COMMUNITY SUPPORT SYSTEMS

For Persons With Long-Term Mental Illness:

QUESTIONS AND ANSWERS

Acknowledgments

The following individuals contributed to the development of this booklet. Their insightful comments and constructive suggestions are acknowledged and appreciated.

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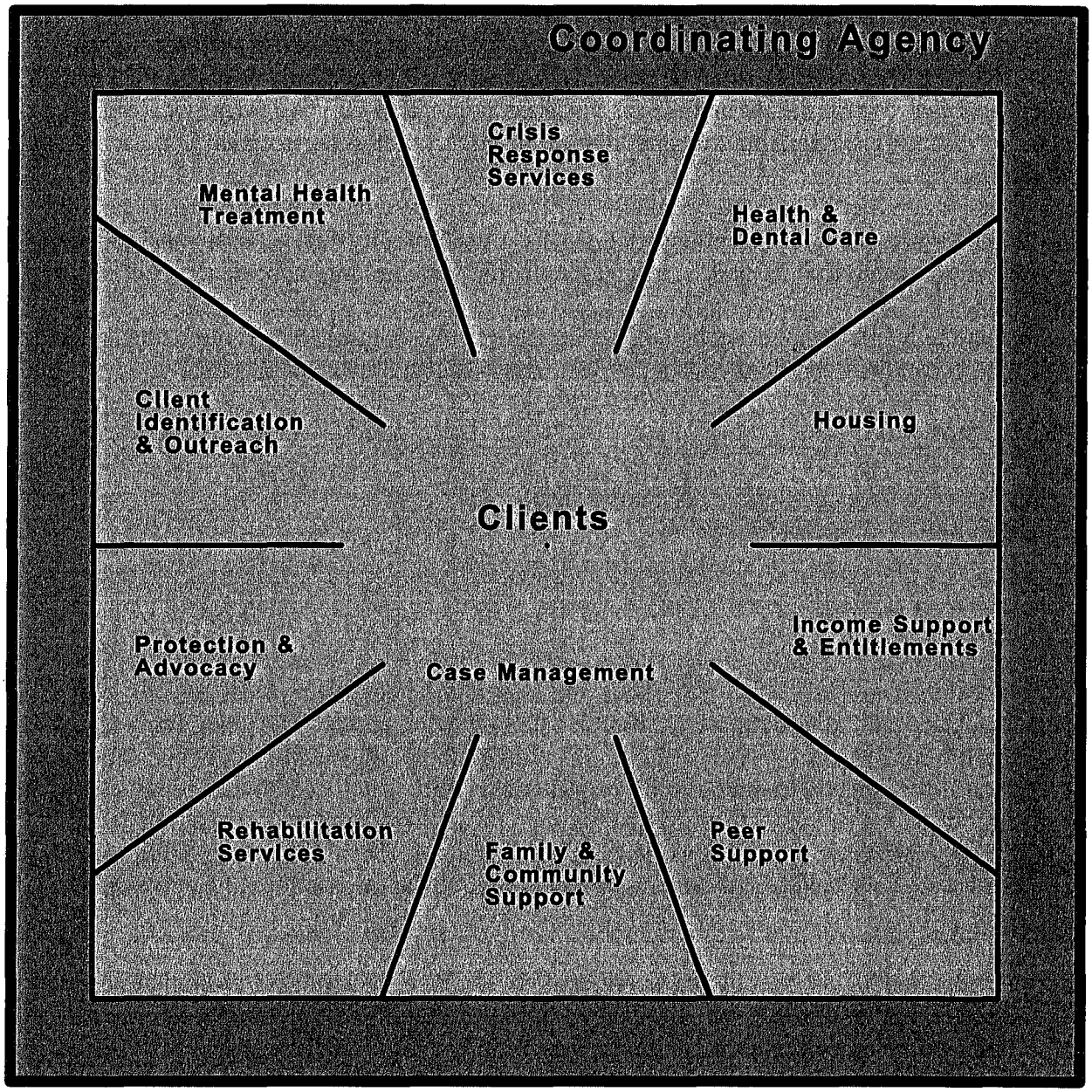

Foreword

In the fall of 1987, the National Institute of Mental Health celebrated the tenth anniversary of the Community Support Program (CSP). CSP was designed as a pilot program to stimulate and assist states and communities in improving opportunities and services for adults with seriously disabling mental health problems. One outcome of the 1977 participatory planning process was the development of a new conceptual framework, the concept of a "community support system" (CSS) to be used as a basis for planning and organizing services for the population.

Although many aspects of CPS have been altered during this past decade, the concept of a community support system and its integral components has remained constant. As a program

concept for states to use in comprehensive, community-based mental health systems planning efforts to meet state and Federal (P.L. 99-660) requirements, the CSS model offers a valuable framework. The components of a CSS represent the array of services and opportunities that an adequate service system should include for the target population - crisis care, prevention of secondary disabilities, rehabilitation, and long-term support - all to be provided in the community.

This booklet represents the current knowledge base on community support systems, including ten years of demonstration programs, evaluation, learning community conferences, and research. Our
hope is that the information provided will be valuable to all - administrators, clinicians, planners, legislators, consumers, family members, citizen advocates, and the general public.

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Introduction

The past decade has seen a rising tide of concern surrounding the treatment of persons with severe, disabling, and long-term mental illness. No longer are persons with long-term illness isolated in the back wards of mental institutions. Increasingly, they are living in community settings and receiving community-based care. However, critics have noted that conditions in the community often are as bad as those in institutions - people with mental illness are isolated, neglected, stigmatized, untreated, and, in some cases, abused. The need for improved care is evidenced by the very visible and growing problem of homelessness among mentally ill individuals.

