



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

PERSONS WITH SEVERE MENTAL ILLNESS:

HOW DO THEY FIT INTO LONG-TERM CARE?

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Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared by DALTCP. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Pamela Doty.

PERSONS WITH SEVERE MENTAL ILLNESS: How Do They Fit Into Long-Term Care?

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I. PURPOSE AND POLICY CONTEXT

A. Background

Long-term services¹ needed by chronically disabled people to carry out activities of daily life have traditionally been viewed as targeted to the elderly. There is increasing recognition, however, that such services may also be needed by younger persons with disabilities, including not only individuals with physical disabilities but also persons with cognitive or mental impairments due to mental retardation and other developmental disabilities, traumatic brain injury, or severe mental illness. Designing a program to provide long-term assistance, specifically in the home or the community, becomes increasingly difficult when including such different populations.

The proposed new benefit for Home and Community Based Services (HCBS) included in President Clinton's Health Care Reform Plan and put before the Congress in the 1993 Health Security Act (HSA) constitutes the most recent and thoroughgoing attempt to develop a legislative and programmatic framework for a generic system for providing long-term services. The term "generic system" refers to a programmatic approach designed to serve all persons, regardless of age, diagnosis, or condition, whose ability to function in daily life without substantial assistance from others is severely limited. The goal of the HCBS benefit was to expand community-based long-term care services to disabled persons without regard to income. Although the HSA was not enacted by the Congress, it provides a likely starting point for future debate around long-term care financing and service delivery reform.

The HCBS provisions adopted a "mixed" approach to the issue of eligibility criteria. Eligibility criteria encompassed individuals who:

1. required hands-on or stand-by personal assistance, supervision, or cues to perform three or more of five activities of daily living (ADLs) which included eating, dressing, bathing, toileting, and transferring in and out of bed;
2. presented evidence of severe cognitive or mental impairment (*shown by one or more ADL dependencies, one or more IADL² dependencies related to the cognitive or mental impairment, or displayed symptoms of one or more serious behavioral problems which created a need for supervision to prevent harm to self or others*);
3. had severe or profound mental retardation;

¹ The terms long-term services and long-term care are used interchangeably throughout this report.

² IADLs are the instrumental activities of daily living and include such activities as medication management, using the telephone, preparing meals, and managing money.

4. (for children under age six) were dependent on technology to remain in the community and outside of a hospital or institution.

This report examines the issues involved in seeking to address the long-term service needs of persons with severe mental illness (SMI) in a generic long-term care financing and service delivery system, as was proposed in the HCBS provisions of the HSA. SMI, as defined by the Center for Mental Health Services (CMHS), is any psychiatric disorder present during the past year that seriously interfered with one or more aspects of a person's daily life. A key issue addressed in this report is whether a common set of eligibility criteria and benefits can apply across populations regardless of age and the underlying diagnoses or conditions responsible for the disability or whether some specialized eligibility criteria and benefits need to be defined for particular subpopulations, such as persons with SMI.

B. Concerns of Advocacy Groups

In principle, advocates for both elderly and younger persons with disabilities (such as the American Association of Retired Persons and the Consortium for Citizens with Disabilities) favor generic "functional" eligibility criteria that can be equitably applied across all age and disability groups and do not decide eligibility due to age, cause, or type of the disability. These viewpoints were strongly expressed at an advisory meeting on eligibility criteria convened by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) Division of Disability, Aging, and Long-Term Care Policy (DALTCP) on February 18, 1994 in Washington, D.C. However, it was also clear that the concept of "functional" eligibility criteria means something quite different to advocates representing disability groups composed predominantly of persons under age 65 than it does to advocates for persons age 65 and older.

Advocates on behalf of younger cognitively or mentally impaired populations are not content to define "function" in terms limited to basic ADLs and IADLs. They would like to see eligibility criteria that also take into account measures of social functioning (or age appropriate functioning) such as inability or impaired ability to work, attend school, form relationships and socialize with peers. This approach results in a much larger definition of the size of the severely disabled population potentially eligible for services than traditional definitions developed around the characteristics and needs of the elderly disabled. Advocates on behalf of younger disabled populations have also stated their preference for having "severe" disability defined in such a way that individuals who have multiple mild or moderate disabilities [which may include mental retardation/developmental disabilities (MR/DD) and SMI] could be determined to meet the severity threshold for program eligibility purposes. Finally, many advocates for younger disabled persons would like to see included in the benefit package services intended to help prepare individuals with disabilities to assume or resume social roles, such as work.

While advocates favor a system that does not determine eligibility by age or type of disability, they also voice concerns that under a federal program modeled after the

HSA where states cannot limit eligibility by income, age, geography, or nature of severity and category of disability, the only method for cost containment may be to limit the services available. There is a fear that the services provided would be tailored to meet the needs of people with ADL, rather than IADL, cognitive, or social functioning impairments.

There is also concern that resolution of the above issues will be futile if some other fundamental problems are not first addressed. Specifically, advocacy groups International Association of Psychosocial Rehabilitation (IAPRS), The American Psychological Association (APA), and the National Mental Health Association (NMHA)] state that legislation should ensure linkages to coordinate services between systems and that case management should be an integral service linking not only health and health-related services but vocational rehabilitation, education, income maintenance, and housing. The purpose of such an emphasis is to enhance continuity of care and provide quick access to services to meet the changing and intermittent needs of persons with SMI.

C. Primary Issues Involving People with SMI and Long-Term Services

This report focuses specifically on how alternative definitions of eligibility for long-term services and benefits (modeled after HCBS provisions within the HSA) affect the SMI population. In particular, the report will address in detail the following challenges that are posed by attempting to take into account the needs of persons with SMI in the design of a generic long-term care services delivery system.

1. *How to delineate the population of persons with SMI for whom long-term services--as distinct from acute psychiatric or other medically-oriented therapies--are appropriate.*

This analytic task involves not only determining who with SMI could benefit from long-term services, but also how the service needs for people with SMI are comparable to those of other target groups with physical and cognitive disabilities.

2. *Whether and how to address needs for assistance--particularly for supervisory and instructional assistance--that are specifically associated with mental illness and that may not be adequately captured by typical measures of need for long-term services (ADLs and IADLs) or by cognitive impairment measures designed for persons with dementia disorders.*

This analytic task is made more difficult by the requirement to distinguish supervisory help that is needed to negotiate daily life outside of an institutional setting from help that may be needed to function productively in an age-appropriate manner in terms of work or attending school. These distinctions are

the basis for drawing boundaries between programs intended to finance and deliver long-term services needs with those whose purposes are to address vocational rehabilitation or special education needs. The difficult nature of defining these boundaries is particularly evident with regard to children with severe emotional disturbance (SED) who may also have diagnoses of MR/DD. Many experts and advocates appear to take the position that clear boundaries cannot and should not be drawn between long-term services and vocational rehabilitation and/or special education services for either the SMI or MR/DD populations.

3. *How to define eligibility and provide services in a manner that recognizes and deals with the cyclical nature of mental illness--without, however, according persons with SMI preferential treatment in comparison with members of other target groups.*

Most persons with physical and/or cognitive disabilities have levels of impairment and associated service needs that are consistent over long periods of time (typically expected to last for three or more months). In contrast, persons with SMI may have periods of need that would qualify them for long-term services, but they are also capable of achieving significant improvements in functioning and then again experiencing crises that can return them to severe levels of functional disability. In these periods of improvement, people with SMI may no longer qualify for services restricted to persons with severe disabilities. Nevertheless, many experts argue for continued service provision to prevent acute exacerbation of symptoms. Thus, there is concern that the bureaucratic gatekeeping mechanisms that restrict access to long-term services to a target population of severely disabled individuals--and which typically impose a lengthy period to establish or to re-establish program eligibility--may be particularly ill-suited to meet the service needs of the SMI population.

