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ABSTRACT

The process called deinstitutionalization, whether of the elderly or mentally disabled, involves complex issues, not the least of which are economic, physical, social, and psychological costs: any attempt to further this process perforce needs a comprehensive, specific plan suited to community needs and to those who are to be served. A workable plan should address the twin "how's" of deinstitutionalization and service delivery, with provision for supportive services to ease the transition to community life. Such services, to meet the mentally disabled's need for emotional support and the elderly's needs (which are often physical), can be home delivered or group centered in focus. Beyond essentials, such as health care, meals, chore services, and transportation, information and referral services may be organized for employment, recreation, group support, and crisis intervention suitable for home, half-way house, foster home, or community-based group residence. The best-designed plan should be consonant with financial resources at the community's disposal, and should include some built-in evaluative mechanism to monitor effectiveness of services, delivery systems, and client need assessment over time. The main focus, above all, should be on that which is viable and appropriate in the given community for the clientele served. (CP)

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ALTERNATIVES TO INSTITUTIONALIZATION

by

Carol Cutler Riddick

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Carol Cutler Riddick is an Instructor of Health Education in the College of Agriculture, The Pennsylvania State University. She received her M.S. in regional planning and B.A. in sociology from Florida State University. Currently she is completing requirements for a doctoral degree at The Pennsylvania State University. Her major interests are in citizen participation, health promotion, and evaluative research. Ms. Riddick's prior experience includes teaching, health planning and research positions with state government, hospital administration, news reporter, and hospital and nursing home volunteer work.

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INTRODUCTION

This paper is organized in two parts. The first section briefly covers the issues that emerge in attempting to develop alternatives to institutionalization; whereas, the second part reviews some of the community support services which are designed to maximize residential choice for the elderly and the mentally disabled adult. The focus is on interventions with adults and excludes community alternatives to children. By dealing with two different populations in one paper, the author does not mean to suggest either that the elderly and mentally disabled are one and the same or that they share the same needs. Typically, the greatest needs for many of the mentally disabled revolved around emotional support. On the other hand, because of degenerative processes, many elderly persons' needs are physical in nature. However, the author's perspective, which is reflected in the paper, is toward a holistic approach when dealing with the needs of either population.

By the most recent estimates, millions of Americans (a) experience mental disabilities (a term used to describe both mental illness and mental retardation) and (b) enter, remain in, or leave and re-enter public mental institutions and nursing homes.¹⁻²

At the outset, it is important to bear in mind two facts about institutionalization which run contrary to popular belief:

¹U.S., Senate, Subcommittee on Long Term Care of the Special Committee on Aging, Nursing Home Care in the United States: Failure in Public Policy, 93rd Cong., 2d Sess., No. 13059, 1974.

²Nursing homes refer to skilled nursing facilities (SNFs), intermediate care facilities (ICFs), and rest homes for the aged.

(1) Only 5 percent of the elderly are in institutions.³

(2) Many persons in institutions have been there before. Fifty-four percent of those in public mental institutions have passed through these revolving doors before; twenty-eight percent of the admissions to public institutions for the mentally retarded are readmissions (the retarded are those who have been defined as having significant subaverage general intellectual functioning, which originated during the developmental period (between conception and age 18), and which is associated with impairment in adaptive behavior).⁴

Mental institutions and nursing homes frequently provide essential care and benefits. However, two factors have tempered the attraction toward institutionalization. First, are social concerns. Although residence in mental institutions and nursing homes frequently provides essential care and benefits, it also can lead to depersonalization and dehumanization. Evidence indicates that when given a choice, individuals overwhelmingly prefer to stay in their own homes or live in settings that offer maximum independence and privacy.⁵⁻⁷ Indeed, the United States Supreme Court, in a landmark decision

³U.S., Senate, Subcommittee on Long Term Care, loc. cit.

⁴U.S., Comptroller General, Returning the Mentally Disabled to the Community: Government Needs To Do More; Report to the Congress. (General Accounting Office Washington, D.C.), January 7, 1977, HRD-76-152.

⁵M. Blekner, "Social Work and Family Relationships in Later Life with Some Thought on Filial Maturity," Social Structure and the Family: Generational Relations, eds. E. Shanus and G. F. Streib, (Englewood Cliffs, NJ: Prentice-Hall, 1965).