Clearly, mental health treatment alone is not enough. There is general agreement that persons with long-term mental illness require a range of basic community services and supports which has become known as a Community Support System (CSS). The CSS concept was designed by the National Institute of Mental Health (NIMH) in collaboration with state mental health officials, family groups, consumer groups, researchers, citizen advocates, and others across the nation. The CSS concept recognizes that traditional mental health services are not enough, and that services such as housing, income maintenance, medical care, and rehabilitation are also essential. Thus, the concept includes the entire array of services, supports, and opportunities needed by persons in order to function within the community.

This booklet describes the current CSS concept and philosophy. It presents basic information about CSSs such as why they are needed, who should be served by CSSs, what principles should govern service delivery, what services should be provided within a CSS, and what progress has been made toward the development of CSSs. The booklet is designed for a wide audience including policy makers, planners, service providers, families of persons with long-term mental

illness, advocates, and consumers themselves. It is designed for all who share a concern for persons with long-term mental illness and an interest in improving the services they receive in our nation's communities.

What is the Population of Concern?

The CSS concept is designed for a particularly vulnerable population - adults with severe and persistent psychiatric disabilities. This population generally is described according to the three major dimensions of diagnosis, disability, and duration. Persons included in the population have major mental disorders such as schizophrenia or other psychoses, severe depression, manic-depressive disorder, and other types of disorders that may lead to chronic disability. They typically have functional limitations in major life activities, and they require treatment and services over an extended time.

Many of the individuals in this population of concern have had extensive contact with the mental health service system, including a history of previous hospitalizations or outpatient treatment. While some individuals are able to live in relative independence in the community, many others struggle with their illness and its disabling consequences over a long period of time - sometimes throughout a lifetime. For many persons, periods of wellness are interrupted periodically by episodes of acute psychotic symptoms or severe depression. Short-term approaches to treatment have proven inadequate to meet their needs. Persons in the population of concern generally require long-term treatment, rehabilitation, and support to control symptoms and address the functional disabilities resulting from their illness.

Persons with serious mental disabilities often lack self-confidence and may display mood fluctuations, poor impulse control, unusual behavior, or disturbed thought processes. Their relationships with others may be strained, resulting from behavior which may be difficult for families, friends, employers, and others to tolerate over time. In general, persons with long-term mental illness are extremely vulnerable to stress, and may have difficulty coping with basic activities of daily living such as self-care, housekeeping activities, money management, socialization, or leisure time activities. They may not be able to locate and sustain employment and, therefore, may be unable to earn adequate money to meet their basic needs for food, clothing, and housing. Despite their need for assistance, many persons with mental illness are unable to seek help from the community's maze of human service agencies which is often complex and confusing.

Although estimates of the size of the population of concern vary, there are approximately 2.1 to 2.8 million individuals who can be considered to have severe, disabling, long-term mental illness. It is important to recognize that the population of concern is diverse. Each individual has unique concerns, abilities, motivations, and problems. Further, the population is comprised of a variety of subgroups, each having different characteristics and service needs. These include mentally ill persons belonging to racial or ethnic minority groups, elderly persons, young adults and youth in transition to adulthood, persons with mental illness and substance abuse problems

or mental illness and mental retardation, and mentally ill individuals within the criminal justice system.

Despite the heterogeneity and subgroups within the population of concern, the CSS concept includes the basic range of services and supports needed within the community by most persons with long-term mental illness.

What Are the Needs?

In the past, persons with serious mental illness were confined to institutions for long periods of time. These institutions typically were far from the person's home community and provided little more than custodial care.

Over the past 20 years, reliance on public mental institutions for the care and treatment of persons with long-term mental illness has been reduced dramatically. The development of new drugs and treatments, court decisions mandating an individual's right to treatment in the least restrictive setting, fiscal incentives, and other factors enabled many persons to be released from institutions to receive care in their home communities.

This trend, known as deinstitutionalization, brought with it a corollary trend of "noninstitutionalization." This is reflected in the practice of admissions diversion, whereby persons are kept out of the hospital if at all possible and are referred instead for community care. Thus, mentally disabled persons who spent much of their lives in public mental institutions now live in the community, and many younger persons, who at one time might have resided in these institutions, now remain in the community as well. To meet their needs, community-based services, including community hospitals, were envisioned.

Despite these trends, most communities are not prepared or equipped to meet the needs of persons with long-term mental illness. In many cases, resources are not available to meet their basic human needs for shelter, food, clothing, income, and medical care. Supportive and rehabilitative services are largely unavailable in many areas, leaving persons with little or no ongoing care. While some persons are able to access needed community services and supports, there are many tragedies including ex-patients wandering the streets and sleeping outdoors and others living in squalid, single-room occupancy dwellings. Continual readmissions to hospitals, overuse of emergency rooms, repeated encounters with the correctional system, and undue burden on families are all problems that result from insufficient community services and supports. The current issue of homeless persons who are mentally ill points out the especially critical need for housing for mentally ill individuals.

The fundamental problem is a severe shortage of supportive and rehabilitative programs in the community to meet the needs of persons discharged or diverted from hospitals. Today, most agree that community-based care is more humane, more therapeutic, and less stigmatizing. Nationwide, however, there has not been enough progress in developing adequate community-based services for persons with long-term mental illness.