II. BACKGROUND INFORMATION ON PERSONS WITH SMI

Before describing the background data on persons with SMI, clarification of terminology is necessary. The terms impairment, disability, and handicap are often used interchangeably but are actually quite different and can result in varied interpretations of the eligible population and cost of a long-term services program.³ Definitions of and differences between cognitive and mental impairment must be clear as well. Mental health professionals identify cognitive impairment and mental illness separately; a person who has a SM may or may not be cognitively impaired. It is important to recognize this distinction and not group these individuals into one category.

It is also important to understand the differences in how mental health professionals conceptualize services for the SMI population as compared with how professionals (e.g. geriatricians and gerontologists) categorize the service needs of the disabled elderly. Long-term care services for the elderly have been defined primarily as assistance with ADLs and IADLs, often excluding rehabilitative services such as physical, occupational, and speech therapies that are considered to be acute or post-acute (medical and skilled-care) and oriented toward achieving improvements, rather than providing assistance, in ADL/IADL functioning. Moreover, the equivalent to psychosocial rehabilitative services (often used by persons with SMI--discussed in section C below) for treating mental disorders is difficult to identify for older persons with traditional long-term care needs (needs resulting from cognitive, not mental impairment). Cognitive impairment in the elderly is usually the result of Alzheimer's disease, multi-infarct dementia, or other underlying conditions that are irreversible degenerative diseases which are not responsive to drugs or other therapeutic treatments. "Psychosocial" services for persons with dementia disorders tend to focus on behavioral psychology methods for managing symptoms (such as emotional agitation) and behavior problems (such as wandering and aggression). As will be discussed below, mental health professionals do not make the same distinctions between medical and non-medical or "social" services and between rehabilitative versus supportive services.

³ The difference is that impairments occur at the organ level, disabilities at the action level, and handicaps within the social environment (Kennedy and Gruenberg, 1987; Kennedy, 1993). For example, blindness is an impairment, inability to read a book through sight is a disability, and the inability to attend school because facilities and material for the blind are not available is a handicap.

A. Description of the SMI Population

1. Size of the population

In the field of mental health, the characteristics of diagnosis, disability, and duration have been used to determine past and present estimates of people with SMI. In 1981 the term chronically mentally ill was used and included those with a diagnosis for a major mental illness, severe disability, and a duration of illness for at least one year (1.5% of the U.S. population ages 18+ qualified). Later the terminology changed and referred to the severely and persistently mentally ill, including all mental illness diagnoses and all severe disabilities with a one year duration (estimates ranged from 2.1-2.6% to 2.8 and 3.2% of the U.S. population ages 18+). The most recent definition refers to persons with severe mental illness, which includes all diagnoses, substantial disability, and no required duration (some estimates show this as encompassing 5-7% of the U.S. population ages 18+).⁴ The definitions of SMI and the estimates of the population have changed in attempts to encompass the heterogeneous group of persons with SMI. While the most recent definition involves more people, it also captures those who have intermittent periods of serious mental illness over a long period of time (CMHS, 1992).

Serious Mental Illness and Disability in the Adult Household Population: United States, 1989 (using data from the 1989 National Health Interview Survey mental health supplement) estimates that 3.3 million people 18 years of age or older had a SMI (a serious mental illness⁵ resulting in disability for at least one year) in the past 12 months; 2.6 million of these individuals had specific limitations in work, school, personal care, social functioning, concentrating, or coping with day-to-day stress; and 1.4 million adults between the ages of 18 and 69 were unable to work.⁶ Since family members served as respondents for some of the individuals, the validity of such data depends on the person's or family's awareness and willingness to report mental illness regardless of stigma; such concerns suggest that the prevalence rate of SMI is probably underestimated.

Another major source of data on adults with SMI is the Epidemiological Catchment Area (ECA) study, a survey from 1980-1985 sponsored by the National Institute of Mental Health (Regier et al., 1993; NAMHC, 1993). The ECA estimates that in a one-year period 2-3% of the population were affected by severe mental disorders (approximately five million people in 1990). While the ECA estimates are useful and provide insightful information when used along with other data sources (Manderscheid et al., 1993), the ECA survey must be interpreted carefully as it is not nationally representative.

⁴ Personal communication, Ron Manderscheid.

⁵ The diagnoses most often included in definitions of severe mental illness are schizophrenia (or other paranoid or delusional disorder), bipolar disorder, major depression, or severe personality disorder.

⁶ These categories of figures are not mutually exclusive.

For children, little reliable data exists. The 1992 National Institute of Mental Health (NIMH) Cooperative Agreement for Methodologic Research for Multi-Site Epidemiologic Surveys of Mental Disorders in Child and Adolescent Populations, which cannot be generalized to the entire population, states that 3.2% of the sample ages 9-17 had a severe mental disorder. NCHS states that among children ages 3-17, 13.4% have an emotional or behavioral problem. These estimates vary greatly due to the differences in defining the population, as well as the lack of information available. More information, however, on children with mental illness and long-term service needs will be available in the next five to seven years. NIMH will be conducting a multi-site study of 30 different programs and the effectiveness of service delivery and need for mental health services for children between the ages of four and seventeen.

More information about SMI and disability will also be available from the Disability Supplement to the National Health Interview Survey. Data from round one of this supplement is currently being collected. For adults who report a need for assistance in (or that they get help performing) ADLs and/or IADLs, information about the condition causing the need for assistance is collected. In addition, an entire section of the survey is devoted to questions about mental health: specific diagnosis of mental disorder; feelings of depression or anxiety; trouble making or keeping friendships; getting along with people in social settings; the ability to concentrate long enough to complete everyday tasks; and how these and other problems interfere with the person's ability to work or attend school. Persons are also surveyed about services they have used: programs that assist in developing skills for employment; programs that provide social, recreational, and developmental activities; and other programs that provide case management, occupational therapy, or other services. Specific questions addressed to children include measures of disability by looking at the use of health care services (e.g. going to a counselor or psychiatrist on a regular basis), delays in mental development, and problems getting along with others. The education section of the supplement addresses reasons for not attending school and behavior problems in school.⁷

2. *Other characteristics of persons with SMI*

Information about the living arrangements of persons with SMI is not available at the national level. A survey by the Alliance for the Mentally Ill/New York State, though not nationally representative, is a rare source of information. The survey showed that 41% of persons with mental illness live with family members (information on specific family members lived with is not available), 28% have some type of employment, 24% have structured daytime programs, 11% attend school, and 14% do volunteer work. Forty-six percent had no particular activity in which they spent most of their time (partly because part-time jobs or structured programs occupy only portions of their day). Forty percent of those surveyed have been arrested at some time, and other problems include difficulty concentrating (79%), impaired judgement (74%), withdrawal around others (60%), and suicide attempts (37%). This survey does not break down its information by severity of

⁷ For more information about the content of the Disability Survey, contact Michele Adler, ASPE/DALTCP, 202/690-6443.

the illness (e.g. if the person has a SMI). Also, this was a mail survey which had a low response rate (42%) of usable questionnaires (Grosser and Vine, 1991).

