses for housing. The definition of housing used here includes the full array of community housing options typically available to people without disabilities.

## Barriers to Housing

### Affordability

The primary barrier to housing for people with disabilities is poverty. People with disabilities who have SSI as their income source are usually at or below 30 percent of median family income (in the extremely low-income category). According to “Priced Out in 1998,”<sup>7</sup> there is not one housing market in the United States in which an individual surviving on SSI can afford even a modest one-bedroom housing unit. Using national averages, the cost of a one-bedroom apartment is 69 percent of the SSI monthly income. This is more than double the standard housing affordability threshold of 30 percent, commonly used by HUD and the housing industry.

In fact, the HUD standard for rent burden or worst case housing needs involves paying 50 percent or more of household income. There are 125 housing market areas in the United States where the fair market rent of a housing unit exceeds the entire SSI check. In the United States today, people with disabilities are the most poorly housed of any group eligible for government housing assistance.<sup>8</sup>

As a result, many people living on SSI alone are forced to live in overcrowded and often substandard living environments that place them at physical and emotional risk. Others are living with aging parents or

relatives, many of whom are also living on fixed, low incomes.

Further, many mainstream affordable housing providers and funding sources, including PHAs, banks, state housing finance agencies, and local public and private community development organizations are reluctant to serve people with disabilities. It is more expensive to make housing affordable to this population compared to others, such as families moving from welfare to work or the elderly. This means that fewer new units will be created and that fewer households will be assisted with rent vouchers. As a result, extreme poverty is a significant barrier for individuals with disabilities, even in the government-assisted housing arena.

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### Fair Share of Housing Resources

Mainstream housing production programs have failed to make significant progress in providing housing for extremely low income households. The block grant programs require that communities use dollars to serve households at or below 80 percent of median family income, but do not require communities to assist households at lower levels. The tax credit program requires that a portion of the units developed with these resources be affordable to people at or below 50 percent to 60 percent of median family income.

The block grant programs allocate resources to local communities, which make decisions about priorities in those programs on the local level. Too often, the tension described above at the federal level between production (which favors higher income households as recipients) and rental assistance is resolved at the local level in favor of production.

Frequently, this decision is not based strictly on the needs of the community, but on political decisions influenced by the need to help the maximum number of households in the most cost-effective way, and on political perceptions regarding the desirability of various households. Because people with disabilities often fall into the extremely low-income category, local decisions based on politics rather than need leave these households out in the cold.

The Low Income Housing Tax Credit program is an excellent vehicle for the development of affordable

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housing. Unfortunately, targeting a portion of the units to households at 50 percent to 60 percent of median family income again leaves out extremely low-income households. A rental subsidy is necessary in order for extremely low-income households to afford to live in this “affordable” housing.

**The Fair Share Strategy.** One remedy for this is the Fair Share strategy. This strategy provides information to people with disabilities, family members, other advocates, local decision makers, and interested citizens about the housing needs of communities. Specifically, this education effort encompasses the needs of extremely low-income households, including the housing needs of people with disabilities. Informed citizens then work toward the allocation of a Fair Share of **all** the housing resources available to a community.

The strategy includes advocating for income targeting within the block grant programs and an equitable mix of production and rental assistance methods for alleviating the housing crisis. It requires determined effort at the local level, a sufficient knowledge of housing programs and issues, and persistent input as mandated by various, local planning processes. It includes the housing needs of people with disabilities as part of a larger agenda of social equity for all people who are most in need in a community.

Unfortunately, there is a significant lack of knowledge among people with disabilities, their families, and advocates about the range of housing resources available to extremely low-income individuals. HUD provides billions of dollars to communities and states to address the housing needs of low-income citizens. As described above, these resources exist within a variety of mainstream affordable housing programs and are allocated primarily on the local level through the Consolidated Plan and the PHA Plan. These planning and funding processes are complex and confusing, even for housing professionals. Few mental health professionals, consumers, and advocates have good information about these programs and processes, and many are led to believe that resources are not available or appropriate for people with disabilities.

This lack of knowledge combined with the lack of affordable housing units leads to a significant gap in the percentage of affordable housing resources that are allocated to people with disabilities, in spite of their worst-case housing status. A 1999 survey of state and local housing officials showed that a mere 10 percent of state/local housing officials and 18 percent of PHAs made housing for people with disabilities a “high priority.”<sup>9</sup>

There is simply no incentive for them to do so, and many disincentives. This issue is especially critical in light of the almost complete shift during the 1990s to decision-making at the state and local level regarding federal affordable housing programs.

Compounding this problem is a significant loss of units that were once available to people with disabilities. Since 1992 HUD has permitted public and private affordable housing providers to designate as elderly-only buildings that once housed adults of all ages with disabilities. This loss of units has been only partially replaced with new targeted Section 8 subsidies, and it has been estimated that more than a quarter of a million units for people with disabilities will be lost by the end of this 2001.<sup>10</sup>

### **Appropriate Supports**

Another barrier to appropriate housing is the perception that people with psychiatric disabilities need supervision or round-the-clock support that would require them to live in a setting with on-site staff (such as an assisted living facility or group home). While this may be true for some individuals, *the overwhelming majority of people with mental illnesses can live in their own homes.* Instead of special housing settings, or high-density group living environments, most people with serious mental illnesses need access to flexible supports that can be provided on and off-site based on the individual’s needs and preferences. In spite of this, home- and community-based services to help people obtain and sustain their housing are lacking in most communities.

### **Access**

In spite of the passage of the Fair Housing Amendments Act (FHAA) of 1988, discrimination against people with mental illnesses is perhaps most prevalent when it comes to housing. Stigma can be overt, such as vocal community opposition to housing for this group, or less obvious, such as steering public funds away from housing initiatives serving controversial populations. Most consumers and advocates do not fully understand the protections afforded under the FHAA, and most are uncertain about how to use these protections. Additionally, since many people with serious mental illnesses do not have stable housing histories, many landlords are reluctant to rent to them, and they will deny housing based on poor credit histories or lack of references.

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## Strategies to Address Housing Barriers

### Affordability

- *Increase the sheer availability of tenant-based rental assistance to people with disabilities.* Tenant-based rental subsidies are the fastest and most flexible way to help individuals with disabilities gain access to regular, community-based housing. In recent years there has been some increase in the Section 8 program, along with small set-asides for people with disabilities, and some new flexibility that permits community-based organizations to administer the program. However, there should be a major, targeted investment in new subsidies for people being discharged from institutions. Some states (Ohio, New York, New Jersey) have created such targeted rent subsidy programs, administered by the state mental health authority. A federal matching program would help other states replicate these very successful efforts.
- *Increase the availability of project-based rental subsidies for units that would house people with disabilities.* To make housing units more affordable to extremely low-income residents, HUD and the private sector could collaborate by offering project-based rental assistance for a percentage of housing units or by offering capital grants to developers. The creation of incentives to house individuals with disabilities helps address the misconception that these individuals are undesirable tenants. Allowing them to pay their own way helps them become more desirable customers.

### Lack of a Fair Share

- *Provide incentives to the housing community to serve people with disabilities.* HUD programs such as HOME allow tenant-based rental assistance as an activity, but do not require communities to use a percentage of the dollars for this purpose. HUD could require communities to use some percentage of HOME funds to help individuals with disabilities, including serious mental illnesses. Similar requirements could be inserted in the PHA plan, especially with respect to the Section 8 program. Such a requirement would be even more effective if there were also financial incentives involved.

- *Provide education and technical assistance to people with disabilities, family members, and other advocates.* Consumers, family members, and advocates need sufficient information and education to advocate effectively for a fair share of housing resources at the state and local levels. There are millions of dollars available at the local level. While this is not enough to meet the need, more effective use of these funds would be an improvement. Educating citizens with a stake in the outcome about the Fair Share strategy will help shape local policy. This is a successful strategy. With this knowledge and expertise, advocates have achieved increases in tenant-based rental assistance under the HOME program, and set-asides for extremely low-income households and people with disabilities. The Technical Assistance Collaborative and the Consortium for Citizens with Disabilities have proposed creation of a National Housing Center for People with Disabilities to provide technical assistance to the disability community in this area. Such an investment in capacity building, when matched with incentives for funders, could significantly address the housing crisis that exists for people with disabilities.

### Appropriate Supports

- *Replicate successful Supported Housing programs throughout the country.* Supported Housing offers flexible, individual supports, combined with affordable housing in community settings. This approach has been extremely successful in helping many people live outside of institutions, and it achieves consistently high rates of consumer satisfaction. When services are truly flexible and individualized, Supported Housing has enabled people with significant support needs to achieve housing stability and community integration. In spite of these positive outcomes, there are no national guidelines or funding streams for Supported Housing, and states have put together a patchwork quilt of standards and funding to implement elements of this approach.
- *Establish Medicaid funding options for home- and community-based, long-term care services for people with psychiatric disabilities.* The Medicaid home- and community-based waiver program is used by many states to provide home-based, long-term care services to people with physical and developmental

disabilities, as an alternative to institutionalization. A bill pending before Congress (MiCassa-the Medicaid Community Attendant Services and Supports Act of 1999) will extend this right to individuals in all states. However, unless they are eligible for nursing home care, people with psychiatric disabilities are not eligible for these programs. As a result, those with long-term care needs are most likely to be institutionalized, in spite of the fact that successful models of home- and community-based services exist.

## Access

- *Increase education of consumers and advocates regarding the Fair Housing law and remedies.* There should also be increased and continued public education to reduce stigma. Visible examples of successful affordable housing partnerships and programs can be the key to changing misconceptions.

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## Endnotes

<sup>1</sup>Proposed Federal Housing Trust Fund. National Low Income Housing Coalition. 1999.

<sup>2</sup>*Going it Alone: The Struggle to Expand Housing Opportunities for People with Disabilities.* Technical Assistance Collaborative and Consortium of Citizens with Disabilities, October 2000.

<sup>3</sup>*Priced Out in 1998.* Technical Assistance Collaborative and Consortium of Citizens with Disabilities. March 1999.

<sup>4</sup>“The *Olmstead* Decision and Housing: Opportunity Knocks.” *Opening Doors*, vol. 12, December 2000. A publication of the Technical Assistance Collaborative and the Consortium of Citizens with Disabilities Housing Task Force.

<sup>5</sup>The material in this section and the table that follows was prepared by HUD staff to highlight selected HUD programs that benefit people with disabilities. The information is intended to be illustrative but not exhaustive.

<sup>6</sup>*Renewing the Pledge: Expanding Employment Opportunities for Adults with Disabilities.* A report to the Presidential Task Force on the Employment of Adults with Disabilities. Washington, DC: U.S. Department of Housing and Urban Development, October 2000.

<sup>7</sup>Orlebeke, C.J. 2000. “The Evolution of Low-Income Housing Policy, 1949 to 1999.” *Housing Policy Debate* (Volume 11, Issue 2). Fannie Mae Foundation.

<sup>8</sup>*Going it Alone: The Struggle to Expand Housing Opportunities for People with Disabilities.* Technical Assistance Collaborative and Consortium of Citizens with Disabilities, October 2000.

<sup>9</sup>TAC, 2000.

<sup>10</sup>TAC, 2000, p.12

## Selected HUD Programs/Initiatives Benefitting People With Disabilities

Current HUD Housing Programs Benefitting People with Disabilities	Program Description	FY 2000 Funding Awarded	Number of Housing Vouchers Available
I Office of Public and Indian Housing (PIH)  A. SECTION 8 HOUSING VOUCHERS			
1. Access Housing Demonstration (initial implementation—FY 2001)	5-year demonstration that will provide Section 8 housing vouchers to selected public housing authorities (PHAs), which will partner with State Medicaid agencies and other entities to assist non-elderly persons with disabilities to transition from nursing homes into the community.	\$2.5 million initially (FY 2001 implementation)	400 initially (2,000 at full implementation)
2. Section 8 Mainstream Housing Opportunities for Persons with Disabilities	Provides vouchers to enable persons with disabilities (elderly and non-elderly) to rent affordable private housing.	\$63.8 million in one-year and five-year funding	4,300
3. Section 8 Rental Assistance for Non-Elderly Persons with Disabilities in Support of Designated Housing Plans ("Designated Housing")	Provides vouchers to enable non-elderly families with disabilities to rent affordable private housing.	\$15.2 million in one-year funding	2,580
4. Section 8 Rental Assistance for Non-Elderly Persons with Disabilities Related to Certain Types of Section 8 Project-Based Developments and Sections 202, 221(d)(3) and 236 Developments ("Certain Developments")	Provides vouchers to enable non-elderly families with disabilities to rent affordable private housing.	\$8.6 million in one-year funding	1,881
5. Section 8 Fair Share Allocation of Incremental Voucher Funding	Includes rating criteria in which rating points are assigned to PHAs that state in their applications that 15% or more of the vouchers being requested (or that are funded by HUD) will be used to house non-elderly/elderly disabled families. Rating points are also assigned to applications that state that the PHA would combine the requested funded vouchers with Medicaid waivers for at least 3% of the new vouchers.	\$346.6 million in one-year funding	60,000