What are the needs of persons with long-term mental illness? What services and supports are needed to ensure an optimal quality of life within the community? Institutional care, despite its many negative aspects, provided for all aspects of a person's life. Shelter, food, clothing, structured activities, medical care, therapy, and rehabilitation were all, therapeutically, part of the services of a "total institution." In order for persons with long-term mental illness to function within the community, all aspects of their lives also must be considered - their basic human needs as well as their needs for treatment and rehabilitation. There is widespread agreement that an array of services and supports (a CSS) is needed in order to maintain the community tenure and enhance the quality of life of persons with long-term mental illness.

What Is the NIMH Community Support Program?

NIMH officially began to address the problems of deinstitutionalization and community-based care in 1974 when an internal work group was formed to design and promote the development of community-based service systems for adults with long-term mental illness. The type of system envisioned by NIMH was one that would enable mentally ill persons to remain in the community and to function at optimal levels of independence.

The Community Support Work Group evolved into a special Federal initiative which was launched in 1977, the NIMH Community Support Program (CSP). CSP is designed to assist states and communities to develop comprehensive CSSs for persons with long-term mental illness. Financial assistance in the form of grants is provided to state mental health agencies in order to facilitate their service system improvement activities. CSP, which began as a pilot effort, soon developed into a national program. All 50 states, the District of Columbia, and two territories have received Federal assistance through CPS for multi-year initiatives to plan and implement CSSs.

Beginning in 1986, CSP extended its activities to provide funds for community services demonstration projects. A number of projects are receiving financial assistance to demonstrate and evaluate community-based service approaches for elderly persons with mental illness, homeless persons with mental illness, and young adults with both mental illness and substance abuse problems.

In addition to financial assistance, CSP provides many forms of technical assistance to support the efforts of states and communities to build CSSs. These include such activities as convening national and regional conferences, sponsoring the development of technical assistance materials and resources, and promoting information sharing and networking. CPS's role also encompasses research evaluation, and analysis activities and working with other agencies at the Federal level to collaborate on program initiatives and to resolve policy issues impacting on services for persons with long-term mental illness.

Pervading CSP's history has been a strategy of encouraging the participation and involvement of

a broad range of individuals and groups in all CSP activities. In order to ensure broad-based participation, CSP set out to foster a national "networking of caring." Providers, policy makers, researchers, families, consumers, and advocates have forged the national coalition and are working collaboratively to promote the development of CSSs. CSP's emphasis on involving family members and consumers has contributed to the growth of the now flourishing family and consumer movements. Family and consumer groups have now become strong and vital forces for persons with long-term mental illness and for promoting CSSs.

What Principles Guide CSSs?

A CSS represents more than a network of service components. Rather, it represents a philosophy about the way in which services should be delivered to persons with long-term mental illness. Although the actual components and organizational configuration of a CSS may differ from state to state and from community to community, all CSSs should be guided by a set of basic values and operational philosophies.

The CSS ideology embraces the notion that services should maintain the dignity and respect the individual needs to each person. Individuals with mental illness are seen, first and foremost, as persons with basic human needs and aspirations and as citizens with all the rights, privileges, opportunities, and responsibilities accorded other citizens. They should have access to the supports and opportunities needed by all persons, as well as to specialized mental health services. Further, the CSS concept is based on creating opportunities for individuals to develop their potentials - for growth, improvement, and movement toward independence - rather than fostering a life of dependency, disability, and "chronic patienthood."

Another basic value inherent in the CSS concept is that the community is the best place for providing long-term care. Inpatient care is a part of the array of needed community-based services and should be used for short-term evaluation and stabilization and for the small percentage of individuals who require long-term hospitalization.

The CSS philosophy is embodied in a set of guiding principles, emphasizing client self-determination, individualized and flexible services, normalized services and service settings, and service coordination:

Services should be consumer-centered. Services should be based on and responsive to the needs of the client rather than the needs of the system or the needs of providers.

Services should empower clients. Services should incorporate consumer self-help approaches and should be provided in a manner that allows clients to retain the greatest possible control over their own lives. As much as possible, clients should set their own goals and decide what services they will receive. Clients also should be actively involved in all aspects of planning and delivering services.

Services should be racially and culturally appropriate. Services should be available, accessible, and acceptable to members of racial and ethnic minority groups and women.

Services should be flexible. Services should be available whenever they are needed and for as long as they are needed. They should be provided in a variety of ways, with individuals able to move in and out of the system as their needs change.

Services should focus on strengths. Services should build upon the assets and strengths of clients in order to help them maintain a sense of identity, dignity, and self-esteem.

Services should be normalized and incorporate natural supports. Services should be offered in the least restrictive, most natural setting possible. Clients should be encouraged to use the natural supports in the community and should be integrated into the normal living, working, learning, and leisure time activities of the community.

Services should meet special needs. Services should be adapted to meet the needs of subgroups of severely mentally ill persons such as elderly individuals in the community or in institutions; young adults and youth in transition to adulthood; mentally ill individuals with substance abuse problems, mental retardation, or hearing impairments; mentally ill persons who are homeless; and mentally ill persons who are inappropriately placed within the correctional system.

Service systems should be accountable. Service providers should be accountable to the users of the services and monitored by the state to assure quality of care and continued relevance to client needs. Primary consumers and families should be involved in planning, implementing, monitoring, and evaluating services.

Services should be coordinated. In order to develop CSSs, service should be coordinated through mandates or written agreements that require ongoing communication and linkages between participating agencies and between the various levels of government. In order to be effective, coordination must occur at the client, community, and state levels. In addition, mechanisms should be in place to ensure continuity of care and coordination between hospital and other community services.

What Is A CSS?