About 703,000, or 23.2 percent of adults with SMI receive disability payments [through Social Security and Disability Insurance (SSDI), Supplemental Security Income (SSI), or the Veteran's Administration] because of their mental disorder. For persons with SMI, SSDI (46%) and SSI (43.5%) were the most reported payments (Barker et al., 1992). In the SSDI and the SSI programs, the largest percent of beneficiaries are receiving payments on a disability due to a mental disorder (Kennedy and Manderscheid, 1992). For SSI and SSDI, a disability is inability to engage in substantial gainful activity because of a physical or mental impairment that will result in death or has lasted (or will last) for not less than twelve months. There are also non-medical requirements: sufficient work history (SSDI) and low income (SSI). In 1991, 23% of disabled workers received SSDI benefits because of a mental disorder and 21.4% individuals received SSI benefits because of a mental disorder. These numbers must be interpreted with caution, as a mental disorder is not equivalent to having a SMI. It is interesting to note, however, that the number of SSI recipients disabled by a mental disorder increased 80% between 1986 and 1991 (Frank and McGuire, 1994).

B. Service Use and Needs of Persons with SMI

Efforts in the past twenty years toward finding more effective alternatives to institutionalization for persons with SMI have led to the development of psychiatric rehabilitation services, also known as psychosocial rehabilitation, a term that encompasses several types of community-based mental health treatments. Current funding for much of these services occurs through the rehabilitation or clinic options of state Medicaid programs. More than 2,000 agencies provide these services throughout the United States. Not all persons with a mental illness require psychosocial rehabilitation services; the most frequent diagnoses of persons needing the service include schizophrenia, manic depressive disorders, depression, and severe personality disorders (Hughes, 1994).

Psychosocial rehabilitation serves to meet several non-medical needs of persons with SMI: assistance with social relationships, recreation, vocational skills, and self-care. Psychosocial rehabilitation's goal is to enable individuals to compensate for or eliminate functional deficits, interpersonal barriers and environmental barriers, and to restore ability for independent living, socialization, and effective life management. After an assessment process, a rehabilitation or treatment plan is developed. Through activities of psychosocial rehabilitation, skills are learned involving daily living, social interactions, and problem solving. The activities of such programs are designed to represent the real activities of every day life, thus much of the rehabilitation must occur within the community (Hughes, 1994).

1. **Models of service delivery**

The TCL Model and PACT

The Training in Community Living (TCL) model developed in the 1970s in Wisconsin. TCL is an intensive program of community care where a team provides a full range of medical, psychosocial, and rehabilitation services. The rationale for TCL is that "...ubiquitous to the field of community treatment and rehabilitation is the question of how to deliver this range of services and supports in a way which reaches the target population in a timely fashion--that is, in a manner which optimizes the chances that clients and significant others will receive what they need, when they need it" (Test, 1990). TCL emphasizes continuity of care through a core services team, assertive outreach, and individualized, on-going treatment. Assertive outreach involves actively going out to meet the client's needs in the community. Attention is continuously given to symptom management through help with medications, 24-hour crisis availability, brief hospitalizations, and one-to-one relationships. In addition, support is given to family members. Evaluation results of TCL have been very positive. TCL patients spent more time in independent living situations, and showed more favorable community adjustment in the areas of employment, social relationships, symptomatology, and satisfaction with their life, as well as effectiveness in reducing hospitalization (Test, 1990).

An example of psychosocial rehabilitation that is modeled on TCL is the Program for Assertive Community Treatment (PACT). PACT is a community-based program targeted to those who have multiple episodes of illness, drug non-compliance, and high use of psychiatric hospitalizations and other services. Since PACT is an intensive approach to reducing symptoms and preventing relapse, it is often only indicated for a small proportion of those with a SMI. Within PACT, the staff to client ratio is 1:10-12. Each team is required to have a wide range of professional skills including social work, psychiatric nursing, occupational therapy, psychology, rehabilitation counseling, and psychiatry (Test et al.; Burns). Services provided under the PACT program used in South Carolina are outlined on the next page.⁸

A number of strong positive findings have been reported in PACT research. All of the trials report more independent living for PACT clients at follow-up. Hospital admissions and length of stay were significantly lower for PACT clients in all but one study and cost-effectiveness has been demonstrated. Perceived quality of life was more positive for PACT clients in eight out of nine studies. Finally, gains in instrumental functioning and community living skills were greater for PACT clients in the majority of studies where this was assessed. Other effects were not so strong, including symptom reduction, social functioning, employment status, and medication compliance. However, the researchers involved in PACT argue that sufficient evidence exists to merit

⁸ The following table is adapted from a presentation by Alberto B. Santos, M.D., Professor, Department of Psychiatry, Medical University of South Carolina.

continued research on this model. Currently, PACT is in statewide use in Delaware, Michigan, Rhode Island, and Wisconsin. Another 20 states have several PACT teams.⁹

DESCRIPTION OF PACT SERVICES	
Medication Support	Order medications from pharmacy Deliver medications to clients Education about medication Monitor medication compliance and side effects
Rehabilitative Approach to Daily Living Skills	Grocery shopping and cooking Purchase and care of clothing Use of transportation Social and family relationships Education about legal rights
Family Involvement	Crisis management Counseling and psychoeducation with family Coordination with family service agencies
Work Opportunities	Support in finding volunteer and vocational opportunities Liaison with and education of employers Serve as job coach for clients
Entitlements	Assist with documentation Accompany clients to entitlement offices Manage food stamps
Health Promotion	Preventive health education; medical screening Schedule maintenance visits Liaison for acute medical care
Housing Assistance	Find suitable shelter Secure leases and pay rent Purchase and repair household items Develop relationships with landlords Improve housekeeping skills
Financial Management	Plan budget; assist with bills Troubleshoot financial problems (e.g. disability payments) Increase independence in money management
Counseling	Problem-oriented approach Integrated into continuous work Goals addressed by all team members Communication skills development Part of comprehensive rehabilitative approach

The evaluation of Michigan's model of PACT and TCL, known as ACT, followed 1000 clients two years before participation in ACT and four years after; there will also be an eight year follow-up. For these clients, hospitalization rates decreased 70% after the first year and 90% after four years. ACT teams are also beginning to address the needs of subgroups: special teams have started to address the needs of older persons who have SMI, as well as those with a dual diagnosis of substance abuse and/or who have criminal records.

⁹ Many other states have programs that have expanded upon the PACT model which are not discussed here. For example, New York state uses intensive case management which is also an assertive, community-based rehabilitation program.

Clubhouses

In addition to TCL, PACT, and ACT, another form of psychosocial rehabilitation is the clubhouse model which, instead of serving individuals primarily in their homes, brings people to one central location in the community to participate in daily activities. In clubhouse models, people who join become members and are expected to play some role in the functioning of the organization. Many activities in the daily operations of the organization (such as bookkeeping or preparing meals) performed by members. Clubhouse models also offer assistance in obtaining employment and housing. Way Station is a clubhouse located in Frederick, Maryland, which has shown several positive results. At Way Station, the cost of serving a member averages \$20,000 per year, while the cost per person at a state mental facility averages four to five times this amount (based on a full-year length of stay). Way Station has also helped its members sustain a low psychiatric hospitalization rate of 4.75%.