## Selected HUD Programs/Initiatives Benefitting People With Disabilities

Current HUD Housing Programs Benefitting People with Disabilities	Program Description	FY 2000 Funding Awarded
B. OTHER PIH PROGRAMS/INITIATIVES		
1. HOPE VI Program	Rating points are provided to applicants who state in their applications that they will make at least 5% of for-sale units in HOPE VI projects accessible to individuals with mobility disabilities and 2% of for-sale units accessible to individuals who have visual or hearing disabilities. Rating points are also provided based on the applicant having an achievable plan for including minorities, women, and/or individuals with disabilities in the overall planning, development, and management team that will be involved in the HOPE VI revitalization effort.	\$563.8 million (includes amounts for revitalization, demolition, replacement housing, and tenant-based assistance)
2. Strategies for Providing Accessibility & Visitability for HOPE VI and Mixed Finance Homeownership (January 2000)	Publication that discusses design strategies for the homes of persons with disabilities that go above and beyond the standard requirements for accessibility and visitability.	Not Applicable
3. Resident Service Delivery Models for Families, the Elderly and Persons with Disabilities (funding category under Resident Opportunities and Self-Sufficiency (ROSS) Program)	Promotes self-sufficiency among non-elderly families by funding services for residents and provides supportive services for the elderly and persons with disabilities to help them maintain independent living.	\$30 million
4. Service Coordinator Renewals (funding category under ROSS)	Provides funds to PHAs to employ service coordinators who help the elderly and persons with disabilities who reside in public housing obtain supportive services that will enable them to live independently.	\$2.5 million
II. Office of Housing		
1. Section 811 Supportive Housing for Persons with Disabilities	Provides funds to nonprofit organizations to develop, construct or rehabilitate rental housing with supportive services for very low-income persons with disabilities.	\$132 million
2. Section 202 Supportive Housing for the Elderly	Provides capital advances to private, nonprofit organizations to finance the construction or rehabilitation of structures that will serve as supportive housing for very low-income elderly persons (including those elderly persons with disabilities). The program also provides funds for project-based assistance, for service coordinators, and for the continuation of existing congregate service grants.	\$597 million
3. Section 202 Assisted Living Conversion Program	Provides funds to owners/borrowers of eligible, existing Section 202 projects designed for the elderly for conversion of some or all of the units into licensed Assisted Living Facilities, which will serve frail elderly persons and elderly persons with disabilities.	\$20 million
4. Service Coordinators Program	Provides funds to owners of private housing developments to employ service coordinators who will help the elderly and persons with disabilities obtain supportive services that will enable them to live independently.	\$29.3 million



## Selected HUD Programs/Initiatives Benefitting People With Disabilities

Current HUD Housing Programs Benefitting People with Disabilities	Program Description	FY 2000 Funding Awarded
III. Office of Community Planning and Development (CPD)		
A. Continuum of Care (COC) Homeless Assistance Programs [2 of the programs (described below) serve persons with disabilities]	COC, which is HUD's overall approach to breaking the cycle of homelessness, provides funds for a coordinated community-based process to identify needs and build a system to address these needs so that homeless persons may move to self-sufficiency and permanent housing.	\$896 million (distribution of funds for each of the 3 programs under Continuum of Care depends largely on locally determined priorities and demand)
1. Supportive Housing Program	Provides funds to states, local governments, PHAs, Indian tribes, private non-profits, and community mental health associations for transitional housing for homeless persons, permanent housing for homeless persons with disabilities, and supportive services. Funding is provided for new construction, acquisition and rehabilitation, leasing of structures, operating and administrative costs, and supportive services costs. Special consideration is given to homeless persons with disabilities and homeless families with children.	See above.
2. Shelter Plus Care	Provides rental assistance to States, local governments, and PHAs, in the form of tenant-based rental assistance, project-based rental assistance, sponsor-based rental assistance, and single-room-occupancy-based rental assistance. The program serves homeless persons with disabilities (primarily people with serious mental illness, AIDS and related diseases, or chronic problems with alcohol or drugs) and their families.	See above.
B. Community Development Block Grants (CDBG)	Eligible uses of the funding include production and rehabilitation of housing for low-income persons, including those with disabilities.	\$4.8 billion
C. Home Investment Partnership Program (HOME)	Provides block grants to States and localities (often in partnership with local non-profits) to fund a wide range of activities that build, purchase, and/or rehabilitate affordable housing for rent or homeownership or provide direct rental assistance to low-income persons, including those with disabilities.	\$1.6 billion

## Employment

Carol Bianco

Gary E. Shaheen, M.P.A.

### Overview

To be unemployed in America means more than living in poverty; it also means living a life outside of the societal mainstream. Having a job is one of the key factors that integrates people within their communities. People with mental illnesses are generally acknowledged as having a rate of unemployment exceeding 80 percent,<sup>1</sup> a statistic that has not diminished since it was presented in 1987. Yet, even this statistic may not portray the extent of unemployment among people with mental illnesses.

Unemployment, for the purposes of setting labor and economic policy and programs, is defined by the U.S. Department of Labor as “all people who had no employment during the reference (surveyed) week, were available to work, except for temporary illness, and had made specific efforts to find employment sometime during the 4-week period ending with the reference week.”<sup>2</sup> Clearly, many thousands of people with mental illnesses who are homeless, discouraged from looking for work by past job failures, or who are working in some type of sheltered work program, may not be included in national rate of employment data. They are the marginalized members of our community who are not even counted among the unemployed.

Lack of good data can be a factor that negatively impacts on coordination between policies and programs that address mainstream employment issues and those that are developed for people with mental illnesses. The mainstream labor, vocational rehabilitation, and mental health systems lack effective methods for coordination, data sharing, and collaboration. Even the current robust employment economy has not been of benefit for people with serious mental illnesses. A recent report by Cornell University found that the number of

people reporting that a physical or mental condition affects their ability to work—either partially or completely—was higher in 1999 than in 1992. This is despite an overall national unemployment rate of 4.2 percent for 1999.<sup>3</sup>

Yet, people with mental illnesses have made some progress in securing better job options than they have had in the past. With the growing shift from sheltered employment to community integrated employment, more individuals with histories of mental illness are employed in integrated work settings today than ever before. Most significantly, they are obtaining jobs in all skill levels—from entry level to the professions. This shift reflects an important evolution in consumer and employment program expectations, as well.

Increasingly, both consumers and program providers are emphasizing that getting a job is not enough. People with serious mental illnesses need access to jobs that have career potential in order to escape from poverty and have a rewarding and growth-oriented working life.

*More individuals with histories of mental illness are employed in integrated work settings today than ever before.*

### Historical Context

There are a number of challenges facing people with mental illnesses, program providers, and policy makers. How can we meet the employment needs of people with mental illnesses within the mainstream labor system? And, how can this be done while also providing supportive services that recognize and address the functional implications of mental illness upon employment? Historically, sheltered employment was assumed to provide the bridge to mainstream employment. Offering a supportive, protective environment to build work skills, attitudes, and behaviors, sheltered employment was intended to facilitate transition to competitive employment. In fact, success in sheltered work often does not translate to success in choosing, obtaining, and retaining a mainstream job.

Sheltered programs reinforced the life role of “mental health consumer” rather than mainstream working per-



son. They often failed to provide industry standard training for jobs that existed in the local economy. Perhaps most importantly, they failed to address a key factor in employment success—the ability to set employment goals based on personal job criteria, real-life work experiences, and knowledge of available options. Furthermore, sheltered employment often provided only menial, entry-level work. Faced with these choices, consumers often “voted with their feet” and endured the additional label of being noncompliant with services.

### Current Emphasis

Increasingly, the shift is away from sheltered employment to education, training, and competitive employment with support. Dissemination of psychiatric rehabilitation and recovery training has also enhanced the menu of employment-related options for consumers, resulting in increased inclusion of consumers in their employment decisions. It has also led to the development of new programs that strengthen their ability to develop employment goals within wage-paying, real work environments.

The workforce of the new millennium requires employees who are trained in demand occupations (i.e., occupations in which there is a high demand for employees). Whether by linking employment services with supported education, or through creating agency-operated businesses that offer skills training in demand occupations and competitive wages and benefits, older sheltered employment models are giving way to newer, more mainstream-oriented approaches.

There is a growing shift away from a “one-model/one-size-fits-all” approach to a menu approach. For example, rather than offering only transitional employment (e.g., the Fountain House Model), agencies are combining supported education, rapid job placement in agency-operated businesses, transitional training, and supported employment in an integrated approach (e.g., the Village Integrated Service Agency). However, as clubhouses that added employment to their services discovered decades ago, getting a job is not enough. People need sources of off and on-job support that friends, peers, families, and co-workers can provide. Fundamental to any particular model is the importance of providing ongoing support as long as needed.

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### Discussion of Federal and State Initiatives

A current challenge is to increase the rate of utilization by people with mental illnesses in federally sponsored vocational rehabilitation (VR) programs.

Authorized originally by the Fess-Smith Act of 1920 to help veterans with disabilities obtain employment, the VR program was later expanded to include services for people with mental illnesses. Although the federal VR program provides matching funds to states to help people with disabilities obtain employment, recent studies have concluded that the VR system has not done an effective job of training its counselors to understand and address the needs of people with psychiatric disabilities.<sup>4</sup> People appear to have little success in accessing mainstream employment, while they are also having limited success in getting and keeping jobs through the programs authorized by statute to assist them.

The psychosocial rehabilitation movement and the emergence of clubhouses have contributed to advocacy around employment issues. National organizations representing clubhouses, including the International Association of Psychosocial Rehabilitation Services (IAPSRS) and its state chapters, have established employment as a priority. They have compiled and disseminated data about the strong relationship between work and recovery that provides an incentive to both VR and mental health systems to address the personal and systemic barriers to employment faced by consumers.

An important ingredient in anyone’s job success is the strength of the personal friendships, both on and off the job, that people have. Many consumers would rather get their mental health supports off the job. Job developers and job coaches—whether or not they work in a transitional, supported, IPS, or social enterprise program—must help employees recognize and develop “natural supports” in the workplace. These natural supports, who often are co-workers and sometimes supervisors, can provide assistance, advice, and insight in a way that is more normalizing than if these services were provided by mental health staff. This combination of on-site and off-site and mental health and natural supports has led to employment success for thousands of consumers throughout the country.

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## Recent Legislative Initiatives Supporting the Right to Work

Employment has gained a stronger national emphasis with the passage of the Personal Work and Responsibilities Act of 1996, the Workforce Investment Act of 1998, and, most recently, the Ticket to Work/Work Incentives Improvement Act of 1999. Each of these major federal initiatives has provided policy guidance, authority, and funding to support the inclusion of more people with disadvantages and/or disabilities into the nation's workforce. Reducing economic disincentives to work is also being given greater attention.

Particularly, the necessity for continued Medicaid eligibility while working is essential so that people with mental illnesses can afford their psychotropic medications and general health and wellness care. Programs that assist Supplemental Security Income (SSI)/Social Security Disability Insurance (SSDI) beneficiaries to build work experiences and earn income while minimizing the loss of their benefits safety net have also been implemented. The Social Security Administration (SSA) Plan for Achieving Self-Support (PASS) program helps people save money to achieve a vocational goal by excluding a portion of their earned income from SSI benefits calculations.

Special federally funded initiatives to increase access to jobs have been developed during recent years. The Job Training for the Homeless Demonstration Program—part of the Stewart B. McKinney Homeless Assistance Act—sought to develop effective ways of employing homeless people, including those with mental illnesses, during its existence from 1988-1995. The Americans with Disabilities Act of 1990 is a key piece of civil rights legislation that seeks to remove barriers to employment for people with disabilities and facilitate their inclusion into the mainstream workforce.

The SSA State Partnership Initiative established 12 cooperative agreements with states to develop innovative projects to help adults with disabilities re-enter the workforce. The majority of these projects focus on removing barriers to employment for people with mental illnesses. Each of the above initiatives holds one piece of the potential solution to increasing the rate of employment among people with mental illnesses, but greater effort is necessary.

## Examples of Programs that Are Achieving Successful Outcomes

Many states are exploring innovative employment approaches. In New York State, a portion of the savings realized from discharging people from psychiatric hospitals to community systems of care is made available to localities through a request for proposals (RFP) process. Many counties have responded by creating employment programs, including affirmative businesses, supported employment, and clubhouse-based training and employment. In Florida, a consortium of behavioral health agencies provides job training, placement, and post-employment support services using a combination of mental health and labor department funding sources as part of their area's one-stop employment network.

Since 1976, the Green Door Clubhouse in Washington, D.C., has helped more than 2,500 people with mental illnesses to work and live independently. Green Door operates both Transitional (TEP) and Supported Employment (SE) programs. TEP is often more appropriate for members who need more help, e.g., those who cannot readily obtain a job due to lack of marketable skills or poor work history, to gain confidence and build their resume. The six-month, usually part-time placement in an integrated, competitive work environment responds to consumers' needs and desire to work. Most importantly, it provides a "slow entry ramp" back into employment and a chance to test their work preferences in real work environments. The SE program can be a next step for TEP participants. Through SE, consumers obtain permanent jobs and receive the assistance they need to keep them.