A CSS is defined as "an organized network of caring and responsible people committed to assisting persons with long-term mental illness to meet their needs and develop their potentials without being unnecessarily isolated or excluded from the community." The CSS concept includes the entire array of treatment, life support, and rehabilitation services needed to assist persons with severe, disabling mental illness to function at optimal levels within the community. Accordingly, the CSS concept delineates an array of essential components that are needed to

provide adequate services and support. Each community should have arrangements to perform these essential functions.

A graphic representation of a comprehensive CSS is provided on the following page, and each specific service component is described briefly below:

Client Identification and Outreach

Mentally ill individuals often have difficulty seeking out services. As a result, mechanisms are needed to locate potential clients, regardless of where they reside, and to inform them of available services. For example, linkages with boarding homes, emergency rooms, inpatient facilities, police departments, family groups, and consumer organizations may be used to identify persons in need of community support services.

Some individuals decline to attend a formal treatment program or center or are unable to do so. Outreach services should be provided to assist these individuals in their own environments. Such outreach services might include crisis intervention, medication checks, assistance in meeting basic human needs, skill training, and referral to appropriate health or welfare agencies.

Effective outreach is particularly critical for homeless mentally ill persons who are among the least able to locate appropriate agencies, programs, and resources and who tend to reject traditional mental health and social services. Outreach to shelters, soup kitchens, drop-in centers, or to people on the streets can reach many homeless individuals who otherwise would be overlooked by the mental health system. Outreach provides a more flexible approach which is often effective in gradually and patiently engaging the hardest-to-reach clients.

Many clients, particularly those in rural areas, have difficulty taking advantage of needed support services because of the lack of transportation. Transportation assistance should be provided to clients to enhance their access to needed services and community resources. Such assistance may be provided through a variety of mechanisms including special arrangements with public transportation systems or through use of vans, buses, taxis, private automobiles, or volunteers.

Mental Health Treatment

Mental health treatment is a critical component of a CSS. The clinical conditions of persons with serious, disabling mental illness change over time, and clients experience periodic relapses or flare-ups of acute symptoms. Clinical management of psychiatric disorders should be an integral part of service delivery and should be provided continuously on a long-term basis.

Accordingly, mental health treatment for persons with long-term mental illness should be directed at helping clients to manage symptoms, manage medications, recognize signs of relapse, and cope with daily living. Specifically, mental health care should include diagnostic evaluation and ongoing assessment and monitoring of psychiatric conditions. Accurate diagnosis of psychiatric and medical problems is essential for the development of an individualized treatment plan including appropriate medications.

A second component of mental health care is supportive counseling and therapy. Counseling can be provided on an individual and/or group basis and generally is directed at helping clients to cope with a variety of life problems and stresses.

Another essential aspect of mental health treatment is medication management. Medication management services include prescribing medications, ensuring that needed medications are available to clients, carefully monitoring medications to ensure maximal therapeutic effectiveness and minimal adverse side effects, and educating the client and family regarding the nature of medications and their benefits, and potential side effects.

Specialized treatment services are needed for mentally ill persons who also have substance abuse disorders. In addition to services provided to the general population, these individuals often require detoxification and other interventions to address alcohol and drug abuse problems. Programs should accept and provide services to persons with mental illness and substance abuse problems and should provide or help access the needed specialized services.

Crisis Response Services

Persons with serious and long-term mental illness tend to experience recurrent crises even when comprehensive and continuous community support services are available. As a result, the capacity to provide crisis assistance is a critical aspect of a CSS. Crises services are needed to provide an immediate response to individuals in crisis and to members of the individual's support system on a 24-hour-a-day, seven-day-a-week basis. In many cases, crises services can assist the client to stabilize and readjust to community living. Further, crisis services often can be effective in averting hospitalization.

Accordingly, the primary goal of crisis services is to assist individuals in psychiatric crises to maintain or resume community functioning. Crisis response services should enable the client, family members, and others to cope with emergencies while maintaining the client's status as a functioning community member to the greatest possible extent. The availability of crisis services should be known to providers, families, clients, community agencies, law enforcement agencies, and the community-at-large.

Crisis assistance can be conceptualized as a range of responses to be used in crisis situations. These include 24-hour crisis telephone services such as hotlines, walk-in crisis intervention services at mental health agencies, and mobile crisis outreach services which involve going to the client and providing services in the setting in which the crisis is occurring. Outreach workers may stay with the client and significant others as long as is necessary to intervene successfully in the crisis - initiating necessary treatment, resolving problems, providing high levels of support, and making arrangements for ongoing services.

With intensive crisis intervention and support, many clients in crisis can be maintained and assisted in their natural environments. When such approaches are not sufficient to achieve stabilization and crisis resolution, crisis residential services should be available. These services

involve providing crisis intervention in the context of a residential, nonhospital setting on a short-term basis. A variety of settings or approaches can be used to provide crisis residential services including family-based crisis homes and staffed residences for small groups of clients in crisis.

Inpatient beds in a protective environment should be provided for crises which cannot be handled in the natural setting or in crisis residential settings. Hospitalization is needed for the most severe crises in which clients need intensive support, structure, and supervision during the period of stabilization. Persons who are acutely dangerous to themselves or others, or who retain little impulse control, or who have complicating medical conditions may require inpatient care. These inpatient beds may be provided in a psychiatric unit or a general or community hospital or in a nearby state hospital and serve as a back-up to other community support services.

Health and Dental Care

Persons with long-term mental illness frequently lack proper health and dental care. This results from the difficulty in locating medical and dental practitioners who are willing to serve this population coupled with the inability to pay for such services.