The previous discussion of TCL, PACT, and clubhouses indicates that various psychosocial treatment programs demonstrate positive effects. An important question to ask, however, is whether these programs will be effective over many years when treating persons with SMI who cycle in and out of the mental health system and need long-term services. DeSisto et al. (1994) examined the long-term outcomes (follow-ups of 32 and 36 years) of psychiatric rehabilitation by comparing two states, Maine (traditional care) and Vermont (rehabilitation). A sample of 269 persons were matched on age, gender, diagnosis, and chronicity. Overall, Vermont subjects still living at follow-up were more productive, had fewer symptoms, better community adjustment, and global functioning than Maine subjects. The issue then becomes whether or not the differences in outcomes were or were not due to Vermont's program which allowed an earlier opportunity for community life. The authors argue that the differences, after adjustment, are likely to be attributed to the Vermont program. What may be more difficult, however, is generalizing these results (average age of 65 at follow-up) to the current group of younger people with SMI because of cohort differences.

2. Existing patterns of service use

Specific information on utilization of community-based mental health services by persons with SMI is not readily available. Many community-based psychosocial rehabilitation centers have developed recently or are small organizations, and there has been little data collection that is useful for policymakers interested in issues related to long-term services. If some data are available, different methods for collecting this information makes comparisons between centers difficult. Furthermore, available surveys describe utilization of treatments for mental disorders with a highly medical focus and do not provide specific information on social or long-term services (i.e. psychosocial or vocational rehabilitation). More nationally representative data are needed to estimate what specific social, long-term, and community-based services of mental health programs are used most often by individuals with different levels of functioning. However, the mental health field has not traditionally divided its services

into acute and long-term services, making it more difficult to assess the amount of "long-term care" that is used by people with SMI.

Way Station, a community-based mental health program in Frederick, MD, has attempted some assembly of data by looking at the utilization of services among different groups who were categorized by the Global Assessment of Functioning (GAF) Scale. GAF scores range from 1 to 90; ninety indicating absent or minimal symptoms and good functioning in all areas, and a score between 1 and 10 indicating persistent danger to self or others or inability to maintain minimal personal hygiene. Way Station divided individuals into four groups, with group one having the lowest GAF scores, and group four the highest. The hours of service utilized per week were (with percent of membership in parentheses): group one (22%)=40; group two (46%)=38; group three (30%)=27; group four (2%)=5.¹⁰ Services that were included in utilization hours were club (adult medical daycare and psychiatric rehabilitation services), clinic (verbal and/or chemotherapy management), housing (psychiatric rehabilitation in supervised houses), outreach (provided at member's home or in the community), and intensive support services (24 hour crisis management services).

Some general information about service utilization at a national level is available. Narrow et al. (1993) used data from the ECA and looked at the treated SMI population and what settings individuals went to, the number of visits per setting and per person, and a breakdown of information by disorder and type of service. This survey of adults shows that 14.7% of the US population (not just those with SMI) reported use of mental health services, irrespective of diagnosis; of those with a mental disorder only 28.5% sought services. The ECA also looked at service use-rates for specialty mental and addictive disorders (SMA), general medical/nursing home (GM), human services (HS), and voluntary support network (VSN). For the total population the utilization was: SMA=5.9%; GM=6.4%; HS=3 % (includes clergy or religious counselors); and VSN=4.1% (includes self-help groups and relatives or friends). While 28.1% of the sample was affected with SMI only about half receive care; the lowest service percentage receiving service were individuals with severe cognitive impairment. Of the VSN group, most service is provided through family and friends, which shows the burden placed on informal caregivers.

3. *Survey-based estimates of service need*

A model of the Community Support System (CSS), developed in Ohio, is an establishment of an array of services including outreach, housing, emergency/crisis response, medication, vocational, and other services to meet the needs of individual clients.¹¹ In a survey of CSS case managers regarding the needs of a randomly selected group of clients, three major categories of need for persons with SMI were found: (1) supplemental services to support case management, (2) day program services, and (3) residential programs. Examples of supplements to case management

¹⁰ GAF score breakdowns: group one, 30 or less; group two, 31-50; group three, 51-70; group four, 71 and above

¹¹ This description of CSS is based on Ohio's use of the model; the CSS model itself was developed by NIMH in the 1970s.

include: psychotropic medication monitoring and home-based medical support, substance abuse treatment services, budgeting and protective payee services, counseling, support groups, and specialized therapy. Forty percent of respondents stated the need for day program services which include social clubs and social functioning opportunities, specialized programs for higher and lower functioning clients, and expanded vocational training and supported employment efforts. Fifty-two percent of the respondents described a need for housing/residential service, and 24% for subsidized apartments (three times the current number available). Other cited needs include group homes or structured residential programs and residential programs targeted toward a special sub-population, such as those with a dual diagnosis of substance abuse or mental retardation (Ford et al., 1992).

A mail survey in New York state had similar results to those mentioned above, demonstrating the need for increased housing. Most individuals also needed help with meals, household chores, and money management. This sample is not representative, as people who are homeless are not accounted for in the sample, and children, lower-income families, and minorities were under-represented; the findings, however, are consistent with other surveys (Grosser and Vine, 1991).

C. Financing of Services for Persons with SMI

State governments are largely responsible for mental health services, especially services for individuals with SMI and persons who are poor. It is difficult to analyze the revenues and expenditures to form a national picture of financing because states structure their mental health systems differently. Furthermore, obtaining information on the financing of "long-term care services" is difficult because this distinction is not made in the field of mental health. Nevertheless, a general picture of the financing can be obtained from Frank and McGuire (1994). They estimate that \$54 billion was spent on mental health and substance abuse services (community and institutional services) in the U.S. in 1990. Of this \$54 billion, 33% was accountable to a relatively small group of persons: the uninsured with a SMI (who account for 2.2% of the population). Costs for these uninsured are paid for through various local, state, and federal programs (also known as public mental health care). The rest of the \$54 billion is allocated to those with private insurance (41.1%), Medicare (4%), Medicaid (17.6%), and the uninsured who do not have a SMI (4%). Only 3% of Medicare payments are due to utilization of mental health and substance abuse benefits. Medicaid, as the authors note, is much more complicated to explain due to its joint federal/state nature and its mixture of mandated benefits and optional state benefits. In addition to Medicare and Medicaid, public mental health care accounted for approximately 59% of all expenditures on mental health services in 1990. Public mental health involves services provided by facilities that are publicly owned, public insurance programs (e.g. Medicaid) that are used to purchase mental health services from a range of provider types, and direct purchase of mental health services by state or local government from private service providers. In addition to these sources of funding, there are intergovernmental transfers among the three levels of government.

No recent work has been done that explains how community-based services such as PACT programs or clubhouses are funded. Anecdotal evidence shows that PACT programs "negotiate" with states to determine which PACT services can be reimbursed through Medicaid and which services must be financed through the development of other mechanisms. More than 30 states have the rehabilitation option; these are the states whose community-based programs are paid with larger portions of Medicaid.¹² As an example of a program at the local level, Way Station receives 52% of its revenues from Medicaid, 29% from the Maryland Department of Mental Hygiene, 12% from members, 5% from Medicare, 1% from contributions, and 1% from other sources. While it is unclear exactly how community-based mental health services, particularly long-term care services, are funded, it is clear that some states do not utilize Medicaid at all, whereas other states use Medicaid to fund a large portion of these services. For the states that fund a large proportion of "long-term care services" through Medicaid, the availability of these services to persons with SMI could change dramatically if modifications are made to the Medicaid program.