In California, a community vocational services agency has developed a partnership with a major national business corporation to create new businesses offering competitive employment for consumers. It successfully blended foundation funding, mental health resources, state VR funding, and sales revenue to grow the business more than 400 percent during its 12-year history. Throughout the country, mental health providers are leveraging U.S. Department of Housing and Urban Development (HUD), mental health, VR, and other sources of funding to provide the four essential elements of effective employment programs: goal development, skills training, job acquisition, and post-employment support services.

## The Impact of Stigma

The national emphasis on increasing the rate of employment for all people with disadvantages and/or disabilities faces a number of significant challenges. In particular, the barriers to employment faced by people with mental illnesses are often complex and have thus far succeeded in preventing thousands of mental health consumers from employment success. One of the greatest of these barriers is the pervasive stigma associated with mental illness. Stigma is manifested in a number of ways. It appears in the reluctance of employers to hire people they fear are prone to unpredictable mood swings, aberrant behavior, and violence that is often the media stereotype. It appears in mental health programs that either fail to prioritize employment or settle on older, protective models in the belief that people with mental illnesses are unemployable. And, it is often felt by consumers themselves. Repeated failure, lack of opportunity and options, and lives lived with a mental illness label can result in self-stigmatization and lack of hope. Given the opportunity for skills training, jobs, and support, individuals can succeed at work. Yet, often their ability to succeed at reversing negative popular stereotypes is a much more difficult challenge.

## Accepting the Challenge of Increasing Community Integration by Increasing Employment

Addressing employment through *Olmstead* planning must be a multi-faceted approach. It must involve better data collection, needs assessment, access to mainstream employment systems, better utilization of vocational rehabilitation services, and anti-stigma efforts. It must promote national adoption of economic safeguards, including the provision of health insurance that people need to not only get jobs, but to build careers. And, it includes re-examining the roles and responsibilities that public mental health authorities, community mental health providers, mainstream employment resources (including labor and economic development), and the business community must have to increase employment among people with mental illnesses. Finally, it must include active participation by mental health consumers and family members so that programs and services truly meet their needs.

Recognizing and overcoming these barriers and seeking new collaborations can result in the inclusion of many more thousands of currently out-of-work or underemployed Americans with mental illnesses as contributing members of a vital and growing national economy.

*Given the opportunity for skills training, jobs, and support, individuals can succeed at work.*

## Barriers To Employment

### Serious Mental Illness

Some barriers to employment are a function of the nature of serious mental illnesses. These include cognitive, perceptual, affective, and interpersonal dysfunctions; side effects of medications; episodic and unpredictable onset and recurrence of illness; interruption of education and/or vocational training; and interruption of the development of a work history.<sup>5</sup> These barriers can/may make it difficult for individuals to complete their education, obtain vocational training, identify available jobs, manage the stress of the job-seeking process, successfully obtain employment, manage the demands of work, and build work experience that leads to employment stability and career growth.

The experience of mental illness also affects one's perception of self in a worker role. For many people, employment has been provided as part of a mental health program. Their co-workers are primarily other people with mental illnesses. Without opportunities to interact with non-disabled co-workers, it is difficult to change self-perception from that of a mental health consumer in work therapy to a member of a mainstream workforce. The effect of this conflict of identity is that many people with mental illnesses have greater difficulty in adjusting to the interpersonal relationships of the workplace than to the job tasks they need to perform after they obtain a competitive job.

### The Service Delivery System

Service delivery barriers include fragmentation among mental health, employment, and vocational rehabilitation providers on the federal, state, and local levels. There are tensions and discontinuities among the various programs that arise from differences in mission, outcomes, professional disciplines, technologies and interventions, nomenclature, and history. As a

result, there are few effective, formal collaborative agreements among the multiple agencies involved in helping consumers return to work.

Because the missions of many traditional mental health organizations have not been focused on helping individuals achieve and sustain employment, there has been a lack of resources to provide training on employment support strategies, Social Security work incentives, employment discrimination management, and functional implications of mental illness. Employment programs are not a priority in the current service delivery system because the financial incentives are not available to service providers. Many providers would like to focus more energy on employment services, but oftentimes the funding mechanisms are not there.

Services fragmentation also affects the ability of mental health providers to develop and manage employment programs for people with multiple disabilities. It often means that providers must develop a “patchwork quilt” of funding from disparate sources, each with its own funding and reporting schedules and each supporting a designated staff.

For example, an employment program serving people with mental illnesses who are homeless and have co-occurring substance abuse disorders may need to obtain funding from HUD, mental health, and substance abuse sources—as well as seek additional labor department, state VR, and/or Social Security funding—in order to hire staff with expertise in each area of disability, as well as employment expertise. Unless an integrated approach to treatment, housing, case management, and employment is in place, program participants may “fall through the cracks” even within one agency.

## Funding and Public Policy

Mental health, vocational rehabilitation, and labor department programs and funding are often incompatible. This discourages an interdisciplinary team approach, although such an approach has proven to be most effective for many people with serious mental illnesses, especially those with co-occurring disorders or other major barriers. The VR system is inconsistent in its ability to engage people with serious mental illnesses in its programs. A report by NAMI (the National Alliance for the Mentally Ill), documented a survey of VR and its ability to serve people with psychiatric disabilities.<sup>6</sup> Results included:

- The time-limited nature of services is contrary to the realities of the fluctuating nature of severe mental illnesses.
- The emphasis on case closures provides few incentives for counselors to work with individuals with more complicated and long-term needs.
- Too many resources were devoted to the eligibility determination process.
- Counselors and administrators lacked knowledge of the needs of people with severe mental illnesses.
- The time-limited nature of funding served as a disincentive for community mental health providers to contract with those agencies.

The agencies primarily responsible for employment services are the state departments of labor and the state offices of vocational rehabilitation, with the increasing involvement of Workforce Investment Boards (WIBs). While state workforce training and employment services are shifting toward a “one-stop” delivery system under the WIBs as a result of the Workforce Investment Act, it is unclear whether this will result in improved or reduced access to services for people with serious mental illnesses. Historically, people with mental illnesses, as well as mental health service providers, have found that employment and training services at state labor departments and vocational rehabilitation offices do not serve them adequately.

These issues are even more complicated by the role that state VRs have yet to claim with a one-stop and Ticket to Work (TTW) system. Beginning in 2001, under the federal Ticket to Work/ Work Incentives Improvement Act of 1999, people who receive SSDI and SSI will be issued a “ticket to work” that allows them to obtain vocational rehabilitation, employment, or other support services from a provider of their choice. VRs can elect to participate in the TTW program as an employment network.

However, if VR is not the designated network provider and does not have a written agreement to provide services to people referred by the network, the networks will not receive payments for those individuals. Since the TTW system is either outcome or milestone payment based, networks may be reluctant to provide the level of service needed by people with mental illnesses who often present significant, recurrent employment barriers. This underscores the necessity of interagency collaboration and coordination and the adoption of flexible standards for employment outcomes for people with mental illnesses.



Mental health consumers and providers raised a number of significant concerns about the regulations for this program. Among these concerns are the differences in payment (as well as the generally low payment rate) between those receiving SSI and those receiving SSDI. Advocates are concerned that networks will be more inclined to prioritize entry and services for SSDI recipients who are reimbursed at a higher rate.

Another concern relates to access and eligibility. Many consumers are placed by the Social Security Administration into the “medical improvement expected” (MIE) category. Consumers may present themselves very well at the time of their interview, but this may not reflect the extent of their disability. Individuals in the MIE category are not eligible to participate in the TTW program until they have gone through their first Continuing Disability Review, thereby ruling out the prospect of early intervention. On the whole, the TTW holds great promise as yet another funding stream to support employment, but there are a number of issues that remain to be addressed to fully realize its potential positive impact.

## Strategies to Address Employment Barriers

Strategies to address employment barriers must occur at the individual, program, and systems levels.<sup>7</sup> The following strategies are among those that have proven effective or that should be considered. However, this is an evolving field, made more complicated by the interplay of labor and economic policy, rapidly changing demands for job skills, and lack of resources for long-term employment support within the mental health sector.

### Strategies for Individuals

- *The most effective medication with the fewest side effects that impact on work performance.*
- *Peer supports and self-help services, especially focused on supporting the individuals in their new role of worker. Working peers provide extremely important role models, mentors, and support.*
- *Services that help develop informed job choices and goals. The urge to work can result in “impulse shopping for jobs” with unclear knowledge of both personal attributes and skills needed for success. A combination of work values clarification and transi-*

tional work involvement to test job preferences can address this issue.

- *Strengths-based approach.* Consumers have often developed an array of skills they needed to negotiate through the mental health system. Often these skills (perseverance, resilience, etc.) have relevance to success in employment when they are recognized, endorsed, and applied.

### Strategies for Programs

- *Establishing work as an agency priority.* Providers should determine their own readiness and capacity to move employment to the top of the agency agenda. This includes articulating employment as a major component of its mission, seeking funding, establishing new partnerships, providing staff training, and dedicating resources.
- *Challenge traditional concepts of readiness.* A “standing offer of work” can replace preoccupation with disability with a new purpose and build a foundation for advanced employment.
- *Individualized job development services* to help individuals gain access to existing jobs in the competitive employment marketplace.
- *Having benefits management expertise on staff.* In-depth knowledge of disability benefits, the eligibility, application and appeals process, and work incentives is an invaluable addition to the employment team. Benefits advisement should occur not only prior to employment, but at intervals during an individual’s job tenure. This is often necessary to help consumers decide if they should increase work hours, accept a raise, etc. that may have an effect upon their benefits.
- *Partnerships with the business and labor sectors.* These partnerships are essential if training and job development efforts are to remain in step with local employment markets.
- *Cultural competency.* Including culturally competent, multilingual, and multicultural staff ensures that employment services successfully serve members of disparate cultures.
- *Consumers as staff.* Consumer perspectives are invaluable in developing employment services. They can offer valuable insights on how they manage work and recovery and become a role model for their peers.



- *On and off-site coaching* to assist with learning job skills and managing personal and interpersonal challenges. This is a critical area that will ebb and flow in intensity with the ebb and flow of the recovery process.
- *Reasonable worksite accommodations* that help the individual perform essential job functions while managing the effects of the illness. Helping individuals understand and choose if and when to disclose their mental illness is an important service.

## Strategies for Systems

- *Revision of Social Security policies to increase work incentives.* Consumers cite fear of loss of benefits as one of the major reasons that they resist working. The lessons learned from the implementation of the SSA State Partnership Initiatives should be widely disseminated together with technical assistance to facilitate local replication.
- *Provide continued Medicaid eligibility while working.* Most entry-level jobs do not provide health benefits that are essential to help people with mental illnesses afford their psychotropic medications and acquire medical, dental, and optical care. Most consumers will not accept employment if it means risking loss of Medicaid. However, it is possible to earn a substantial annual income and retain Medicaid by using the 1619B option. And, if states elect to adopt a Medicaid buy-in provision that is made possible through recent federal legislation, people with serious mental illnesses can have the security of working and advancing in both salary and careers without the danger of losing their health insurance. One of the greatest challenges that systems face is ensuring that all consumers and providers receive up-to-date training and technical assistance on these new initiatives.
- *Funding for long-term employment services, values clarification and development of informed job choices, and ongoing support services.* Most employment funding is short-term. The cyclical nature of mental illnesses, combined with often lifelong deprivation, requires that employment supports are available upon request for months or even years after a consumer begins work.
- *Interagency employment initiatives.* Integrated agency approaches to employment and support services and blended funding arrangements are among the strategies that can reduce services frag-

mentation. This must include efforts to integrate systems and resources at both the federal and state levels.

## Current Programs That Address Employment Barriers

**Individual Placement and Support (IPS) Program.** In the IPS model, employment specialists link with all of the treatment teams within a mental health center and collaborate directly with the clinicians to ensure that employment is part of the treatment plan for every client who is interested in working. They emphasize integration of vocational and clinical services, minimal preliminary assessments, rapid job searches, normal work settings, matching consumers with jobs of their choice, and ongoing supports.<sup>8</sup> Work is considered both treatment and outcome, and vocational rehabilitation becomes a vital and essential component of a client's ongoing treatment.

**Transitional Employment.** Fountain House Foundation in New York City implemented the first Transitional Employment Programs (TEP) in 1964.<sup>9</sup> TEP participants work in a series of time-limited, competitive jobs to gain employment experience and skills. The jobs are developed through an agreement between the rehabilitation agency and one or more private businesses. The agency commits to filling the job slot(s) on a continuing basis with trainees (and assigning staff to the job if trainees are not available), and the business commits to providing the slot(s). On and off-site job coaching is provided to participants by club staff. Trainees usually work on a part-time basis, at competitive wage for between four to six months, after which they are rotated to another job placement. The desired outcome is the eventual acquisition of either full or part-time permanent employment.<sup>10</sup>

**Supported Employment.** Federally defined as "competitive employment in an integrated setting with ongoing support services for individuals with the most severe disabilities," the purpose of supported employment is to provide a wide range of supports to facilitate employment success for as long as the individual needs support. From the beginning, this "place, then train" approach has differed significantly from extensive use of pre-employment testing and "pre-vocational work" that had been widely used for people with disabilities. Supported employment staff can help job seekers or employees to manage their illness while they address their employment goals.