Severely mentally ill persons have been found to have significantly higher rates of physical illness than the general population. Further, a significant number of persons with long-term mental illness have undetected physical diseases which may contribute to their mental disorders. Adequate health care services for this population is, therefore, particularly important.

Creative arrangements and procedures may be needed to ensure that persons with long-term mental illness have access to adequate health and dental care services. First, the CSS should have mechanisms to ensure that clients who are entitled to medical assistance benefits such as Medicaid or Medicare receive these benefits. Further, mechanisms and procedures to access medical and dental services for clients should be in place. These may include establishing linkages and agreements with private practioners, hospitals, clinics, or other medical organizations and families to provide service to clients. Services may be provided by bringing clients to medical and dental resources in the community or bringing such services to clients at the mental health program or agency. For example, some programs contract with community physicians to perform physical examinations and provide medical care to clients on a regular basis. Assistance with transportation to medical and dental appointments may be needed for many clients.

Housing

Adequate housing is essential to the well-being of any person. Many persons with long-term mental illness to not have stable, affordable housing and have difficulty locating, securing, and maintaining housing. CSSs should include a range of residential options for clients, offering the opportunity for decent, affordable housing in the community. Without an appropriate range of housing options, the success of other treatment and rehabilitation approaches is jeopardized.

Stability in housing is a crucial factor which often has been overlooked in the care of persons with long-term mental illness. Long-term, stable housing should be a goal rather than requiring clients to progress through a series of time-limited, transitional housing environments. Frequent moves create dislocation, readjustment, and require the learning of new skill - all of which create stress for mentally disabled individuals. Further, mechanisms should be devised to ensure that a client's housing is protected when he or she is absent due to a crisis or a period of hospitalization.

An array of residential alternatives that provide varying levels of support and supervision should be offered. An individual consumer's preferences, values, and goals with regard to housing, along with functional level, should be primary considerations in determining an appropriate housing arrangement. Many currently believe that the emphasis should be on the most normalized housing options, and that training, supports, and services should be provided to enable individuals to reside successfully in these more normalized community residential settings. Apartment settings with various levels of supervision and support are examples of the use of this approach. A variety of more specialized or structured residential settings may be used for the small number of extremely disabled individuals who require a greater degree of attention, supervision, or structure. These include homes of various types, family foster care homes, board and care homes, and other settings. An individualized approach to housing is needed whereby the client's needs and choice dictate the selection and development of housing options.

Special residential assistance for homeless mentally ill persons is an essential aspect of the housing component. These individuals require a range of additional living situations with varying degrees of supervision and structure. Emergency shelters are needed to provide an immediate, short-term alternative to the streets. Shelters should have mechanisms to identify persons who are mentally ill and to link them with needed mental health and support services. Drop-in centers should be provided in locations where street people can have easy access. These centers may offer daytime refuge, daytime and evening programs, counseling, vocational training, recreational activities, and housing or some combination of these services. Crisis residential services are needed for homeless individuals who are in periods of acute stress and require intensive treatment and close supervision. Such crisis residential settings can serve as alternatives to hospitalization for homeless individuals and can focus on both treatment and housing needs. Transitional housing also is needed for homeless mentally ill individuals, since it is often impossible to make permanent living arrangements during the short stay permitted at emergency shelters. Temporary residences allow time for homeless mentally ill persons to receive the treatment and assistance needed to make the physical and emotional transition from a shelter to long-term housing. Finally, as for all persons with psychiatric disabilities, long-term, permanent housing linked to supportive services is essential for homeless persons and is the ultimate goal.

Income Support and Entitlements

Severe and persistent mental disorders interfere with an individual's functional capacities in daily life. Thus, many persons with long-term mental illness have sporadic employment

histories and have difficulty securing and maintaining stable jobs. In addition to suffering from psychiatric disabilities, many individuals also must endure poverty and are unable to earn the money needed for basic necessities such as shelter, food, clothing and medical care.

A variety of public assistance and entitlement programs are available to persons with mental disorders to help with subsistence and medical expenses such as Supplemental Security Income provided by the Social Security Administration and Medicaid. Many persons, however, have difficulty locating the appropriate agencies, communicating effectively with agency personnel, understanding complex eligibility requirements, and completing cumbersome application forms and procedures.

Assistance should be available to help clients obtain income supports and other entitlements they may need in order to live in the community. Staff might screen clients for eligibility, provide transportation to the appropriate agencies, accompany clients to the various locations, assist in the completion of application procedures, and serve as an advocate for the client with the agency in question. Efforts must be devoted to ensure that clients receive the benefits to which they are entitled and which are critical factors in successfully remaining in the community.

Peer Support

Peer support or self-help is rapidly becoming an important force in the mental health arena, with increasing numbers of consumers coming together to share their common experiences, pain, problems, and solutions. Peer support can counter feelings of loneliness, rejection, discrimination, and frustration by offering mutual support, companionship, empathy, sharing, and assistance. Emotional support and practical help for dealing with common problems foster a sense of community as well as a sense of empowerment. Self-help groups are the most common form of peer support and involve groups that meet regularly on a formal or informal basis to share ideas, information, and mutual support.

Consumer-operated services are service programs that are planned, administered, delivered, and evaluated by consumers. Consumer-run service programs are an outgrowth of the self-help movement and provide a variety of services in nonthreatening atmospheres. Consumer-operated services are voluntary and are based upon the values of freedom of choice and consumer control.