¹² Collette Croze, personal communication, 11-94

III. POLICY IMPLICATIONS

A. Options for Establishing Eligibility Criteria for Long-Term Services

One of the difficulties in establishing a long-term services benefit that covers a diverse population is ensuring that the eligibility criteria are suitable, equitable, and capture the most severely disabled of various disability groups. Many proposals for health care reform throughout 1994 included long-term care provisions with eligibility criteria requiring severe mental or cognitive impairment and need for assistance in ADLs or IADLs. Considerable debate has occurred regarding the appropriate choice of eligibility criteria, whether eligibility should only be based on functioning, without looking at the cause of the disability, or if diagnostic measures should be used along with the functioning screens. Because the needs (measured with ADLs and IADLs) of elderly persons have traditionally been the focus in determining the eligibility for long-term care, the validity of using these measures should come under scrutiny when determining eligibility for a program that targets additional disability groups under the age of 65, including persons with SMI. Even though the HCBS provisions of the HSA included a separate list of criteria for mental or cognitive impairment, this particular criterion also stated that need had to be demonstrated by ADL or IADL dependencies.

1. *GAF scores and service need*

In one of the estimates to determine the eligible population for the HSA, the number of persons with a Global Assessment of Functioning (GAF) score of 40 or less,¹³ in combination with limitations in three ADLs (or a combination of three ADLs and IADLs) were estimated. The result of the analysis, conducted by Dr. Susan Bassett of Johns Hopkins, was an eligible population within the entire United States of .05 percent (excludes those with cognitive impairment, i.e. individuals with primarily Alzheimer's and other dementias and those above age 65, as well as individuals with mental retardation). This analysis results in a small number of people with SMI who would be eligible for long-term services, but if the criteria used only IADL limitations (not combinations of GAF, ADLs, and IADLs), the eligible population expands to the point where the benefit becomes financially unmanageable.

2. *Combinations of ADLs and IADLs*

A second method of determining eligibility is using ADL and IADL scales similar to that in the proposed HSA. The benefit of using IADLs along with ADLs is that considerable agreement exists that IADLs are a better indicator of disability than the ADL criteria for people with SMI. Results of analyses of the 1989 Mental Health Supplement to the National Health Interview Survey (NHIS) of the household population

¹³ These individuals have some impairment in reality testing or communication or major impairment in several areas such as work or school, family relations, judgement, thinking, or mood.

show that persons with a diagnosis of a severe mental illness have difficulty primarily with IADLs, and very few report problems with ADLs only. For example, of the 3,264 individuals with a SMI, 2.7% of the population 18-69 years of age had limitations in personal care ADLs, while 22.9% of this population had limitations in IADLs. For the population 70 years of age and above, 24.3% had limitations in personal care ADLs and 62.3% in the IADLs (Barker et al., 1992). IADLs that were measured included managing money, doing everyday household chores, shopping, and getting around outside the home. Analysis of data from the Survey of Income and Program Participation (SIPP) shows similar trends: for individuals ages 18-64, 90,000 of those with mental illness need help in three or more ADLs (109,000 for age 65+), while 219,000 need help in a combination of three or more ADLs or IADLs (189,000 for age 65+).¹⁴ While SIPP and the NHIS provide some estimates of the number of people with SW, questions arise about whether other eligibility criteria and sources of data would be more useful in capturing those people who have a SMI and need long-term services.¹⁵ Furthermore, showing level of severity with IADLs versus ADLs is difficult, because no hierarchy exists among the IADLs.

3. *Executive cognitive function*

A third, less-known method for determining eligibility in people with cognitive and mental impairments is the Cognitive Dysfunction test, which was developed by researchers at Brown University and the University of Texas. Although the subject of considerable debate, Fogel et al. (1994) argue that one test which measures executive cognitive functions (ECF), the functions which allow persons to engage in goal-directed behavior, (as well as ability to plan, use judgment, follow through on activities, and exercise self control) can be used as an eligibility determinant for all *mentally and cognitively* impaired populations and predict the need for long-term services among these groups. They state that tests of ECF address the insufficient ability of physical and cognitive screens to capture those individuals with a SMI. The rationale behind ECF is that "a person with impaired cognitive function (ECF) may have completely adequate physical and sensory function, and adequate cognitive function in many areas, but still not be able to function safely and appropriately or to carry out necessary activities of daily living." An example is a person who can walk without difficulty, but who cannot walk to a specific destination to accomplish a certain task. The developers of ECF indicate that this criteria could be used for persons with physical disabilities; they believe that executive deficits undermine the independence of elderly persons and lead to the expression of behavior problems in nursing homes. The problem with implementing an entirely new screening test such as the ECF is that there are no national surveys to accurately estimate the eligible population or costs of the program. Furthermore, this method has not been generally appreciated due to practical limits in formal testing (Royall et al., 1993).

¹⁴ Source: unpublished data, Michele Adler, ASPE.

¹⁵ These numbers do not include persons who are homeless or have a SMI.

4. Use of individual states' criteria

To address the limitations of the previous measures, consideration of other methods to determine eligibility should be examined, including methods used at the state level. Schinnar et al. (1990) conducted a study that looked at whether the populations of chronic mentally ill patients were comparable across states and if state estimates could be used in developing a national estimate of this population. The study applied the definitions of chronic mental illness from ten states to a representative sample of patients receiving public mental health services in Philadelphia. The prevalence of chronically mentally ill persons ranged from a low of 38 percent to a high of 72 percent. In another study, Schinnar et al. (1990) applied eligibility criteria from seventeen definitions of severe and persistent mental illness in the literature over the past decade. The variance was even greater, ranging from four to 88 percent. As the authors note, variance is not only caused by different definitions of eligibility, but also in the manner that the criteria are operationalized and because of sub-state variation at the county and local levels (states may have an overall definition of SMI, but additional eligibility criteria are used for different programs). A sample of the various criteria used to determine eligibility for services in the SMI population among different states is listed below.¹⁶

Despite the lack of national data on patterns of long-term care services use and needs of the SMI population, there is a clear conceptual consensus among mental health experts on how to define the SMI target population for long-term services. The experts agree that eligibility criteria should target persons with SMI who are at high risk of multiple and/or longstay mental hospital admissions and who need services that would be financed under a long-term care program. Conceptually, this approach meets a preliminary test of promoting parity across disability groups, because most severely disabled persons among other disability groups are individuals who are considered to be either "at risk" or likely to be eligible to seek placement in institutional or alternative community-based residential care settings. What is less clear, however, is whether a **single** set of eligibility criteria can distinguish a limited size group of individuals across all age groups and diagnosis/condition categories.

For example, based on analyses of the 1989 National Long-Term Care Survey (NLTCS), it appears that the elderly population with dementia, defining "severe cognitive impairment" by means of a certain combination of IADL impairments is feasible. Persons aged 65 and older who require assistance with at least three out of four specific IADLS (meal preparation, telephoning, money management, and medication management) show patterns of service use (measured in terms of formal/informal caregiver hours received weekly and number of hours that the primary caregiver reports that the care recipient can be safely left alone) that are comparable to those of elders who have three ADL impairments or who score as "severely cognitively impaired" by virtue of their error scores on the Short Portable Mental Status Questionnaire (SPMSQ). Unfortunately, it is not currently possible to obtain comparable measures for persons

¹⁶ This information was collected through informal discussions with various state mental health departments. No standardized questionnaire was used for collecting the information, and not all states were contacted.

with SMI having this same profile of IADL impairments. Not only are there no comparable data available on hours of formal/informal service use among the SMI population, nationally representative surveys of persons with SMI do not even include all four of the relevant IADL measures (medication management is missing). Thus, it is impossible to estimate how many persons with SMI have this particular profile of at least three out of the four IADLs listed above.