**Vocational Case Management.** When case management services are offered, employment goals are integrated into the service or treatment plan. Additionally, case managers are involved in the delivery of pre-vocational and follow-up services once the individual obtains employment. Case managers are often most familiar with participants' abilities and can help to identify skills that will be transferable to the work place. Finally, case managers can address many of the issues and obstacles individuals face, such as entitlement/benefit questions, substance abuse, and the shift in the sense of self related to being a "worker."

**Social Enterprises (Affirmative Businesses).** Social enterprises are business ventures that are created specifically to provide training and employment for people who are unemployed, disabled, or otherwise disadvantaged. From the outset, a social enterprise has a dual purpose: to operate a viable and sustainable business, and to assist otherwise "unemployable" people to achieve success and satisfaction in a real work setting. In order to operate as a viable business, a social enterprise must adopt standard business practices, employ experts in the particular type of business venture, and expect all employees to learn and practice the technical skills that will enable the business to offer a competitive product or service. Employees see themselves not as patients in a treatment program, but as workers in a local business, receiving industry-scale, competitive wages. Social enterprises add to the jobs available within a locality, not relying solely on the existing job market to meet the employment needs of consumers.

Though more common in Europe and Canada, another type of social enterprise is the consumer-owned or managed co-operative. It incorporates shared decision-making and responsibility and peer support, and has the advantage of a number of co-managers who contribute their own special skills and aptitudes to making the business grow.<sup>11</sup>

**Supported Self-Employment.** Thousands of people with mental illness have at some time in their lives developed or operated a small business. With the right combination of business technical assistance and mental health supports, self-employment can be a road to self-sufficiency. In rural locations, where employers and jobs may be scarce, self-employment may be one of the few alternatives to chronic unemployment among peo-

ple with a physical or mental disability. In spite of the obstacles, self-employment is becoming an increasingly desired work option for many individuals with disabilities. Self-employment provides a high degree of independence and satisfies a personal work objective. For many people with disabilities who feel that traditional vocational programs promote "learned helplessness," self employment is an opportunity to take control of one's vocational future.

***Supported  
education programs  
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keep-grow" principles and  
strategies of supported  
employment programs.***

**The "No-Model" or Blended Strategy.** The Corporation for Supportive Housing and the Village Integrated Service Agency are but two agencies that endorse the value of offering a wide range of employment services to meet people's needs at whatever stage of employment readiness they are. For example, a job as a one-hour per day receptionist in a supportive apartment building may be among the options available for some individuals. This may meet an individual's need to acquire work quickly, as well as his or her need to have a slow entry ramp to jobs with more hours or more complex skill demands. For others, the type of short-term, transitional, competitive placements that are part of a program like TEP build exposure to work and help define job preferences. For still others, supported education or supported employment may be the answer. No matter what approach is offered, the key attributes are 1) integrated employment, mental health, housing, and support planning; 2) consumer choice; 3) real jobs at real wages; and 4) ongoing support as long as needed.

## **Supported Education**

Mental illness often manifests itself in late adolescence and early adulthood. These are critical years in a person's life, when important decisions concerning education and careers are made. People whose job and career development has been interrupted by psychiatric disability must have opportunities to regain exposure and experience in the world of work. Similarly, people whose education is interrupted need help to reconnect and continue with their educational development.<sup>12</sup>

Supported education programs use the same "choose-get-keep-grow" principles and strategies of supported employment programs. People receive help defining their educational objectives, including getting their high school GED or post-secondary degree. There

are a number of ways to provide support and assistance for education. Some programs use an “on-site support approach.” People receive individual counseling, college placement, and support aided by an “educational coach” who provides ongoing assistance both on and off-campus as needed.

Other programs use a mobile team approach that is similar to the on-site model, but mobile teams—often a part of the local community mental health center—provide services to more than one post-secondary site. Still other programs provide preparatory training and support for school re-entry by offering remedial education and educational readiness services in on-campus “self-contained classrooms” to ease re-entry into the college mainstream.

Two pieces of legislation, the Individuals with Disabilities Education Act (IDEA) and the Carl D. Perkins Education Applied Technology Education Act, have language addressing the coordination of vocational and educational planning for people with disabilities. Within higher education settings, the office of disabled student services handles issues related to accommodations under the ADA and can be a valuable partner in the supported education program. This office often has information about mental health treatment services and about counseling services to help students adjust to college life. Counselors also work with academic staff to help raise awareness about disabilities and to provide supports and accommodations to help students meet classroom requirements.

Consumers re-entering school need similar types of support services to those provided for people who are acclimating to a competitive work environment. For example, consumers may have more trouble managing and negotiating the interpersonal relationships at school (or on the job) than they do in meeting their class or job requirements. Helping people accept praise and criticism, attend to task, work with classmates and supervisors, and identify and acquire “natural supports” are critical components for success.

Mainstream public and private sources, as well as state departments of vocational rehabilitation, can provide tuition assistance, and mental health departments often support case management and educational counseling and support staff. The key is coordinating all the funding needed to pay tuition, support oneself while in school, ensure a safe and affordable place to stay and study, and provide ongoing supports.

Barriers to supported education are in many respects similar to those for supported employment. Students

must contend with such issues as the stigma associated with mental illness, the side effects of medication that affect concentration and functioning, and poor support systems, as well as the need to manage a job, one’s recovery, and school demands. In addition, people whose mental illness occurred when they were in school or about to enter school might be fearful about resuming a path that they may associate with the onset of their illness.

## **New Programs and Initiatives That Can Address Employment Barriers**

- Integrated substance abuse and mental health treatment that is linked to employment.
- Cross-trained staff, including peer case managers.
- Federal and state-level interagency agreements and blended funding initiatives.
- Training for on-going needs assessments and development of training and best practices tools.
- Federal and state-level policy statements and outcome expectations that establish employment as a priority and recognize a flexible definition of work.
- Collaborations with one-stop employment programs to increase access to services.
- Participation as members of local Workforce Investment Boards.
- Re-examination of roles and responsibilities of the publicly financed mental health system and community-based system that is consistent with the principles and practices of recovery, rehabilitation, and integration.
- Land-for-services agreements that return a portion of the sale of unused psychiatric center campuses to mental health programs to establish housing and jobs.
- Systems integration initiatives that include agreement about data collection, dissemination, and employment outcomes between the federal Center for Mental Health Services, the Center for Substance Abuse Treatment, the Rehabilitation Services Agency, the Social Security Administration, and the U.S. Department of Labor.
- Data collection initiative to determine how well consumers are able to access VR-sponsored employment services.
- Continuing benefits advisement services including the development of PASS and IRWE plans.

## Federal Agencies/Programs That Can Address Employment Barriers

A recent GAO report indicated that there is great deal of fragmentation and program overlap in federal government-sponsored programs.<sup>13</sup> Each of the agencies listed below have programs or services that address employment for people with disabilities, including those with mental illnesses. Such a myriad of agencies and initiatives compels an examination of ways to coordinate and streamline interagency efforts on employment.

- Department of Education Rehabilitation Services Administration that administers state vocational rehabilitation services.
- Department of Labor Employment and Training Administration that provides funding and technical support to programs that help people with barriers to gain mainstream employment.
- Department of Housing and Urban Development that provides funding for employment services as a component of its Supportive Housing Program.
- Substance Abuse and Mental Health Services Administration, which provides funding, technical

assistance, and training to address the functional barriers of mental illness.

- Center for Medicare and Medicaid Services for Medicaid-reimbursable services and health insurance supports.
- Social Security Administration to address entitlements-related disincentives to work.

## State/Local Public and Private Organizations That Can Address Barriers

Each of the following agencies provides resources for, or operates, employment programs.

- State departments of labor
- State vocational rehabilitation agencies
- State and local Workforce Investment Boards
- Community rehabilitation providers
- Community mental health agencies
- Independent living centers
- Peer advocacy and support organizations

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## Endnotes

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<sup>3</sup>Fishman, Michael E./The Lewin Group, "Framing the Issues: Economic Research on Employment Policy for People with Disabilities," October 1999.

<sup>4</sup>Bevilaqua, Joseph J. "The State Vocational Rehabilitation Agency: A Case for Closure," *Journal of Disability Policy Studies* 10(1) 90-98 1999.

<sup>5</sup>Matrix Research Institute, *Barriers to Employment Decisions for People with Psychiatric Disabilities*, September, 2000.

<sup>6</sup>Noble Jr., John, et al. *A Legacy of Failure: The Inability of the Federal-State Vocational Rehabilitation System to Serve People with Severe Mental Illness*. Arlington, VA: National Alliance for the Mentally Ill.

<sup>7</sup>Shaheen G. *Work as a Priority: Employing People with Mental Illness Who Are Homeless*: In press.

<sup>8</sup>Drake, R., Becker, D., Clark, R., Muesser, K., 1999; Becker, D., Drake, R., 1993.

<sup>9</sup>Beard, J.H., Probst, R.N., & Malamud, T.J. "The Fountain House Model of Psychiatric Rehabilitation," *Psychosocial Rehabilitation Journal* 11(1), 1982.

<sup>10</sup>Shaheen, G. In press.

<sup>11</sup>Church, K, Fontan, JM, Ng, R. and Shragge, E. *Social Learning Among People Who Are Excluded from the Labor Market: Context and Case Examples*. Toronto: Network for New Approaches to Lifelong Learning, 2000.

<sup>12</sup>Unger, K. "Supported Post-Secondary Education for People with Mental Illness." *American Rehabilitation*, Summer 1990:10-33.

<sup>13</sup>Report to the Hon. Fred Thompson, Chairman, Committee on Governmental Affairs, "Managing for Results: Barriers to Interagency Coordination," General Accounting Office GAO/GGD-00-106 March 2000.

## Overview of Employment Program Approaches for People with Serious Mental Illnesses

Program Type	Approach	Objective	Possible Funding Sources	Staff Expertise Required	Advantages	Disadvantages
<b>Transitional Employment Programs (TEP)</b>	Time-limited placement in competitive jobs. Agency commits to keeping job slots filled. Often clubhouse-based.	Build experience, competence, job goals with the objective of attaining a permanent job.	State VR, HUD, MH, foundations.	Skills teaching, job development, placement, support, ability to perform job in consumer's absence.	Basis for establishing links with employers. Builds credentials, experience, and resume.	Time limitations not always congruent with consumer preference. Staff may need to fill in for absent worker. Unclear outcomes re: how TEP facilitates competitive employment.
<b>Supported Employment</b>	Direct placement into integrated competitive jobs.	Part-time or full-time employment at prevailing wage.	State VR, MH, HUD, DOL, foundations.	Skills teaching, job development, placement, intensive/extended support, re-placement, case management.	Employee hired by the employer, not by the MH program. Works with non-disabled co-workers. Salary, growth potential like co-workers.	Clash between short-term VR funding and long-term support needs requiring use of MH/other funds for extended job coaching, case management.
<b>Program for Assertive Community Treatment (PACT)/ Individual Placement and Support Program (IPS)</b>	Six principles <ul style="list-style-type: none"> <li>• The goal is competitive employment</li> <li>• Rapid job search</li> <li>• Integrated rehabilitation and mental health</li> <li>• Consumer preferences</li> <li>• Ongoing assessment</li> <li>• Time-unlimited support</li> </ul>	Re-orientation to work using rapid job (full-time/part-time) entry with "place-train" assessments.	MH, Medicaid, VR, HUD.	Interdisciplinary team structure with vocational specialist.	Work fully integrated with treatment. Employment is a priority shared by all team members.	Unclear that all of the six principles are proven effective with consumers who have other compounding factors (co-occurring disorders, homelessness, etc.).



## Overview of Employment Program Approaches for People with Serious Mental Illnesses

Program Type	Approach	Objective	Possible Funding Sources	Staff Expertise Required	Advantages	Disadvantages
<b>Social Enterprises</b>	Agency-sponsored businesses that provide affirmative employment.	Job goal/skills development, work experience, supportive milieu, transitional/career employment.	VR, MH, business revenue, economic development, HUD, foundations.	Business/production experts, training/job coach staff, job development/ placement staff.	Can offer both full and part-time jobs with intensive or diminished support. Creates wider pool of available jobs for consumers.	Requires sound business planning. High business risk factor. Need for start-up capital facilities, business systems (accounting, etc.).
<b>Self-Employment</b>	Consumer owned business (sole proprietorship, partnership/cooperative).	Employment as full-time/part-time self employed business owner.	VR, SSA, MH, federal, SBA, State community business lenders, private capital.	Business-related technical assistance/support, MH support.	Responsibility for success relies upon the individual. Independence, control.	Responsibility for success relies upon the individual. High financial risk factors. Requires sound business planning as well as coordinated MH support services.
<b>Supported Education</b>	Help acquiring GED, assisted placement into post-secondary schools, and ongoing support provided on or off-site.	Part or full-time school enrollment and achievement of educational credentials.	State VR, MH, public or private tuition assistance programs, tuition reimbursement from employers.	Skills teaching, placement assistance, intensive/extended support, help with accommodations, re-placement case management.	Participation in mainstream education system with opportunities to build/rebuild skills, credentials, and competitive advantage in the job market. Attends with non-disabled students and gets help through both natural and professional supports.	Often difficult to manage together with all other priorities in a person's life (need to work, get better housing, continue mental health treatment etc.) unless all services are coordinated and integrated.