Consumer-operated services often are organized around a drop-in center. The peer-run drop-in center provides an open, comfortable setting and often serves as the nucleus for a wide variety of support, service, and socialization activities. Services provided by consumer-operated programs include self-help groups; training in independent living skills; advocacy and assistance in locating needed community resources and services such as housing and financial aid; education about patients' rights, psychiatric drugs, and other topics of interest; social and recreational activities; and community or public education on mental illness. Consumer-run programs may also provide services including housing, job counseling and employment assistance, employment in consumer-operated businesses, crisis assistance services, and respite care. The programs generally supplement the services of the formal mental health system and may meet a variety of social and life support needs.

Self-help and consumer-run programs should be part of each CSS to provide opportunities for peer support, consultation, education and assistance. Peer support opportunities can provide social supports that the formal system is unable to provide and can assist persons who decline to use formal mental health services or who have moved beyond the need for intensive, formal services.

Family and Community Support

Many mentally ill individuals live at home with their families. Families often must fend for themselves while coping with persistent symptoms, unpredictable behavior, and inadequate community support services. In the past, families often were blamed and ignored by mental health professionals. Currently, the need for family involvement in services, as well as support and education for families, is increasingly recognized.

Families should be involved appropriately in the treatment planning process and in service delivery. In addition, assistance to families should be provided including education regarding the nature of the illness, consultation and supportive counseling to assist families in handling daily problems and intermittent crises, and respite care. Additionally, opportunities for mutual support among families of persons with mental illness should be encouraged and promoted by the CSS. Families should be apprised of and referred to family support and advocacy organizations and the development of such groups should be encouraged.

Support and education for the community is another essential aspect of a CSS. In order to promote community integration and acceptance of persons with long-term mental illness, back-up support, consultation, and education should be provided to key individuals and agencies within the community. Landlords, employers, friends, community agencies, law enforcement agencies, and others who come in frequent contact with mentally ill individuals should be the focus of such educational and supportive efforts. In addition, there should be efforts to educate the general public about mental illness to reduce stigma and to promote community acceptance. Consumers, family members, and providers all should be involved in efforts to educate the public. Media campaigns and presentations to civic organizations, schools, agencies, and the community-at-large are among the strategies that may be used.

Rehabilitation Services

Despite the symptomatic improvement resulting from medications and other mental health treatment, many persons with long-term mental illness experience continuing social and vocational handicaps. Rehabilitation services help persons with psychiatric disabilities to learn the social and vocational skills and acquire the supports needed for survival in the community. Rehabilitation services traditionally have been provided by psychosocial rehabilitation centers, but many other programs and settings are changing their service delivery to a rehabilitation orientation. Both social and vocational rehabilitation should be integral parts of a CSS with the goals of building the skills and accessing the supports needed to function as actively and independently in society as possible.

Social rehabilitation is directed at helping the client to gain or regain the practical skills needed to live and socialize in the community. Services should include activities that teach daily and community living skills and address diet, personal hygiene, cooking, shopping, budgeting, housekeeping, use of transportation, and use of other community resources in the natural settings where clients live, learn, work, and socialize. Educational approaches should teach clients how to cope with and compensate for their disabilities, how to manage medications, recognize danger signs, and utilize professional resources when necessary.

Social rehabilitation also involves assistance in developing interpersonal skills and leisure time activities and interests which provide a sense of participation and personal satisfaction. Opportunities should be provided for age-appropriate, culturally appropriate daytime and evening activities which offer the chance for companionship, socialization, and enjoyment. The use of social recreational opportunities available in the community should be maximized.

Because of the importance of productive activity in any person's life, vocational services are an essential ingredient of a CSS. The goal of vocational rehabilitation is to help clients to become productive, contributing members of society by achieving the best possible vocational outcome. There should be a range of vocational services and employment opportunities available to assist clients to prepare for, obtain, and maintain employment. These may include vocational assessment and counseling, pre-vocational work experiences, vocational training, job trials or transitional employment opportunities, training in job seeking and job keeping skills, job development with local employers, and job placement. In addition, mechanisms to offer assistance to both clients and employers to enhance job retention often are needed.

Some persons are unable to handle the stresses or demands of independent employment situations and require alternatives with greater support and supervision. For such persons, a variety of supported employment opportunities should be provided which combine paid work with the ongoing support services needed by individuals to maintain their jobs. Supported employment can take many forms including small groups or enclaves or disabled individuals working in a business or industry with a staff supervisor; individual client in job placements dispersed around the community with mobile staff to provide support; mobile work crews of clients performing a variety of services within the community; job coaches at the work site; or small businesses operated by a mental health or rehabilitation agency. Such services allow most persons with long-term mental illness to be productive and to make a contribution in accordance with their abilities.

Protection and Advocacy

The protection and advocacy function of a CSS should be evident in several areas. First, the CSS should include mechanisms to ensure the protection of client rights in both residential and nonresidential settings. Such mechanisms may include statues, regulations, statements of rights of mental health clients, grievance procedures, case review committees, and protection and advocacy systems. Additionally, there should be procedures for informing clients and families of their legal rights and of resources available to assist them in upholding those rights.

One basic right of all clients is the right to treatment in the least restrictive, appropriate environment. Safeguards may be necessary to ensure that this right is upheld as well as safeguards to protect clients' rights upon admission to hospitals and upon consideration of involuntary commitment to inpatient or outpatient treatment settings.