California	detailed information is available (Rehabilitation Option and Targeted Case Management Manual); services offered through local funds have differing eligibility criteria across the state
Connecticut	(1) diagnosis of severe mental illness, has a psychiatric disorder of sufficient severity to cause a current disturbance, or has been hospitalized for psychiatric treatment one or more times in the past three years (or receipt of community-based psychiatric services in last twelve months; and (2) does not have a principal diagnosis of mental retardation, alcoholism, or drug abuse; and (3) does not have private insurance or insurance benefits have been exhausted
New Hampshire	determine eligibility for four different categories: Severe and Persistent Mental Illness (SPMI), Severe Mental Illness (SMI), Former Severe Impairment (FSI), and Low Utilizer; eligibility for each category by looking at psychiatric diagnosis, functional impairment due to mental illness, duration of the functional impairment, and service utilization (detailed flowchart of process is available)
New Jersey	level of functioning at or below average and a length of the current treatment episode of at least one year or previous admission to a psychiatric hospital
New York	three criteria: psychiatric diagnosis; functional disability and impairment in self-care, social functioning, ADLs, economic self-sufficiency, self-direction, and the ability to concentrate; and usage of mental health services over the past two years with a history of repeated hospitalizations, emergency room contacts, etc., or qualification for SSI or SSDI due to mental illness
Ohio	(1) eligible for SSI or SSDI for a mental disability; (2) meeting two of the three criteria: mental illness diagnosis, amount of time hospitalized or in continuous community treatment, and level of functioning (looking at past two years)
Pennsylvania	must meet two of three conditions: diagnosis of schizophrenia or affective disorder; lengthy stay in a state hospital, multiple admissions to a general hospital, multiple emergency room contacts, or continuous or intermittent course of outpatient treatment over a three-year period; and low level of functioning (or somewhat higher for young adults with a history of aggressive behavior)
South Dakota	has severe mental disability demonstrated by frequent, recent, or extensive hospitalizations, by need for psychotropic medication, and by frequent crisis contacts; impaired role functioning demonstrated through employment (or lack of), inappropriate social behavior, lack of basic living skills, lack of social support systems, non-compliance, need for financial assistance, etc.
Texas	(for adults) diagnosis of schizophrenia, bipolar disorder, or major depression along with a score below 50 on the GAF scale and a need for either crisis resolution or long-term mental health care
Virginia	persons age 18 and over who at any time in the past year have had a diagnosable mental, behavioral, or emotional disorder that meets criteria specified under DSM-III-R that has resulted in functional impairment which substantially interferes with or limits one or more major life activities; within this standard definition, a priority population is defined as well; this consists of persons who have been diagnosed with a major mental disorder that have either undergone psychiatric treatment more intensive than outpatient care more than once in a lifetime or have experienced a single episode of continuous, supportive residential care for a period long enough to disrupt the normal living situation

Several approaches to developing eligibility criteria for the SMI population have been discussed: (1) GAF Scores and service need; (2) Executive Cognitive Function;

(3) Combinations of ADL/IADLs; and (4) Use of States' Definitions. The pros and cons of each of these methods are summarized in the chart on the next page.¹⁷

	PROS	CONS	ELIGIBLES
GAF Scores and Service Need	<p>scores are believed to be closely correlated with risk status for repeat, longstay mental hospitalization</p> <p>many states are already using similar systems; mechanisms already in place</p>	<p>relies on clinical judgment (i.e. usually a psychiatrist); cannot be applied by a generalist social worker in a one-hour home visit</p> <p>diagnosis-specific approach that is a blend of functional and cognitive impairment measures; not a purely "functional" approach</p>	varies on GAF score used with other measures
Executive Cognitive Function	<p>according to Royal et al.:</p> <p>accurately captures disability for people with both mental and cognitive impairments; possibility of use for persons with physical disabilities; determines eligibility without being age or disease specific</p> <p>can be administered in a short amount of time (15 minutes) by laypersons and nonmedical personnel; internal consistency has been shown; interrater reliability is high</p> <p>ability to capture stress of caregivers; more sensitive to detecting mild impairments than Folstein Mini-Mental State</p>	<p>national estimates of the population are not available, currently unable to predict eligible population, utilization, and costs of long-term services using this method</p> <p>very recent approach, effects are hard to predict</p>	unknown
Combinations of ADLs/IADLs	<p>some national data exists on people affected</p> <p>easier to apply universally to other groups needing long-term services</p>	<p>while adequate data exists on older populations, less data is available about non-elderly groups</p> <p>not sure if this is best measure of disability for people with SMI, may be biased towards elderly care or physically disabled</p> <p>difficult to show severity with IADL scales</p>	under estimates for HSA: 1.25 million (cognitive and mental impairment)
Use of Individual States' Criteria	each state may be best able to tailor its program to its particular needs	service availability may differ widely among states; some states may underserve or overserve individuals	varies by state
SSI or SSDI	system already in place	<p>measures for determining eligibility include medical and nonmedical methods (income and work history, not just ability to engage in "substantial gainful activity")</p> <p>SSDI is tied to sufficient earnings from work history and ability to work</p>	<p>SSDI: 731,500; SSI: 596,800 (1991)</p> <p>(these persons have mental health problems, may or may not have SMI)</p>

Given the previous descriptions of state definitions of the target population of SMI and the options for determining eligibility for a program offering long-term services, several unresolved issues remain. The list of states' definitions and options for eligibility

¹⁷ Since many states use eligibility for SSI and SSDI as criteria for determining a person eligible for community-based mental health services, this option is presented separately in the following chart.

criteria described within this report are not finite. Many more options exist, but are not described. And among the options that have been described, no clear criteria emerge as the best method. It is also not clear that allowing states to develop their own definitions is the best route for determining eligibility. There is substantial variation in how states define their target population. Some states use very general guidelines, others have very detailed criteria. This variation may or may not be beneficial. If states are appropriately serving persons with SMI, allowing state flexibility may be the best way to continue determining eligibility for services. However, determining if the state's definition works well, especially since sub-state variation occurs, is very difficult.

B. Are the Needs of Persons with SMI Addressed by Long-Term Services?

Benefits proposed in the HSA's HCBS provisions included a requirement of states to provide personal assistance services and the flexibility to include as many of the following services: case management, homemaker and chore assistance, home modifications, respite care, assistive technology, adult day services, home health, habilitation and rehabilitation, and supported employment. A key issue is determining whether traditional long-term services and the above list of benefits would appropriately serve individuals with SMI. Case management services are an example of the complexity of this issue. Case or team management is a beneficial service for individuals with SMI. What becomes problematic is that the definition of case management can vary widely. Some models of community-based mental health services emphasize an intensive team approach to monitoring patients, involving daily interaction with clients in their own living environments. This is quite different from using case managers who interact with a client once per week in a facility outside of the clients home. The costs and outcomes of these two approaches can vary widely due to differences in case management staffing, work load, client characteristics, and service intensity.