Source: Shaheen, G. *Work as a Priority: Employing People with Mental Illness Who Are Homeless*. In press.

## Behavioral Health Care

Jenifer Urff, J.D.

### Overview

Often, people with mental illnesses—especially the most serious and persistent mental illnesses—are uninsured, impoverished, and dependent on the public mental health system for services and supports. Even people with private health insurance, however, face considerable obstacles in accessing appropriate community-based services. These obstacles include discriminatory health insurance coverage that often favors inpatient care over community-based services, requires higher co-payments and deductibles for mental health treatment than for other physical health treatment, and restricts the number of outpatient interventions that may be provided for mental health care. As a result, many privately insured consumers are unable to access community-based services through their private health insurance plans and turn to the public mental health system for services.

### The State Role

Historically, individual states, rather than the federal government, have assumed principal responsibility for providing services to people with mental illnesses. As a result, the public mental health system in the United States really is a collection of 59 different state and territorial mental health systems, each with its own approach to identifying priority populations and financing and delivering services.

One advantage of this state-by-state system is that states and communities are able to tailor their programs to meet the unique needs and environments of the people they serve. However, the lack of a unified system also has resulted in crucial state-by-state disparities in the pace of deinstitutionalization and the quality of community-based services provided. In addition, the strong state role may perpetuate the belief by some that providing services to people with mental illnesses

should remain a “state responsibility.” This belief has resulted in discrimination against people with mental illnesses in federal health programs such as Medicare and Medicaid, and is a contributing factor to chronic underfunding in the public mental health system.

### The Federal Role

Despite gaps in federal support for the public mental health system, the federal government plays a critical role in providing effective services and treatment. The Community Mental Health Services Block Grant, for example, provides small but important grants to states to initiate and implement programs of community-based services. After almost a decade of level or decreased funding, the Block Grant has received substantial funding increases over the last three years, increasing its importance as the most significant federal funding stream designed specifically to meet the needs of people with mental illnesses. Fiscal Year 2001 appropriations for the Block Grant of \$420 million mean the Block Grant has increased by more than 50 percent since Fiscal Year 1998.

Other federal agencies and programs provide crucial support for programs serving people with mental illnesses. The Center for Mental Health Services (CMHS), part of the Substance Abuse and Mental Health Services Administration not only administers the Block Grant program, but also provides key guidance to states through services research, technical assistance, and the dissemination of “promising practices.” The National Institute of Mental Health supports research on the causes of mental illness and effective approaches to treatment and service delivery. In addition, federal agencies such as the U.S. Department of Veterans’ Affairs provide treatment and support for certain individuals with mental illness.

Ironically, the most important services for people with mental illnesses may not be mental health services at all. To be served effectively in community settings, people with mental illnesses must have access to a

*Federal agencies provide crucial support for programs serving people with mental illnesses.*

broad range of non-mental health services—housing, income support, employment and education, and treatment for co-occurring medical or substance abuse disorders. The federal government invests billions of dollars each year to help individuals meet these fundamental needs. However, because these programs generally are not designed to meet the unique needs of people with mental illnesses, the public mental health system is challenged to blend programs and funding streams in a way that provides a comprehensive system of services and supports for this population.

### **The Impact of Managed Care**

Over the last decade, many states have turned to managed care to help coordinate care and decrease the costs of providing behavioral health care. Most of these states have contracted with private managed care companies to administer mental health benefits provided by the state. Well-designed and well-funded managed care programs may help to overcome some of the coordination and financing barriers to community care described later in this chapter. However, the cost-saving tools used by managed care companies create the risk that medically necessary mental health services may not be delivered in an appropriate, timely manner. In addition, some managed care plans are biased toward institutional care and may frustrate attempts to coordinate mental health services with critical non-mental health supports, such as housing and employment.

### **Protection and Advocacy**

An important component of the public mental health system is the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. PAIMI was established in 1986 to protect and advocate for the rights of people with mental illnesses and to investigate reports of abuse and neglect in facilities that care for or treat people with mental illnesses. Each state has a designated PAIMI agency, which receives funding from CMHS to implement PAIMI activities. Although PAIMI originally was developed to provide services to individuals who are in institutions or were recently discharged, many PAIMI programs were instrumental in achieving, through advocacy and litigation, significant progress toward deinstitutionalization in their states. In addition, legislation adopted in October 2000 expands PAIMI authority to include individuals who receive mental health services in community settings or in their own homes.<sup>1</sup>

## **Barriers to the Delivery of Community-Based Mental Health Services**

Over the past 30 years, as states have downsized state hospitals and emphasized the delivery of community-based care, states also have shifted resources from hospitals into community-based services. In 1993, for the first time, state mental health agency spending on community-based mental health services exceeded that spent in state psychiatric hospitals.<sup>2</sup> That trend has continued, and in 1997 (the most current year for which data are available), 56 percent of state mental health agency expenditures were used to support community-based services (as compared to 41 percent for state hospitals).<sup>3</sup>

Although this trend represents clear progress, the pace of the transition of both people and resources from institutions into the community is occurring more slowly than many people believe is appropriate. In addition, gaps in community-based service systems sometimes result in inadequate treatment and even “reinstitutionalization” of people with mental illnesses who could effectively be served in the community if the right services and supports were available. The reasons for this are many, including lack of coordination among federal and state agencies, failure to implement the most effective clinical and service delivery practices, and financing.

### **Lack of Coordination**

Perhaps the most difficult barrier to community integration for people with mental illnesses is a lack of coordination among the many community programs and services designed to meet their multiple and complex needs. People with mental illnesses require a broad range of housing, health and mental health care, and social services, all of which typically are administered by separate agencies and often are handled by different levels of government (federal, state, and local). The burden of coordination too often falls on the consumer, who may be overwhelmed by the complexity and competing demands of these disparate programs.

Service coordination is especially important in two key areas: (1) planning an individual’s transition from an institutional setting, such as a hospital or jail, into the community; and (2) providing effective treatment to people with mental illnesses and co-occurring substance

abuse disorders, medical needs, or developmental disabilities. Numerous studies indicate that people with mental illnesses who are most at risk of long-term institutionalization often have several co-occurring needs.<sup>4</sup> Yet coordination across these service systems is sometimes hindered not only by bureaucratic barriers, but also by differences in treatment philosophies, disparate funding streams, and “turf battles.”

## Outdated Service Delivery

The delivery of community-based mental health services has evolved significantly over the last 40 years. For example, while public mental health services were once provided principally in hospitals or community mental health centers, outreach is now considered to be a key element in a successful, integrated system of care for people with mental illnesses.

Despite a wealth of knowledge about “promising practices” in providing community-based services, many states do not implement some or all of these practices. The reasons for this vary from resource limitations to political concerns and stigma. However, there is little doubt that better dissemination of best practices, technical assistance, and flexible federal funding streams would greatly expand the number of people who have access to these effective programs. Several examples of these programs are identified later in this chapter.

## Financing

As previously noted, state governments historically have played the most significant role in providing services to people with mental illnesses. More than two-thirds of the revenues controlled by state mental health agencies are state general fund or Medicaid dollars; approximately 25 percent of the revenues come from federal sources.<sup>5</sup>

Although state mental health agency expenditures increased by 33 percent during the 1990s, when adjusted for inflation, these expenditures actually decreased by about 7 percent.<sup>6</sup> In addition, mental health spending has declined as a percentage of state budgets and as compared to other state spending on health, welfare, and corrections.<sup>7</sup>

In developing community-based alternatives to institutional care, states must piece together financing from dozens of disparate and uncoordinated funding streams. Many of these programs are categorical and

include restrictions on the blending of funds, further complicating the need to develop comprehensive, flexible service delivery systems that can be tailored to meet the individualized and varied needs of people with mental illnesses. In addition, many funding options favor institution-based services, creating an additional barrier to the delivery of services in community settings.

**IMD Exclusion.** Current Medicaid policy bars from coverage all services provided to adults ages 22 to 64 in an Institution for Mental Disease (IMD), which includes psychiatric hospitals and community-based residential facilities of 16 or more beds. Many state-level policy makers and some advocates, as well, believe that this policy (the “IMD Exclusion”) isolates individuals with mental illnesses from all other Medicaid-eligible populations in its refusal to pay for medically necessary inpatient services. They feel the policy stems from the outdated belief that states, rather than the federal government, should retain principal responsibility for the care of people with mental illnesses, and they have urged its repeal.

On its face, the IMD Exclusion provides a disincentive to institutionalization, and some advocates and providers believe that it may encourage the development of community-based alternatives. In fact, they fear that repeal of the IMD Exclusion will result in more money for institutional care at the expense of developing community-based services. However, others point out that the policy is blatantly discriminatory and has resulted in the loss of millions of federal dollars that could be used to supplement state resources and strengthen the delivery of public mental health services across the continuum of care.

**Home- and Community-Based Waivers.** Those who urge repeal of the IMD Exclusion do so, in large part, because they believe it is a principal barrier to states receiving home- and community-based (HCB) waivers to provide community-based services to people with mental illnesses under Medicaid.

Under Section 1915c of the Social Security Act, the federal government has the authority to permit states to waive certain requirements of the Medicaid program in order to provide services in home- and community-based settings, rather than in institutions. The waiver program is popular among states because it provides critical flexibility to: (1) cover a broad range of services and innovative delivery systems; (2) tailor services to meet the unique needs of a particular population; and (3) limit the number of people eligible to receive services under the waiver (thereby ensuring that new pro-

gram costs will not exceed a state's available resources). Every state but one has at least one waiver to provide home- and community-based services tailored for a particular population of Medicaid recipients.

HCB waivers have become a critical component of many state strategies to reduce reliance on inpatient services in favor of effective, accessible home- and community-based care. For example, the waiver program is the most important source of financing for community services for people with developmental disabilities and is often credited with facilitating the successful (and ongoing) transition of this population from state-run institutions into home- and community-based settings.

HCB waivers generally are not available, however, to support community-based programs for people with mental illnesses. In order to receive a waiver from the federal Medicaid program, a state must demonstrate that its proposal to provide home- and community-based services is "cost neutral" to Medicaid—that is, that the costs of providing home- and community-based services under the waiver will be offset by savings to the Medicaid program resulting from decreased inpatient use. Because the IMD Exclusion bars Medicaid reimbursement for services provided in psychiatric hospitals, there is no cost offset to justify an HCB waiver.

Though the IMD Exclusion does not apply to children, and most states have chosen to cover individuals over age 64 in an IMD, only four states have implemented home- and community-based waivers for these groups—three states have them for children and one has a waiver for adults. Opponents of repealing the IMD Exclusion believe there is little evidence to indicate states will request waivers for other IMD residents if the exclusion is repealed. Groups on both sides of this issue agree, however, that federal resources for providing community-based services to people with mental illnesses lag far behind the resources available for people with other chronic and persistent health needs.

**Other Medicaid Issues.** Despite the barriers described above, Medicaid provides important support for community-based services for people with mental illnesses. Most states exercise one or more options under Medicaid to expand the range of Medicaid services to include psychiatric rehabilitation, targeted case management, and intensive case management services. The Medicaid Rehabilitation Option generally is consid-

ered the most comprehensive and flexible of these options.

The range of services covered under the Medicaid Rehabilitation Option varies significantly from state to state. In some cases, this may reflect legitimate differences in the needs of priority populations. In other cases, however, the disparities may be due to: (1) a lack of information or technical assistance to states about permissible services under the Rehabilitation Option; (2) conflicting guidance from the regional offices of the federal agency administering the Medicaid program; or (3) lack of resources and political will at the federal and state levels.

These disparities are exacerbated by a lack of clarity in federal law regarding permissible services under the Rehabilitation Option. Confusion over what services can be provided undermines accountability for decisions by state and federal policy makers and contributes to gaps in community-based service delivery systems.

***Most states exercise one or more options under Medicaid to expand the range of Medicaid services.***

**Medicare.** Many people with serious mental illnesses are recipients of the Social Security Disability Insurance (SSDI) program. As a result, they are entitled to receive benefits under Medicare. Older adults (over 65) with mental illnesses also are likely to rely on Medicare for their health care, including mental health services.

There is widespread agreement among mental health advocates that the Medicare program discriminates against people with mental illnesses by requiring higher co-payments for mental health services than for other health services and by imposing more restrictive limitations on the number of mental health interventions that may be reimbursed. In addition, an "institutional bias" inherent in the Medicare program encourages the use of inpatient services and creates barriers to the delivery of community-based services that may be needed to prevent future hospitalization.

For people with mental illnesses, these barriers may mean the difference between recovery in the community and the need for frequent hospital readmissions. These barriers include:

- *A prescription drug policy that reimburses Medicare recipients for prescription drug services provided in inpatient hospitals but not for prescription drugs they administer themselves at home or in non-medical community settings. Access to appropriate medication is*



a critical component of almost every comprehensive, effective community-based program for people with mental illnesses.