⁶M. S. Riley and A. Toner (eds.), Aging and Society, Vol. 1 of An Inventory of Research Findings (N.Y.: Russell Sage Foundation, 1968).

⁷William G. Bell, "Community Care for the Elderly: An Alternative to Institutionalization," Gerontologist, Autumn 1973, Part I, 13(3), pp. 349-354.

has ruled that mentally disabled persons have a right to live in the least restrictive environment appropriate to their needs.⁸ Second, the evidence clearly shows that institutionalization is costly and is becoming increasingly more expensive.⁹ The costs of long-term institutional care paid for primarily by public tax money runs into billions of dollars.¹⁰

These concerns have brought government and communities to intervene in the interests of consumers and patients in long-term care institutions, not only to upgrade the quality of care in institutions, but to look for alternatives to institutional care for those capable of using such alternatives.

⁸ Donaldson v. O'Connor, 422 U.S. 563 (1975).

⁹ Nancy E. Abel, "Daytime Care Lets People Stay Home at Night," Modern Health Care, 6 (1) 23-28, July 1976.

¹⁰ U.S., Senate, Subcommittee on Long Term Care.

DEINSTITUTIONALIZATION: THE MAJOR ISSUES

"Deinstitutionalization" has become the popular expression to convey the notion of alternatives to institutionalization. Deinstitutionalization is here defined as:

Preventing unnecessary admission to and retention in institutions (nursing homes and mental institutions) by:

- * Finding and developing appropriate alternatives in the community for housing, treatment, rehabilitation, and education of the mentally disabled and elderly who do not need to be institutionalized.
- * Finding the least restrictive environment for each individual.

In each culture, people develop their own way for caring for those who do not need to be institutionalized. In numerous instances, however, the problems connected with alternatives to institutionalization have resulted from a failure to understand what public or social function an alternative is intended to perform. The basic, beginning steps are to answer the following questions:

1. Who is to be served?
2. What major function is the alternative to serve--public safety, custodial care, or treatment and rehabilitation?

Issues related to deinstitutionalization are complex but may be seen to fall into seven major groupings:

- * Selection of patients for community care
- * Treatment and quality of life
- * Community resistance
- * Effects on significant others

* Financial issues

* Legal issues

* Evaluation

I. Selection of Patients for Community Care

A. *Who's Chosen? And on What Basis?*

In the past, there has been a tendency to shy away from placing or treating severe and/or chronically ill persons in the community. One reason for this has been the prevalent belief that if these individuals were to live in the community, they could possibly become a high risk to themselves as well as to health care providers. These individuals have also been ignored in part because they are viewed by professional community care takers, as well as society in general, as an undesirable or less rewarding "clientele," and because the community-based services needed for treating them are lacking.¹¹

Typically, the means of determining whether an individual should leave an institution are varied. In many cases the professional(s) treating the individual makes the decision. However, in the last few years the decision process has generally involved both the client and the professional, thus giving people an opportunity to advocate for themselves. Some institutions go so far as to rely on still another group--"significant others" (which include the parents and/or other persons in the client's life)--to have a major input into the

¹¹S. A. Kirk and M. E. Therrien, "Community Mental Health Myths and the Fate of Former Hospitalized Patients," Psychiatry, 38:209-217, August 1975.

decision.¹²

Related to the question of criteria for selecting patients/clients for community care are questions concerning who decides on the range and amount of services provided and the frequency of review on the needs for the addition and elimination of services.¹³

B. *Preparation of Institutionally Released Patients for Life in the Community*

Investigators have concluded that in the past there has been a lack of programs designed to provide discharged emotionally disturbed patients with the practical skills (e.g., food preparation, budgeting) needed to function in an ordinary community.¹⁴⁻¹⁵

Because of the conflicting and powerful emotions experienced before leaving an institution, individuals must understand what is happening, where they are going, and what to expect when they get there. They must have begun acquiring skills and attitudes which foster social and economic independence.¹⁶

¹² Edward Burling et al. Preinstitutionalization in Oregon - A Review of Sciences Within the Human Resources System: (Salem, Oregon: Oregon Department of Human Resources, 1975).

¹³ U.S. Senate, Special Committee on Aging, Alternatives to Nursing Home Care: A Proposal, Stock No. 5270-1248, (Washington: U.S. Government Printing Office, October 1971).