A further example of the issues related to defining benefits can be shown with the case management design within the Robert Wood Johnson (RWJ) demonstrations. RWJ announced its initiative in December 1985 with the goal to strengthen the potential of individuals with SMI to live independently. The demonstration operated on the belief that it was possible to connect previously alienated service sectors such as mental health and housing through case management. A service integration approach was used to enhance the possibility of creating innovative solutions to service delivery problems. The goals of the demonstrations were to ensure continuity of care, flexible financing, a range of housing options, and an enhanced range of rehabilitation programs. An evaluation of the RWJ demonstrations found improved continuity of care in three out of four cities that were studied, yet analysis was unable to detect improvements in client outcomes, and psychiatric symptoms were even worse in the second cohort studied. The RWJ demonstration succeeded in advancing structural goals and improving continuity of care, yet no significant improvements were found in quality of life even though satisfaction of clients was high. In any future demonstrations

examining the efficacy of case management, these results indicate a need to focus on clinical and social care as well as organization and financing when designing a system which relies highly on case management. While coordination is important, some energy should focus on creating the services that people really need because case management alone is not enough.

An additional problem can be demonstrated with the case management benefit, as complications occur when trying to determine what services a long-term care benefit will cover. For example, if psychiatrists and social workers are members of a case management team, would it be a medical or long-term services benefit? Case management is not the only benefit where these issues become increasingly difficult. For example, are some clubhouses for persons with SMI analogous to adult day services provided to elderly individuals, even if the clubhouses provide other services such as employment and housing assistance? Those involved in clubhouse models of care emphasize that although the clubhouse is assisting in "employment" by having an individual work in and/or outside the facility, the benefit received is really a long-term service benefit because the ability to concentrate on and complete an entire task is being enhanced, thus increasing independence and self-sufficiency.

	PACT	PACE (On Lok)
Focus/Eligibility	most severe cases of SMI population (multiple episodes of illness, drug noncompliance, high hospitalization and use of services); specifies vary by program	frail elderly, age 55 and older; assessment by team showing need; eligibility shown for nursing home level of care
Goal of Program	keep individuals in the community; prevention, rehabilitation, and symptom reduction; increased quality of life; optimization of social functioning	keep individuals in the community; prevention and rehabilitation
Treatment Base	at central community location or the homes of those in the program	day health center
Continuity of Care	team follows client through hospital, legal, health, and social services	not as intensive; delivers outpatient services directly; trying to increase linkages with supportive housing options
Benefits	housing, occupational, rehabilitation, medication management, social services, counseling	primary care, social services, restorative therapies, personal care, nutrition, recreational therapy, meals
Staff Structure	10:1; team provides integrated clinical services and case management	interdisciplinary team to manage and deliver services
Emergency Treatment 24 hours a day	team on call	PACE provider must have services accessible 24 hours/day
Frequency of Contact with Client/Family	daily if needed/weekly	information not available
Responsibility for Health/Medication	actively monitored by team; home delivery of medication if required	actively monitored by team
Length of Benefit	ongoing, not time-limited	ongoing, not time-limited

The prominent issue is determining if there can be universal definitions of benefits for varied disability groups. To help analyze this issue, a comparison of psychosocial rehabilitation (PACT model) for the SMI population and the Program of All-Inclusive care for the Elderly (PACE) is given below. Please note that psychosocial rehabilitation encompasses many services, and the description of PACT given below may vary within specific PACT programs.

From the above comparisons, many similarities are evident. Both focus on the most severely impaired segments of the population. Both have the goal of keeping individuals in the community. Efforts are made through both programs to enhance the continuity of care. The commonalities of traditional long-term services and services needed by those with SMI are evident; the biggest differences appear to be the need for employment assistance for individuals with SMI, as well as the cyclical nature of the illness.

C. ADDITIONAL ISSUES

1. Children

When looking at children, a primary concern is determining whether or not they are under the rubric of long-term services. In a policy paper endorsed by the APA, IAPSRs, NASMHPD, and the NMHA, it was stated that children with mental or emotional disorders cannot be clearly identified as having a disabling mental illness until they reach late adolescence and that the needs of children can be met in a reformed health care system, not through long-term care and services. (Although a small proportion of children may still need long-term services.) Others would argue that it is not important how these services are labeled, but that the services are available and accessible.

One of the biggest challenges facing children is the lack of coordination of information between families, the educational system, and the medical profession. The juvenile justice system has a different perception of what constitutes emotional disturbance than the mental health profession, and the legal system does not have a good understanding of mental health needs and vice versa. There are also problems within the mental health system itself. In a 1982 study, the Children's Defense Fund found striking differences among the states. Only 21 states had a designated child and adolescent mental health staff person, only seven states could report how much money was spent on children, and many states had no separate standards for children. Compounding the above problems is the lack of services and supports to parents of troubled children to assist them in navigating through a complex and uncoordinated system.

Finally, a current policy concern is deciding how to define mental impairment in children for purposes of eligibility for the SSI program. Anecdotal evidence suggests

that some children with behavior disorders currently receiving SSI are not disabled enough to warrant receipt of benefits and that families are coaching children to act in a certain manner in order to receive benefits. Proposals on Capitol Hill have addressed this concern by eliminating the "maladaptive behavior" criterion for SSI, an elimination which is questionable in its effectiveness.

2. *Caregivers*

Since informal caregivers provide a substantial amount of care, the ability to offer benefits to assist them and to establish criteria that captures high caregiver burden and stress is crucial. While one of the stresses caregivers face is the stigma of having a family member with SMI, what often is more troublesome is the continued presence of severe symptoms and the cyclical nature of the illness. Studies on the impact of families who care for someone with mental illness reveal that all aspects of a caregiver's life can be affected. Just as the nature of mental illness is dynamic, so are the needs of individuals with SMI and their caregivers. Problems faced by caregivers include fears about the future, difficulty with the unpredictable nature of SMI, and struggles in relationships and communication. Even though studies of caregiving show that caregivers sometimes participate in support groups, they still feel a lack of understanding of their problems by others (Lefley, 1989).

If a major stressor for caregivers are the cyclical and extreme behaviors of people with SMI, should the eligibility criteria address these characteristics? Fogel et al. (1994) argue that "Measurements of executive cognitive dysfunction complement measures of physical dependency in determining the amount of effort caregivers must make"; implying that eligibility criteria can be designed to measure caregiver burden. The ability of eligibility criteria to capture the stress of caregivers may be difficult to determine, but such criteria could ensure that appropriate benefits are targeted toward caregivers who are experiencing a great amount of stress, if this is an important goal.

3. *Homeless persons with SMI*

Individuals who are homeless also have needs that are difficult to identify and address. It is estimated that of the approximately 600,000 people homeless on any given day, 200,000 of these individuals are suffering from SM. What increases the severity of the situation is lack of income, insufficient social supports, and problems with alcohol or drug abuse. The assistance needed by homeless individuals with SMI is similar to the benefits needed by other groups of people with SMI, but these individuals need other services as well to assist them in a complex and uncoordinated environment: housing, alcohol and drug abuse treatment, health care and treatment of mental illness, and income support and benefits. It is unclear how the provision of long-term services would affect those who are homeless and have a SMI. But to qualify for long-term services, these individuals would obviously need to be determined eligible. Assertive outreach would be necessary to reach the appropriate individuals so that the system can assist them (Federal Task Force on Homelessness and SMI, 1992).