In addition to rights protection, the CSS should actively promote advocacy activities on behalf of clients. Advocacy activities involve efforts to ensure that individual clients and families receive appropriate services, benefits, and protections. Advocacy efforts also are needed at the system level to seek improvements in services, benefits, or rights on behalf of all persons with long-term mental illness. The Protection and Advocacy for Mentally Ill Individuals Act of 1986 requires states to establish protection and advocacy systems to protect persons with mental illness. These systems are intended to protect and advocate for the rights of mentally ill individuals to ensure compliance with Constitutional, Federal, and state mandates and to investigate incidents of abuse and neglect of mentally ill individuals. The Act also includes the "Bill of Rights for Mental Health Patients" which should be reflected in state law. CSSs should be based upon the principles contained in the Bill of Rights and should coordinate their protection and advocacy activities with the state protection and advocacy system.

Case Management

Case management services should be available for all clients who receive services supported through public funds. Case management is intended to ensure that clients receive the services they need, that services are coordinated, and that services are appropriate to their changing needs over time. Case management involves providing a single person or team to assume responsibility for maintaining a long-term, caring, supportive relationship with the client on a continuing basis, regardless of where the client is residing and regardless of the number of agencies involved. The case manager serves as a helper, service broker, and advocate, assisting clients and families to negotiate the system in order to meet their needs.

Among the specific functions performed by case managers are identifying clients to be served, assessing the client's needs, coordinating and assisting in the development of a comprehensive service plan based on the client's needs and goals, helping the client to make an informed choice about services, assisting the client to obtain needed services and resources, monitoring the adequacy and appropriateness of services, ensuring the continuity of service provision, and advocating for treatment and services for the client. Most of these functions cannot be accomplished in an office or behind a desk. Case managers must work in the community with clients, families, and agencies to manage, coordinate, and unify the many components of the CSS.

Particularly for homeless mentally ill individuals, effective case management must be intensive and ongoing and must take place kin shelters or on the streets. Case management activities must be based upon an aggressive outreach approach in order to engage clients, build trust, and prepare clients to receive needed services.

A summary list of the components of a CSS are presented on the following page.

It should be recognized that a small percentage of individuals are profoundly disabled as a result of their mental illness. Regardless of the level and continuity of services and supports, they may be unable to function in community settings. These individuals require the highly specialized treatment and supervision that only can be provided in a hospital setting. Thus, in certain cases, long-term hospitalization is needed.

COMPONENTS OF A COMMUNITY SUPPORT SYSTEM

Client Identification and Outreach
- Client Identification
- Outreach
- Transportation Assistance

Mental Health Treatment
- Diagnostic Evaluation
- Supportive Counseling
- Medication Management
- Substance Abuse Services

Health and Dental Services

Crisis Response Services
- Crisis Telephone Services
- Walk-In Crisis Services
- Mobile Crisis Outreach Services
- Crisis Residential Services
- Inpatient Services

Housing
- Supportive Housing
- Residential Assistance for Homeless Mentally Ill Persons

Income Support and Entitlements

Peer Support
- Self-Help
- Consumer-Operated Services

Family and Community Support
- Support and Assistance to Families
- Support and Education for the Community

Rehabilitation Services
Social Rehabilitation
Vocational Rehabilitation

Protection and Advocacy

Case Management

How Should CSSs Be Provided and Organized?

The CSS model is flexible in that it does not prescribe how states or communities should provide or organize the essential components. The concept includes the range of functions that should be performed to meet the needs of mentally ill individuals and leaves states and communities to decide how this might best be accomplished. Thus, the CSS concept is not a prescription, but rather a guide.

The CSS model also avoids specifying the type of agency that should provide a particular type of service. States and communities are encouraged to make effective use of resource and facilities that are in place such as community mental health centers, psychosocial rehabilitation agencies, community residences, a variety of public and private human service agencies, and mental hospitals. In defining and implementing the ideal CSS, states and communities can use varying approaches and configurations depending upon geographic, political, socio-economic, and ethnic factors. For example, in rural areas it may not be financially possible to develop a comprehensive CSS in each locality. Alternative approaches, such as shared services among several communities with accompanying transportation capability, may be needed under these circumstances. The CSS model itself, and the way the model is implemented, can easily be adapted to the needs, circumstances, and resources of each state or community.

While the CSS concept leaves considerable flexibility for implementation, a CSS is more than just a collection of discrete programs or service components. The components must be organized into a coherent, integrated system. Only by organizing a system of care can the community ensure that the necessary array of human services will be made available. In order to constitute a system, there must be formal arrangements in a community for planning, developing, financing, coordinating, monitoring, and evaluating community support services. This involves the designation of one agency or entity as the "managing agency." This agency should have broad authority to convene other agencies and responsibility for assuring the delivery and coordination of all services for clients in a geographically or politically defined area. The most logical structure and process of these management functions must be determined by each state and community.
The managing agency could be a unit of local government or another agency. Regardless of the type of entity assigned this role, there should be a single focal point of authority, responsibility,

and accountability for community support services at the local level.

In considering the organization and development of CSSs, it is important to distinguish between community support services and community support systems. Community support services are the specific, discrete services needed by persons with mental illness such as mental health treatment, rehabilitation, and housing. These are the components that make up a comprehensive system of care. A system includes all essential components along with mechanisms to ensure proper management and coordination. Much attention often is devoted to the development of individual service components, while the concept of a comprehensive, coordinated system of care is neglected. The needs of persons with severe, disabling mental illness will remain unmet until states and communities develop the full range of services and establish community-level focal points for management and accountability.

Are CSSs Effective?