- *Requirements that physicians be involved in the delivery of Medicare-reimbursable services.* Many clinical services necessary to promote recovery in the community for Medicare recipients may not require the presence of a physician, and compliance with this requirement may impose a significant barrier on the ability of local providers to deliver services, especially in rural areas.
- *The use of Medicare Fiscal Intermediaries who lack specific training in mental health service delivery.* Many Fiscal Intermediaries are unfamiliar with the specific needs of people with mental illnesses; the range of effective community-based treatment approaches, the relationships among providers offering a continuum of care for people with mental illnesses; and best practices regarding treatment, medication management, and discharge planning.

**Managed Care.** As previously discussed, many private health insurance companies and states have turned to managed care to help control costs and better coordinate services and supports for people with chronic needs. Whether or not managed care has accomplished those goals is a matter of great controversy.

Of even greater concern, however, is whether the pursuit of these goals has resulted in lower quality of care and decreased access to services. In theory and practice, managed care has the potential to impose significant barriers to effective treatment for people with mental illnesses. These barriers may include:

- Financial incentives for lack of treatment, particularly for those with potentially difficult-to-treat, comorbid conditions. These incentives may include bonus payments to doctors who successfully limit access to specialists or services.
- Better reimbursement for services provided in hospitals or residential facilities than in non-institutional care.
- Better reimbursement for medication and other “medical” treatment than for psychotherapy or other non-medical interventions.
- Restrictive formularies for prescription drugs.

Public managed care plans may impose other barriers on the effective delivery of services to people with mental illnesses, such as eligibility or enrollment procedures that terminate services for people who miss appointments or otherwise fail to comply with a treat-

ment plan. Because people with mental illnesses may, for a range of reasons, be unable or unwilling to comply with a treatment plan prescribed by their physician, these discriminatory procedures undermine their ability to access effective services.

## Strategies to Facilitate Community Integration

Each of the issues discussed above creates a barrier to recovery for consumers who rely on the public mental health system for the services and supports they need to live fulfilling lives in the community. Strategies to overcome these barriers should involve consumers at every stage to ensure that solutions integrate system-level policy issues with individual needs and concerns.

### Coordinate Services across Agencies and at Every Level of Government

Although maintaining the public mental health system remains principally a state function, it is critical to develop a comprehensive, coordinated mental health strategy at the federal level. Agencies responsible for providing health care, housing, education, employment, and income support—and advocates who have built relationships with those agencies—must work together to ensure that all federal programs affecting people with mental illnesses support the following principles: (1) people with mental illnesses can and do recover; and (2) to further the goal of recovery, programs that impact people with mental illnesses should encourage the delivery of services in the most integrated setting appropriate for an individual’s needs.

At the state level, agencies responsible for providing services and supports affecting people with mental illnesses should develop plans to coordinate services and, where necessary, integrate funding streams to provide flexible support for needed services. The goal of these activities should be to ensure that the needs of each individual are met through the development and implementation of an individualized, comprehensive treatment plan.

As previously noted, service coordination is critical in a few key areas. In these circumstances, coordination must occur both at the policy level and in practice. For example, in planning an individual’s transition from an institutional setting, such as a hospital or jail, into the community, it is essential that federal and state programs supporting mental health services and social

services be flexible enough to meet the diverse needs of each individual. Housing, income support, employment services, peer support, and medical services all must be available immediately and be integrated in a way that ensures a comprehensive safety net for the individual entering the community.

The issue of coordination is also essential to providing effective treatment to people with mental illnesses and co-occurring substance abuse disorders, medical needs, or developmental disabilities. Coordination will be enhanced by the development of flexible funding streams and implementation of promising practices at the state and provider levels.

### **Promote Evidence-Based Service Delivery and Promising Practices**

National and state coalition members can play an active role in identifying technical assistance opportunities to facilitate the adoption of promising practices and effective, evidence-based service delivery. Technical assistance should address not only the mechanics of program development but the political and policy context in which the program will operate, barriers to implementation, and strategies for securing needed resources.

Some promising practices will be new, innovative approaches to providing services and will need to be evaluated. However, several approaches to service delivery already are supported by a considerable body of scientific research and other evidence of effectiveness, but still have not been implemented in all states or to their full potential. A few of these approaches are described below.

- **Consumer and Peer-Support Services.** Much of what the mental health community has learned comes from the experience and expertise of consumers and others who have first-hand experience with the mental health system. Both public and private mental health systems should support a broad range of consumer and peer-support services, which have been proven effective and often can be provided at lower cost than more expensive, “professional” care.<sup>8</sup>
- **Assertive Community Treatment (ACT).** Assertive community treatment (ACT) is an intensive approach to providing a comprehensive array

of services to people with serious mental illnesses who are living at home or in community settings or, frequently, who are homeless. Studies have shown ACT and similar models of intensive case management to be effective in reducing inpatient use and promoting continuity of outpatient care.<sup>9</sup>

*Coordination  
will be enhanced by  
flexible funding and  
implementation of best  
practices.*

- **Integrated Treatment for People with Co-occurring Mental Health and Substance Abuse Disorders.** At any given time, as many as 10 million Americans have co-occurring mental and addictive disorders.<sup>10</sup> Among individuals with serious mental illnesses, about half will have a co-occurring substance abuse disorder at some point during their lifetime.<sup>11</sup>

Despite a significant base of scientific evidence demonstrating that integrated treatment is most effective for people with the most severe mental health and substance abuse disorders, federal agencies funding community-based programs pose barriers to the use of federal dollars for integrated services. In addition, states are hindered by “turf battles” between mental health and substance abuse agencies, and advocates for consumers of one service often stigmatize consumers of the other. Advocates should work together to overcome these barriers to ensure implementation of programs that have been proven to be most effective for consumers.

- **Understanding Trauma.** Study findings clearly demonstrate that adults in psychiatric hospitals have experienced high rates of physical and/or sexual abuse. Effective community treatment for these individuals should be based on concepts, policies, and procedures that recognize and respond to the unique needs of this population.
- **Managed Care Design.** Many states continue to struggle with identifying an appropriate role for managed care in controlling mental health costs without jeopardizing quality. While no managed care model can be considered the ideal in all circumstances, a large body of research provides guidance in understanding the implications of different contracting and service delivery choices (e.g., mental health “carve-outs,” provider incentives, etc.). States and advocacy groups should be well-versed in understanding these options and advocating effectively with state legislatures and Medicaid agencies.

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## Advocate for Additional Resources for Community-Based Services

The institutional bias inherent in many health insurance plans—including Medicare, Medicaid, and other public health programs—contributes to the chronic underfunding that characterizes the public mental health system in many states. Members of the National coalitions and others concerned about mental health services can work together to advocate for additional resources for non-institutional, community-based care.

At the federal level, advocacy efforts should focus on increasing access to federal health programs, especially Medicaid’s home- and community-based waiver program and Medicare prescription drugs. Advocates also should work together to expand the Community Mental Health Services Performance Partnership Block

Grant and to ensure that these funds are able to be used flexibly and creatively to meet the diverse needs of people with mental illnesses. Mental health advocates should also join forces with advocates for other social services programs that support people with mental illnesses, including Supplemental Security Income (SSI) and the Title XX Social Services Block Grant.

At the state level, mental health advocates should join forces with other interest groups and agencies to broaden the constituency calling for increased state mental health funding. For example, mental health and criminal justice advocates should work together to divert dollars currently being spent on people with mental illnesses in courts, jails, and prisons into evidence-based, community programs that help prevent further contact with the criminal justice system.

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## Endnotes

<sup>1</sup>Children’s Health Act of 2000, signed into law on October 17, 2000 (P.L. 106-310). The new law permits PAIMI to serve this new population only when the total PAIMI appropriation in that year is \$30 million or more. Section 3206(d). The law further provides that PAIMI agencies must continue to give priority to serving people with mental illnesses who are in institutions or were recently discharged.

<sup>2</sup>*Funding Sources and Expenditure of State Mental Health Agencies: Fiscal Year 1997*, published by the NASMHPD Research Institute under contract with the Center for Mental Health Services (1999).

<sup>3</sup>Ibid.

<sup>4</sup>See, e.g., William H. Fisher, Ph.D. et al., “Long-Stay State Hospital Patients at the End of the Twentieth Century: A Massachusetts Study” (submitted for publication).

<sup>5</sup>*Funding Sources and Expenditure of State Mental Health Agencies: Fiscal Year 1997*, published by the NASMHPD Research Institute under contract with the Center for Mental Health Services (1999).

<sup>6</sup>Ibid.

<sup>7</sup>Ibid.

<sup>8</sup>*Mental Health: A Report of the Surgeon General*, U.S. Department of Health and Human Services, Washington, DC (1999).

<sup>9</sup>Ibid.

<sup>10</sup>SAMHSA National Advisory Council. *Improving Services for Individuals at Risk of, or with, Co-Occurring Substance-Related and Mental Health Disorders*. Rockville, MD: Substance Abuse and Mental Health Services Administration, 1997.

<sup>11</sup>*Mental Health: A Report of the Surgeon General*, U.S. Department of Health and Human Services, Washington, DC (1999).



## Primary Health Care

Elizabeth Priaulx, J.D.

*Note: Appendix A includes a brief summary of the Medicaid program (including CHIP, EPSDT, home- and community-based waivers, and Medicaid Buy-In) and the Medicare program. This material is designed to be used as a reference while reading the balance of this section.*

### Overview

The primary vehicle for people to receive community services and supports in this country is through the health care system. As a result, compliance with *Olmstead*, which requires provision of community-based services, will be heavily influenced by the structure of a state's health care delivery program. An essential part of *Olmstead* planning will require states to correct inadequacies within the health care system that may restrict or limit access to quality community-based services and supports.

The role of the primary care system to diagnose and treat mental health needs cannot be understated. A recent study by the National Mental Health Association found that nearly 74 percent of Americans who seek help for depression or symptoms of depression will go to a primary care physician rather than a mental health professional.<sup>1</sup> A second reason the primary health care system must be equipped to diagnose and treat individuals with mental health needs is because of the high percentage of individuals with both a mental illness and a co-occurring acute disability. In fact, the rate of depression among those with medical illnesses in primary care settings is estimated at 5 percent to 10 percent.<sup>2</sup> Among those hospitalized, the rate is estimated at 10 percent to 14 percent.

A National Mental Health Association report explains why mental illness and other acute illnesses often occur together, including the fact that: 1) medical disorders may contribute biologically to depression; 2) medically ill people may become clinically depressed as

a psychological reaction to the prognosis, the pain and/or incapacity caused by the illness or its treatment; or 3) though occurring together, depression and a general medical disorder may be unrelated.<sup>3</sup>

### Barriers That Hinder Community-Based Care

#### Lack of Integration with Behavioral Health Care Services

As previously noted, people with serious mental illnesses often have significant co-morbid medical conditions. These include obesity, diabetes, and pulmonary and heart disease, among other chronic conditions. In addition, estimates suggest that up to 10 million people in this country have a combination of at least one co-occurring mental health and substance-related disorder in any given year.<sup>4</sup> Another study in 1990 found that more than half the patients admitted to general hospitals with a serious psychiatric illness have concurrent medical problems.<sup>5</sup> The overlap between their mental and physical health problems makes easily accessible, comprehensive health care a priority.

Unfortunately, the traditional U.S. health care system enforces a "wall of separation" between behavioral health and general health care. In the past decade, numerous studies have shown that this lack of integration is contradictory to quality of care, and that the most effective medical care treats the mind and body as inseparable.<sup>6</sup> This wall of separation can be seen in private insurance plans that often exclude mental health services from their standard health care package or charge higher premiums for mental health services than they do for other health services. It can also be seen in Medicare and Medicaid programs, which impose greater limitations on funding for mental health treatment.

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The trend toward separation continued in the 1990s as states rushed to enact mandatory Medicaid managed care plans. Many states initiated separate carve-out programs for mental health services or required people with mental health needs to use a fee-for-service model, while those with general health care needs used a managed care model. While the goal of these approaches to managed care is to enhance the quality and availability of behavioral health care services, they may also have the unintended consequence of contributing to the lack of integration between primary and behavioral health care.

A 1999 Report on Mental Health by the U.S. Surgeon General found that lack of integration between the general health and behavioral health care systems results in numerous impediments to quality services and supports, including the following:

- *“Continued stigma to seeking treatment because it is seen as outside the purview of general health services.”* Stigma continues to be a huge barrier to ensuring adequate mental health care. A recent survey regarding the causes of mental illness published by the National Mental Health Association illustrates the breadth of stigma that exists today. The survey found that: 71 percent believed that mental illness is caused by emotional weakness; 65 percent believed that mental illness is caused by bad parenting; 35 percent believed that mental illness is caused by sinful or immoral behavior, and 43 percent believed that mental illness is brought on in some way by the individual.<sup>7</sup>

Stigma can have a detrimental impact on an individual’s ability to access treatment, for several reasons. First, people may not seek treatment because they fear the label of mental illness will cause them harm. In addition, insurance companies might try to argue that mental health is a personal problem and not a medical problem, and, as a result, decline payment for mental health services that are not considered to be “medically necessary.”

- *“General practitioner’s training does not properly emphasize skills required to differentiate accurately the causes of cognitive, emotional, and behavioral symptoms that may, in some instances, rise to the level of mental disorders and in other instances be expressions of unmet general medical needs.”* This is particularly troubling in a managed care environment where primary care

providers, who lack the training to identify mental health needs, are in control of referrals to other doctors, including mental health providers.