4. *Substance abuse and persons with SMI*

The needs of the homeless relate to an additional problem, individuals who have a dual diagnosis of substance abuse and mental illness. It is often not clear what caused the substance or drug abuse problem, but what is clear is that this makes receiving successful assistance with a mental illness more difficult, especially for homeless individuals because housing programs often will not accept people with substance abuse problems, even though the individual may not be capable of finding accessible treatment. The number of people with this problem is large. According to the analysis by Kessler et al. (1994) of The National Comorbidity Study, 45% of individuals with at least one lifetime alcohol abuse disorder reported a co-occurring mental illness; 72% with a life time history of drug abuse reported alcohol abuse, mental illness, or both; and 29% of those with a mental disorder have a alcohol or drug abuse problem.

IV. CONCLUSIONS

Given the information presented in this report, what can be concluded about the major policy issues presented at the beginning: delineating the SMI population with long-term, versus acute care needs; meeting the needs of persons with SMI through appropriate eligibility criteria; and addressing the cyclical nature of SMI?

The first issue is whether or not the distinction of long-term versus acute care should even be made for persons with SMI. In the description of PACT presented earlier, the services provided ranged from medication support to assistance with daily living skills to housing assistance. Some persons would argue that the composition of the team and the medical nature of PACT services illustrate that these are acute services. However, when looking closely at the services provided, many of them seem to mirror services provided to elderly persons through long-term care programs (e.g. assistance with medication, grocery shopping, money management).

Since the line between acute and long-term care is blurry when looking at the services provided, perhaps examining the nature of the services (whether the services aim to support or improve functioning) would be beneficial. Acute services (which are often associated with hospital or outpatient services provided by a physician, psychologist, or other licensed provider) aim to improve the condition of the person whereas long-term care services are largely supportive. Some would argue that PACT services aim to improve performance and are not supportive in nature. This argument, however, may be incorrect. Many psychosocial rehabilitation programs such as PACT are highly supportive, as many persons with SMI served by these programs are *members for life*. What may cause some confusion is the term "rehabilitation". Rehabilitation lies somewhere between acute and long-term care, and often is closer to the "acute" side of the scale. While some of the services within PACT (and other similar programs) may provide rehabilitation through attempts to improve clients' independence, they are largely long-term and supportive in nature. This is not to say that all services under PACT should be provided under a long-term care program (e.g. assistance with obtaining entitlements, serving as a job coach) for an indefinite period of time; many advocates for persons with SMI would agree that this is not possible. But to make sincere efforts toward incorporating persons of all ages and all disabilities in a long-term program, some rethinking of what is traditional long-term care may be necessary.

Answers to the second issue, determining appropriate eligibility criteria, are also unclear. The conceptual needs for appropriate eligibility criteria are apparent (combining functional and social criteria), but sufficient data do not exist to analyze the impacts of using these criteria. The 1989 Mental Health Supplement to the Health Interview Survey (and the current Disability Supplement) does include some detail about social functioning, which may help provide a better picture of the types of needs persons with

SMI have.¹⁸ There is also the possibility of using state data, or data from specific programs such as PACT. Through informal discussions with various states and inquiries about the availability of data on the levels of functioning of clients and correlating service use when developing this report, many states responded that they did not have the data categorized by long-term services, but expressed interest in learning about information need by policymakers, as well as the willingness to listen to suggestions in modifying their databases.¹⁹ Thus, efforts should be made at the federal policymaking level to work with states and organizations to identify methods for collecting data that will be useful to all parties.

As mentioned earlier, no clear methods for determining eligibility have been proposed that address the third conceptual issue, the cyclical nature of SMI. If the use of states' definitions and criteria continue, this may not be a major concern, as states may have the capability to quickly address needs. If larger long-term care reform is ever implemented, however, this need will again resurface. Mental health experts state that many eligibility criteria, as presently designed, require an individual to decompensate to receive benefits. In contrast, a system which is available and accessible when a person is functioning well would be a step toward preventing episodes of care that require longer and intensive provision of services. While this is an important goal, it leads to further problems.

For example, beyond establishing general criteria to enter the system, decisions must be made about establishing additional criteria to determine at what level of functioning a person will stop receiving benefits. Even though programs such as PACT often profess a member-for-life philosophy, such a philosophy is not feasible under a generic long-term care program. The next problem is coordinating services that are provided under a long-term care program with additional services, such as PACT or other psychosocial programs. For example, if a person is currently at a high level of functioning, how is the actual linkage made to those services that will be available when the individual decompensates? Will persons with SMI be assigned to a contact person with a program such as PACT who will contact them periodically to see how they are doing? One final problem to address is reassessment, whether or not there will be a new screening every time a client re-enters the long-term service system. Traditional long-term care services have been provided to a population (e.g. elderly) with needs that are not as dynamic. Dealing with persons who have a SMI and move in and out of the system will be difficult and expensive.

Addressing all of these issues around the cyclical nature of SMI, however, will be irrelevant if the criteria chosen for a long-term care services benefit do not capture persons with SMI who are the most disabled and have such cyclical needs. What may become more of an issue is not establishing criteria for reassessment, but determining

¹⁸ ASPE is in the process of further analyzing this data (and other data as well) to determine the ability of various data sets to capture the most severely disabled persons with SMI.

¹⁹ States do have data on length-of-stay in inpatient settings, which can be used as a proxy for determining the population that would receive benefits in a long-term care program.

criteria up-front that capture persons most disabled due to a mental disorder, persons with a SMI.

From the information presented in this report, do people with SMI do need long-term services? Their conditions are often chronic, persistent, and severe. However, they often do not need help with ADLs, such as assistance in toileting or getting in and out of bed. What they do need is some assistance in the IADLs, as well as constant encouragement and support in participating in activities such as socialization and work. What becomes crucial is (1) identifying the line between what is and is not a long-term service that will be paid for under a generic program and (2) identifying comparable services for persons with SMI relative to persons with physical disabilities or to elderly persons who are disabled.

This report suggests that there are some generic or at least comparable services between these disabled populations, even though guidelines for making distinctions remain unclear. Furthermore, the need for better linkages to different service sectors is apparent. Even though housing and employment are often considered different and separate services, they are also directly linked to the long-term success of individuals with SMI. If persons with schizophrenia cannot find a safe home or a supportive work environment, this may partially cause the deterioration of their condition to where they will cease taking care of themselves. Thus, while functioning problems may ultimately be evident in measures of IADL and even ADL limitations, they are a result of an unwillingness to look at the financial (i.e. housing and employment) and social needs of these individuals. However, long-term services will be expensive even with limited benefits and eligibility. To assume that a broad expansion can be made to help all individuals find a job under the funding of long-term care is unwise. But, if benefits such as housing cannot be provided under long-term services, perhaps improved linkages to these services can. This would be a step toward recognizing the goals of quality, consumer choice, and flexibility.

One final note: an assumption made in this report is that a future long-term care program will be modeled after the proposed HCBS benefit in the HSA. Such a generic program requires individuals to be categorized in two ways: having acute care needs or having long-term care needs. Looking at other models for delivering long-term care are possible as well, even though they were not discussed in this report. For example, such models might place individuals into three different categories: those with acute care needs, long-term care needs, and rehabilitative needs. Individuals with SMI may fall into this third category, and a program that provides rehabilitative services may be developed which better meets their needs and has more appropriate eligibility criteria than a program providing traditional long-term care services.

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