The effectiveness of CSSs appear to be substantiated by accumulating evidence from both experience and research. Most researchers agree that, when comprehensive, coordinated services are provided, clients respond with improvements in their clinical and social functioning. Further, when comprehensive CSSs are provided, the use of long-term hospital services is dramatically reduced and clients' quality of life is improved. Additionally, clients receiving comprehensive community support services are more satisfied with services and with their lives in the community, and families report a reduction in "family burden." Several research reviews have analyzed studies pertaining to community care for persons with long-term mental illness. They have found not only that individuals can be treated in the community, but that community treatment often is more effective than long-term hospital care. Across diverse settings and programs, studies consistently have supported the efficacy of community-based services.

From the current knowledge base, it can be concluded that comprehensive CSSs reduce reliance on hospitalization and improve the level of functioning, quality of life, and satisfaction of mentally disabled persons in the community. Further, most studies indicate that the cost of long-term community care is less than the cost of long-term hospital care. Thus, community care appears to provide many benefits at no greater cost.

It is important to regard the CSS concept as a dynamic one, a concept which will evolve and change as continued research and experience dictate. The CSS concept presented in this booklet represents the current state-of-the-art regarding community-based systems of care for persons with long-term mental illness, and it is corroborated by research and evaluation results. These concepts also form the basis for a model plan developed by NIMH and which describes a comprehensive system of care for individuals with severe, disabling mental illness. The document, Toward a Model Plan for a Comprehensive, Community-Based Mental Health System, is designed to assist states and communities in planning for community-based service systems.

What Progress Has There Been?

To date, all states have received financial assistance from the Federal CSP to initiate service system improvements for persons with serious, disabling mental illness. Most states have made significant strides in improving services for this group. This can be seen most clearly in the high priority now placed by most state governments on the population of persons with long-term mental illness and on CSS development. CSS concepts have been introduced into state legislation, plans, guidelines, and regulations. States also have made important strides in educating mental health and other human service providers about CSS concepts. And further, states have made some progress in allocating resources to CSS development. While the majority of state and mental health funds still support the operation of state mental hospitals, increasing resources are being provided to serve this population in more appropriate ways in the community. In sum, most state mental health systems are in the process of reorienting to focus on community care of persons with severe, disabling mental illness as the highest priority.

On the whole, states and communities report an increased availability of community support services resulting from two primary factors. First, new community support services have developed. Many states, for example, have selected priority CSS components and have concentrated their efforts on developing these on a statewide basis. Rehabilitation and housing programs are two such components. Second, many existing services have been reorienting toward CSS concepts and principles. This shift in philosophy is particularly evident in day treatment programs which increasingly are adopting a social and vocational rehabilitation orientation and are providing more meaningful and appropriate rehabilitation opportunities for mentally disabled individuals.

No discussion of progress at the community level would be complete without mention of the many excellent model programs that have been developed to provide community support to persons with long-term mental illness. These models have been replicated and adapted widely in many communities. Many psychosocial rehabilitation programs have evolved from Fountain House in New York City which provides a model comprehensive psychosocial rehabilitation center. The Fairweather Lodge model includes transitional programs at hospitals followed by community-based "lodges" or group homes to teach persons the skills needed for community living. The Training in Community Living model, which originated in Madison, Wisconsin, focuses on teaching the basic coping skills necessary to live as autonomously as possible in the community. The community worker model, developed in Rhinelander, Wisconsin, uses lay citizens of the community to provide extensive support and "case management" to persons with long-term mental illness. This model has been adopted by many communities, particularly in rural areas with shortages of resources and professional staff. Thus, at the local level, a wide variety of approaches to serving persons with metal illness have been tested. Evaluation results consistently demonstrate the effectiveness of these community services. New models also have been developed, and community support services of all types have begun to proliferate across the nation. Further, there is growing attention to the important role of self-help in a CSS.

What Remains to be Done?

Despite clear progress, much remains to be done. The task of creating systems of community-based services for persons with mental illness is complex. Although many community support services and programs have developed, we are not yet close to comprehensive systems of care in each community. The gaps in local systems are apparent. The lack of safe, affordable housing linked to treatment and supportive services is perhaps the most significant gap in CSS development. This shortage of housing has resulted, in some areas, in pressure to reopen institutions to care for homeless mentally ill persons,. In communities where services exist, often these services are not organized into systems of care. Leadership and accountability at the local level generally are weak or nonexistent. In some communities, comprehensive CSSs are beginning to emerge. However, many communities must develop additional community support services and must create a focal point for systems management.

One of the impediments to the large-scale development of CSSs has been the lack of resources. Over the past years, shrinking service dollars have hampered efforts to develop the mental health and other health and human services needed by persons with long-term mental illness. Current funding mechanisms for clients' multiple service needs are fragmented and complex. There has been experimentation with various approaches, but to date there is no coherent financing strategy for CSSs. Strategies must be directed at promoting more appropriate and judicious use of limited resources as well as accessing other resources to provide a stable funding base for CSSs. In addition, since human resources account for more than 70 percent of the total costs of community support services, states and communities must address the need for training, recruiting, and retaining qualified personnel.

We have learned a great deal about developing community-based systems of care, and the "technology" for providing comprehensive services to persons with long-term mental illness is evolving. Still, the most up-to-date technology regarding community support is not as yet being implemented on a sufficiently broad scale.

Perhaps the most heartening sign of progress has been the development of a network of individuals and organizations, a national coalition of concern, dedicated to promoting the development of CSSs. The ever-growing network includes policy makers, providers, researchers, family members, consumers, and citizens who work in their own states and communities as well as the national level to advocate for CSSs and for the resources needed to develop CSSs. The vision shared by members of the network is to have a CSS in every community in the nation. This goal can be realized only through continued individual and collective commitment at all levels. There has been progress, but there is a long way to go.

For Additional Information Contact:

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