- *“Providers are unaware of the most recent research or most beneficial treatment for mental illnesses.”* A person with mental health needs can be at serious risk for inadequate care if the primary care provider lacks training in, for example, the potential side-effects of certain psychiatric medication or the possible negative interactions between a psychiatric drug and another course of treatment, or if proper medication management and follow-up is not provided.

**The  
lack of appropriate  
community-based  
long-term care services is  
a barrier to Olmstead  
compliance.**

### **A Focus on Acute Rather Than Long-Term Care**

The primary care system is biased in favor of acute care and disfavors long-term care. As a result, most Americans with mental health needs must impoverish themselves paying for this care. A report by the National Council on Disability found that:

Americans with disabilities find that the acute care orientation of the health care system fosters deterioration of health until serious medical services are required. Preventive services directed at maintaining health are typically not covered by private or public insurance, even though lack of these services may cause eroding health and secondary disability in some.<sup>8</sup>

The lack of appropriate community-based, long-term care services is a barrier to *Olmstead* compliance because it often means that individuals must go to psychiatric hospitals to receive treatment. The lack of service can result from either lack of any services (e.g., long waiting lists for free or reduced-price services, clinics that are not conveniently located or that have limited hours for walk-in services, and difficulty scheduling and maintaining appointments), or from a lack of choice of services (i.e., a range of services, designed to meet the specific needs of an individual in a community setting.)

Medicaid is the largest public source of funding for long-term care in the U.S. Medicaid favors payment for long-term care in the most acute and expensive setting—the nursing home. This focus has resulted in inadequate funding of long-term care in other community settings. The fact that the long-term care delivery system is different for different types of disability com-

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pounds the problem, according to a white paper by the National Academy of Elder Law Attorneys.

Parallel long-term care delivery systems serve people with a diagnosis or history of mental illness, people with developmental disabilities, people with physical disabilities, the elderly, people with AIDS, etc. These divisions have pitted groups against each other to compete for dollars and have led to indefensible inequities and significant economic inefficiencies in the delivery of long-term care.<sup>9</sup>

### **An Emphasis on Institutional and Group Care**

The public health care system traditionally favors institution-based care, provided in groups, over individualized, community-based care. Though this is beginning to change, delivering individualized, flexible services is still quite a challenge because even most community-based services are underfunded, provide services in groups, and have limited service options.

In 1955, about three-fourths of individuals receiving care for mental illness by a specialty provider would have been hospitalized overnight, typically in a state or county medical hospital.<sup>10</sup> In the 1960s and 1970s, states dramatically reduced the inpatient populations of their psychiatric institutions, and many of the older residents were institutionalized into nursing homes.<sup>11</sup>

This historically heavy reliance on institutional-based services has been shifting over the past few decades, so that the majority of mental health services today are provided on an out-patient basis. However, the roots of institutional bias still exist in the system of financing mental health treatment. In fact, mental disorders remain the leading risk factor for institutionalization.<sup>12</sup> The 1999 Report of the Surgeon General on mental health finds that two-thirds of older adults living in nursing homes have some kind of mental disorder. Yet, despite these large numbers, nursing facilities are generally ill-equipped to provide mental health services and supports, in large part because the Medicaid IMD (Institution for Mental Diseases) exclusion discourages nursing facilities from providing mental health services.

Risk of institutionalization is not just a problem for older adults. The Bazelon Center for mental health Law exposed this as a chronic problem in a March 2000 report detailing how Medicaid policies sometimes result in families having no other option than to relinquish custody of their children to the state in order to receive appropriate mental health services.<sup>13</sup> This often means that children are placed outside of the home in therapeutic group homes and other institutional settings.

### **Lack of Adequate Health Insurance**

A high percentage of individuals do not have adequate private or public insurance to cover mental health treatment and services. A lack of adequate health insurance is often cited as a primary barrier that prevents individuals from living in the community and succeeding in employment. Lack of insurance also contributes to unnecessary institutionalization because uninsured individuals do not seek mental health care until their mental status has deteriorated to the point that they qualify for emergency/crisis services for stabilization, which usually are offered only in an institutional setting.

## **Strategies to Promote Community-Based Care**

### **Integrate Primary and Behavioral Health Care**

**Place Mental Illness Treatment in the Mainstream of Healthcare Services.** This could be accomplished by requiring training in identifying and treating mental illnesses as a core requirement of all education programs for primary care providers, including internists, family practitioners, pediatricians, physician assistants, and nurse practitioners. Another method is for Medicaid and Medicare to offer incentives to managed care organizations to allow people with a diagnosis or history of mental illness to have a mental health specialist as their primary care provider.

**Promote Full Parity for Mental Health and Substance Abuse Services.** This will also help to bring mental health care into the fold of general health care. The 1996 Mental Health Parity Act, provided that a group health plan or insurance offered in connection with a plan that provided both medical/surgical benefits and mental health benefits could not impose an aggregate lifetime dollar limit or annual dollar limit on mental health benefits that is less than such a limit on medical/surgical benefits.

Proposed legislation being considered by Congress would further prohibit health insurance plans from imposing differential inpatient-hospital day and out-patient-visit limits or applying different deductibles, co-payments, out-of-network charges, and other financial requirements for mental health and substance abuse treatment than for other health services. Its provisions apply to individuals diagnosed with any mental illness or substance abuse disorder. The bill applies only to plans that provide mental health benefits; it would not require plans to offer such benefits.

A 1998 federal report estimates that providing full parity for mental health and substance abuse services increases premiums by 3.6 percent, on average.<sup>14</sup> Cost increases are lowest in systems with tightly managed care and generous baseline benefits. The report also concluded that employers have not attempted to avoid parity laws by becoming self-insured, and they do not tend to pass the costs of parity to employees.

## Ensure the Provision of Long-Term Care

**Expand the “Partnership for Long-Term Care Model.”** For individuals with a diagnosis or history of mental illness who have private insurance, the “Partnership for Long-Term Care Model” (initiated in several states by the Robert Wood Johnson Foundation) could be expanded. This model involves an alliance between state governments and private insurers to offer long-term care insurance that is affordable to people with disabilities. Consumers who purchase policies that meet state certification standards can become eligible for Medicaid long-term care services after their private insurance is exhausted, without spending down all of their assets as is typically required to meet Medicaid eligibility criteria.

**Provide Increased Access to Long-Term Care through Medicaid.** The Medicaid program could be reformed to provide increased access to long-term care in the community. The Bazelon Center for Mental Health Law has identified various ways that adequate, comprehensive, community mental health services can be provided under the standard state Medicaid plan.<sup>15</sup> These include:

- Enforcing a broad definition of the Medicaid option for “other diagnostic, screening, preventative and rehabilitative services.” This option could be interpreted to cover a wide array of individualized psychiatric and rehabilitative supports in the community.
- Allowing for case management services that are specifically targeted to individuals with a diagnosis or history of mental illness, including such person-centered strategies as assertive community treatment (ACT).

## Fund and Provide Community-Based Care

**Facilitate Modification of State Medicaid Plans to Allow for Assertive Community Treatment (ACT).** This is consistent with a June 7, 1999, letter to state Medicaid directors from the Center for Medicare and Medicaid Services (CMS) stating that, “Programs based on ACT principles can be supported under existing Medicaid policies, and a number of states currently include ACT services as a component of their mental health service package.”

Programs based on ACT principles employ interdisciplinary treatment teams, shared caseloads, 24-hour mobile crisis teams, assertive outreach for treatment in clients’ own environments, individualized treatment, medication, rehabilitation, and supportive services.

Assertive case management programs which incorporate shared caseloads also provide this array of individualized, community-based services.

*Full  
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health and substance  
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**Pass the Medicaid Intensive Community Mental Health Treatment Act.** Introduced October 26, 2000, this bill would create a new Medicaid option for states to finance an array of intensive, community-based services for adults with severe and persistent mental illnesses, and children with serious mental and emotional disturbances. This Medicaid option would target the following specific populations: individuals who have had repeated psychiatric hospitalizations; people who have been repeatedly arrested for minor offenses; and children and adults who have had poor outcomes in less intensive mental health services.

**Fully Implement Medicaid EPSDT Requirements.** Medicaid is an enormously important funding source for mental health services for children. Children with mental illness who are eligible for Medicaid are entitled to receive Early and Periodic Screening to identify mental health needs, Diagnostics of any needs suspected by the screen, and all appropriate medically necessary services (covered under federal Medicaid law) to Treat (“correct or ameliorate”) these mental health needs (see Appendix A).

According to a report by the Bazelon Center:<sup>16</sup>

Many children are denied access to EPSDT services because of a failure to properly screen all eligible children. Inadequate screening often means a condition is

not diagnosed and any entitlement to services is lost. Also, the Federal definitions of services covered under Medicaid are worded poorly, often allowing a State to claim that a service is not covered when in fact it should be, or a provider to not offer a service for fear it is not covered. The definitions are also limiting because they are limited to medical services.

**Examine the Role of Medicaid in the Care of Older Adults.** The *Olmstead* decision is important to older adults with psychiatric disabilities for whom an institutional placement would be inappropriate. The AARP Public Policy Institute advises advocates to examine the state's Medicaid program design as it applies to older beneficiaries. In particular, the group recommends asking the following questions:<sup>17</sup>

- Does the state's Medicaid home and community waiver program reach older individuals as well as children and young adults?
- Does the state Medicaid plan (or the home and community waiver program) provide coverage for the types and range of services identified by experts as important to the successful community integration of older persons with disabilities?
- How aggressively does the state screen nursing home and other institutional residents to determine the appropriateness of their placements? [See the paragraph on PAS/RR that follows.]
- In the case of older persons with disabilities who are without access to satisfactory informal caregiver arrangements, what resources are available in addition to their own income (e.g., SSI or Social Security benefits) to help meet the cost of community housing, particularly assisted living arrangements?
- Are older consumers represented in the planning process? Does the process include persons who are knowledgeable about the design of community-based programs and services for older persons with disabilities?

**Fully Comply with PAS/RR.** PAS/RR—pre-admission screening and resident review requirements—was designed to prevent inappropriate placement of people with mental disabilities in Medicaid-certified nursing facilities, pursuant to Title 19 of the Omnibus Budget Reconciliation Act of 1987, also known as the Nursing Home Reform Act. It requires states to conduct pre-admission screening and resident reviews of all nursing home applicants and residents suspected of having serious mental illness (excluding dementia), mental retardation, or a related disorder.<sup>18</sup> PAS/RR also requires

that individuals with disabilities are provided with specialized services while confined in nursing facilities.

**Advocate for Medicare Home Health Benefits for Adult Day Care.** A major barrier to Medicare funding of community-based care is the Medicare "Homebound Care Rule." In order to receive Medicare home health benefits, a beneficiary must need skilled nursing care on a part-time or intermittent basis, physical therapy, speech-language pathology, or continued occupational therapy. The services must be ordered by a physician and provided by a licensed home health agency pursuant to a plan of care ordered and reviewed periodically by the physician. Finally, the beneficiary must be confined to the home. In adding the last eligibility criterion, Congress did not intend to prohibit or prevent a beneficiary from ever leaving home, nor did it intend to require that the beneficiary be totally bedridden.

CMS narrowly interprets the "homebound" criterion. For example, CMS has taken the position that adult day care programs are not considered medical treatment under Medicare law, despite the fact that some advocates have successfully argued that the psychosocial benefits achieved from attending an adult day care program are medical treatment. This is an important distinction because a person who leaves the home to get medical treatment is still considered homebound and, therefore, eligible for services.

**Expand Funding for Crisis and Emergency Community-Based Services.** The typical community mental health centers are not designed for emergency services, and individuals in crisis are sent to hospitals for treatment.

## Expand Health Insurance Coverage

**Expand the CHIP Program to Include More Children with Mental Health Needs.** The State Children's Health Insurance Program (CHIP) provides federal funding to states to provide child health insurance to low-income children who are not eligible for any other health insurance program (see Appendix A). The program is aimed specifically at those children with family incomes too high to qualify for Medicaid but too low to pay for private insurance.

**Adopt the Medicaid Buy-In Program.** The buy-in program allows states flexibility to provide Medicaid coverage to people with disabilities who, because of relatively high earnings, cannot qualify for Medicaid under another provision (see Appendix A). A common structure for such a program allows an individual or



family to pay monthly premiums to the state in an amount equal to the difference between family income (reduced by unpaid expenses, if any, incurred for medical care in previous months) and the Medicaid income eligibility standard.

As this document is written, approximately 10 states had adopted and were implementing buy-in programs. An additional 25 or more states were at various stages of pre-implementation (including several that had been adopted and were awaiting federal approval, and several pending in state legislatures).<sup>19</sup>

In 1999, CMS funded a one-year grant to four protection and advocacy agencies to promote enrollment of people with disabilities and senior citizens in the Medicaid Buy-In program and to work with the state to identify and fix barriers to enrollment. Programs like this could be replicated in all states.

#### **Include a Medicare Prescription Drug Benefit.**

Low-income Medicare beneficiaries cannot afford high

deductibles and other out-of-pocket costs. For many low-income beneficiaries, imposition of an additional deductible would preclude them from ever using a drug benefit.

The Center for Medicare Advocacy's Healthcare Rights Project recommends that a prescription drug benefit be based on the following five principles.<sup>20</sup> 1) Prescription drug coverage should be universal for all Medicare beneficiaries and should work the same for all beneficiaries. 2) Prescription drug coverage should be included in Part B of Medicare. 3) The deductible for prescription drug coverage should be combined with the Part B deductible. 4) Beneficiary co-payments should be affordable and should be a flat amount per prescription. Alternatively, co-payments should be capped. 5) Consistent with other Part B services, the prescription drug benefit should be designed without a cap. Alternatively, a cap on the benefit should be set very high.

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## Endnotes

<sup>1</sup>*Mental Health Facts*, on the National Mental Health Association Web page, November 2000.

<sup>2</sup>*Co-Occurrence of Depression with Medical, Psychiatric, and Substance Abuse Disorders*, by the National Mental Health Association. Fact Sheet 2000.

<sup>3</sup>*Ibid.*

<sup>4</sup>Substance Abuse and Mental Health Services Administration (SAMHSA) National Advisory Council. *Improving Services for Individuals at Risk of, or with, Co-occurring Substance-Related and Mental Health Disorders*. Rockville, MD: SAMHSA, 1997.

<sup>5</sup>*Modern Healthcare*, April 23, 1990, p. 28.

<sup>6</sup>*Mental Health: A Report of the Surgeon General*, U.S. Department of Health and Human Services (1999).

<sup>7</sup>Survey results published on the "Mental Health Facts" section of the National Mental Health Association Web site in November 2000.

<sup>8</sup>*Sharing The Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-related Services*, A Report to the President and the Congress of the United States, March 4, 1993, National Council on Disability.

<sup>9</sup>*White Paper on Reforming the Delivery, Accessibility, and Financing of Long-term Care in the United States*, by the National Academy of Elder Law Attorneys (Fall 2000).

<sup>10</sup>(Witkin et al. 1998) As cited in *Mental Health: A Report of the Surgeon General*, DHHS, (1999).

<sup>11</sup>*Ibid.*

<sup>12</sup>(Katz & Parmelee 1997) as cited in *Mental Health: A Report of the Surgeon General*, DHHS (1999).

<sup>13</sup>*Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs*, by Mary Giliberti and Rhoda Schulzinger.

<sup>14</sup>Sing, M. et al. *The Costs and Effects of Parity for Mental Health and Substance Abuse Insurance Benefits*. Rockville, MD: Substance Abuse and Mental Health Services Administration, 1998.

<sup>15</sup>*Under Court Order*, Bazelon Center for Mental Health Law, October 1999.

<sup>16</sup>*Ibid.*

<sup>17</sup>Rosenbaum, S. *Olmstead v. L.C.: Implications for Older Persons with Mental and Physical Disabilities*. Washington, DC: AARP Public Policy Institute Issue Paper #21, November 2000.

<sup>18</sup>Omnibus Budget Reconciliation Act of 1987, 42 U.S.C. Section 1395i-3(a)(Medicare) and Section 1396(a)-h (Medicaid).

<sup>19</sup>*Making Medicaid Work to Finance Assistive Technology*, Neighborhood Legal Services, (October 2000).

<sup>20</sup>The following principles are taken from *Medicare Prescription Drug Coverage*, by Vicki Gottlich of the Center for Medicare Advocacy's Healthcare Rights Project.



## Primary Health Care Public Funding Sources

### Medicaid

Medicaid, also known as Medical Assistance, is a cooperative federal-state program authorized by Title XIX of the Social Security Act. 42 U.S.C. §§ 1396 *et seq.* It is designed to serve people with limited income and resources. Administration of the Medicaid program occurs at the state level, with the state Medicaid agency often delegating decision-making to other state agencies, to local Medicaid units, or to health maintenance organizations.

Within broad national guidelines which the federal government provides, each of the states: 1) establishes its own eligibility standards; 2) determines the type, amount, duration, and scope of services; 3) sets the rate of payment for services; and 4) administers its own program. Thus, the Medicaid program varies considerably from state to state, as well as within each state over time.

Medicaid is often the only health insurance plan for people with disabilities who have limited income, and it is the largest public source of funding for long-term care in the U.S.<sup>1</sup> Medicaid spending for long-term care has more than doubled from 1987-1997. According to the Center for Medicare and Medicaid Services (CMS), formerly the Health Care Financing Administration (HCFA), 5 percent of the Medicaid budget is spent on home-based care.<sup>2</sup>

### Eligibility

There are three main categories of individual who can qualify for Medicaid.

**1) Mandatory Needy.** Some examples are Supplemental Security Income (SSI) recipients (in 30 states); children under age six; certain Medicare beneficiaries; and special protected groups who may keep Medicaid for a period of time. Examples are people who lose SSI payments due to earnings from work or increased Social Security benefits.

**2) Categorically Needy.** These optional groups share characteristics of the mandatory groups, but the eligibility criteria are somewhat more liberally defined. Examples of the optional groups that states may cover as categorically needy are targeted low-income chil-

dren; certain aged, blind, or disabled adults who have incomes above those requiring mandatory coverage, but below the federal poverty level; institutionalized individuals with income and resources below specified limits; and people who would be eligible if institutionalized but are receiving care under home- and community-based waivers.

**3) Medically Needy.** An optional program that allows states to extend Medicaid eligibility to additional qualified people who may have too much income to qualify under the mandatory or optional categorically needy groups. This option allows individuals to “spend down” to Medicaid eligibility by incurring medical and/or remedial care expenses to offset their excess income, thereby reducing it to a level below the maximum allowed by that state’s Medicaid plan.

### Services Covered

Although participation in Medicaid is voluntary, once a state chooses to participate (and all states do), it must comply with federal requirements. A state must offer an extensive list of “required services” and may also choose to cover any number of “optional services.” States have great leeway on what categories of service to cover.

**Required Services.** Certain basic services must be offered to the mandatory and categorically needy population in any state Medicaid program, including, among others: inpatient hospital services; outpatient hospital services; nursing facility services for individuals aged 21 or older; home health care for people eligible for nursing facility services; rural health clinic services; and federally qualified health center services.

Another required Medicaid service to all Medicaid-eligible individuals under 21 years old is EPSDT. This program entitles children and adolescents to Early and Periodic Screening to identify mental health needs, Diagnosis of any needs suspected by the screen, and all appropriate medically necessary services (covered under federal Medicaid law) to Treat (“correct or ameliorate”) these mental health needs. This EPSDT entitlement covers many of the services that are vital for children in need of individualized, wrap-around supports, including outpatient rehabilitation services, targeted case manage-

ment and service coordination, any state home- and community-based waiver service, crisis services, prescription drugs, and services of licensed professionals.

If a state chooses to include the medically needy population, the state plan must provide, at a minimum, home health services to individuals entitled to nursing facility services. States may also receive federal funding if they elect to provide other optional services, including, among others, clinic services, rehabilitation services, and prescription drugs.

**Optional Services.** States may also receive federal funding if they elect to provide other optional services. The most commonly covered optional services under the Medicaid program include clinic services; nursing facility services for individuals under age 21; intermediate care facility/mental retardation services; optometrist services and eyeglasses; prescription drugs; tuberculosis (TB)-related services for people infected with TB; prosthetic devices; and dental services.

### **Children's Health Insurance Program (CHIP)**

Another optional program is the Children's Health Insurance Program (CHIP), enacted in the Balanced Budget Act of 1997 as Title XXI of the Social Security Act. CHIP provides federal funding to states to provide child health insurance to low-income children who are not eligible for any other health insurance program. Under CHIP, states have the option to expand their Medicaid program to cover children up to age 19 with family incomes below 200 percent of the federal poverty level, create a separate state program to do so, or use a combination of both approaches. Within broad federal guidelines, a state has considerable flexibility to design the CHIP benefit package, establish eligibility criteria, and implement administrative requirements.

### **Medicaid Home- and Community-Based Waivers**

A third important optional program is the Medicaid home-and community-based waiver program. Home-and community-based waiver provisions allow states, with approval of CMS, to waive specific requirements of the Medicaid Act 42 U.S.C. § 1396n(c) (often referenced as "section 1915c waivers"). All states participate in these optional waivers to varying degrees.

- *Waiver of Statewide-ness:* Ordinarily, the state's Medicaid plan must offer comparable coverage in all regions of a state. 42 U.S.C. § 1396a(a)(1). A waiver can be approved to offer a level of Medicaid cov-

erage in one or more sections of the state that is not available statewide.

- *Waiver of Comparability:* Ordinarily, the state's Medicaid plan must treat all similarly situated recipients equally. 42 U.S.C. § 1396a(a)(10)(B). A waiver could select a targeted group of recipients (such as people with traumatic brain injury) and offer them a scope of services not available to people who have different disabilities but similar needs.
- *Waiver of Certain Income and Resource Rules:* A waiver can be implemented that exempts certain populations from the general income and resource requirements. For example, the Katie Becket waiver allows a Medicaid program to disregard parental income and resources for certain children.

These waiver programs are structured to provide an alternative to institutional care and often provide greater access to personal assistance services, assistive technology, and rehabilitation therapies than is available under other covered services within the state plan. A number of other services may be available under each state's unique waiver program or programs, such as case management, homemaker services, home health aide services, adult day health, habilitation, respite, home modifications, partial hospitalization, and psychosocial rehabilitation for people with psychiatric diagnoses. Some of these are optional services that a state may not cover in its regular state plan. Others are services that are not otherwise available as either required or optional services.

### **The Medicaid Buy-In Program**

A fourth optional program is the "Medicaid Buy-in," created by the Balanced Budget Act amendments of 1997. It is designed to provide health insurance to working people with disabilities. The original 1997 buy-in program included several key eligibility components: 1) individuals are not required to have been on SSI; 2) eligibility was set at net income of less than 250 percent of the federal poverty level, with all SSI exclusions applied; 3) except for their earnings, the person with a disability would be eligible for SSI; 4) performance of substantial gainful activity (i.e., earnings in excess of \$740 monthly) is not an eligibility consideration; 5) states could increase the resource limits to as high as \$14,000; and 6) states could charge premiums or other cost-sharing charges.

Section 201 of the Ticket to Work and Work Incentives Improvement Act of 1999 included several key provi-

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sions to make the buy-in program more attractive: 1) it allows states to offer a buy-in to people with earnings greater than 250 percent of the poverty level; 2) states will be allowed to set income limits and require cost-sharing and premiums, based on income, on a sliding scale; 3) a state could require some individuals to pay the full premium as long as the premiums do not exceed 7.5 percent of the individual's total income; and 4) states must require a 100 percent premium payment for individuals with adjusted gross incomes greater than \$75,000 unless states choose to subsidize the premium using their own funds.

## Medicare

Medicare is the national health insurance program to which all Social Security recipients who are either over 65 years of age or permanently disabled are entitled. In addition, individuals receiving railroad retirement benefits and individuals suffering from end-stage renal disease are eligible to receive Medicare benefits.

Medicare is not a welfare program, and should not be confused with Medicaid. The income and assets of a Medicare beneficiary are not a consideration in deter-

mining eligibility or benefit payment. Medicare is a national program, and procedures should not vary significantly from state to state.

Coverage under Medicare is similar to that provided by private insurance companies: i.e., it pays a portion of the cost of medical care. Often, deductibles and co-insurance (partial payment of initial and subsequent costs) are required of the beneficiary.

Medicare has two substantive coverage components, Part A and Part B. Part A covers inpatient hospital care, hospice care, inpatient care in a skilled nursing facility, and home health care services. Part B covers medical care and services provided by doctors and other medical practitioners, home health care, durable medical equipment, and some outpatient care and home health services.

Part A of the program is financed largely through federal payroll taxes paid into Social Security by employers and employees. Part B is financed by monthly premiums paid by Medicare beneficiaries and by general revenues from the federal government. In addition, Medicare beneficiaries themselves share the cost of the program through co-payments and deductibles that are required.

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## Endnotes

<sup>1</sup>*White Paper on Reforming the Delivery, Accessibility, and Financing of Long-Term Care in the U.S.*, National Academy of Elder Law Attorneys, Fall 2000, p. 9.

<sup>2</sup>*Medicaid Recipients by Type of Service*, CMS, accessed by [www.hcfa.gov/Medicaid](http://www.hcfa.gov/Medicaid), March 2000.

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## **Authors and Reviewers**

**Carol Bianco**

Advocates for Human Potential, Inc.  
Delmar, NY

**Ann Denton**

The Enterprise Foundation  
Austin, TX

**Gail P. Hutchings, M.P.A.**

Behavioral Health Policy Collaborative, LLC  
Alexandria, VA

**Edward L. Knight, Ph.D.**

Advocates for Human Potential, Inc.  
Colorado Springs, CO

**Rick Kugler**

MATRIX Research Institute  
Philadelphia, PA

**Elizabeth Priaulx, J.D.**

National Association of Protection and Advocacy Systems  
Washington, DC

**Gary E. Shaheen, M.P.A.**

Advocates for Human Potential, Inc.  
Delmar, NY

**Jenifer Urff, J.D.**

University of Massachusetts Donahue Institute  
Hadley, MA

**Susan Milstrey Wells**

Advocates for Human Potential, Inc.  
Delmar, NY