¹⁴ W. S. Anthony et al. "Efficacy of Psychiatric Rehabilitation," Psychological Bulletin, 78:447-456, December, 1972.

¹⁵ D. M. Place and S. Weiner, Reentering the Community: A Pilot Study of Mental Ill Patients Discharged from Napa State Hospital (Menlo Park, CA: Stanford Research Inst., June, 1974).

¹⁶ J. A. Roth, "The Public Hospital: Refuge for Damaged Humans," Where Medicine Fails, ed. A. L. Strauss (Chicago: Aldine Publishing Co., 1970).

II. Treatment and Quality of Life

A. *Range of Services*

It has been suggested that a major reason for the existence of long-term facilities is that they can house those whom society has labeled "deviant" or can become a "home" to those who simply have no place to stay.¹⁷⁻¹⁸

Successful alternatives to hospitalization on a county-wide basis can be, and have been, developed.¹⁹ However, the major problem is a lack of knowledge about what constitutes effective and inexpensive community-based care and treatment, and the economic and managerial systems to make such care possible.

B. *Accessibility of Services*

Provision of a service does not guarantee its use by those in need of the service. Once the person leaves the institution or is at the risk of being admitted to one, there is the matter of educating the client and the public regarding the significant role of community support programs. It has been suggested that the use of community care programs could be increased through concentrated effort to educate people about the services and

¹⁷Talcott Parsons, The Social System (New York: Free Press, 1951).

¹⁸S. Feldman, "Community Mental Health Center: A Decade Later," International Journal of Mental Health, 3 (2-3), 18-34, 1974.

¹⁹Harry Gottesfeld, "Alternatives to Psychiatric Hospitalization," Community Mental Health Review, January/February, 1976, 1(1), 1-10.

benefits of home health care.²⁰ Ignorance about whom to call is often the reason people fail to use available services. Educational programs which describe home health services accessibility and are aimed at the professional medical community are also needed.²¹

Utilization is also related to location and travel costs to make a trip to the service site, hours of operation, waiting time for the service, and affordability. Indirect costs (such as loss of time from work and babysitting fee) also have a bearing on whether the offered service is accessible.

Still another barrier to use is insensitivity to the beliefs and practices of special populations such as ethnic minorities, the elderly, or rural residents. For example:

Symptoms of mental illness in a rural situation which reach the mental health worker are frequently much more gross and would usually be considered much more severe than those observed in a more highly sophisticated social unit. This is because of the prevalent attitude that people living in a rural condition must be "very, very crazy" before they can receive attention from the network of interpersonal attendants surrounding them.²²

20

U.S., Department of Health, Education and Welfare, Characteristics of Persons with Chronic Activity Limitation: United States - 1974, Vital Health Statistics Series 10, Number 2, DHEW Publication No. (HRS) 77-1539 (Washington: U.S. Government Printing Office, October, 1976).

²¹ D. T. Nash, "Making Use of Home Care Services," Geriatrics 29 (9), 140, September, 1974.

²² Ned Tranel, "Rural Program Development," The Practice of Community Mental Health, ed. Henry Greenbaum, (Boston: Little, Brown, and Co., 1970).

C. *Coordination of Services*

Deinstitutionalized persons usually require the services of more than one human service agency. A fundamental issue is the coordination and sharing of responsibility for mutual clients. Whether a person "falls between the slots" when needing support services from several sources depends upon the interorganizational relationships, agency objectives, the degree of conflict and communication between the agencies, and the role of the political and governmental actors when controlling agency purse strings.²³

One approach to coordination is to have a single agency or person (such as a social worker) acting as sole agent or advocate for the patient or having primary responsibility for seeing that his/her many needs are adequately met.²⁴ Another approach is to have service agencies cooperate in overlap—a process in which two or more systems come together at the same time to implement a plan for a client.

When a client is leaving the institutional system to move to a local community system, overlap is the meshing of needed services to be provided to a given client so that his or her movement between the systems will be a smooth one. At this time, everyone (the client, significant others, professionals, etc.) has the opportunity to give his/her input as to the various pieces of the support plan. Each part involved in the plan leaves understanding what roles they will play in the person's community system.²⁵

²³Howard M. Held, "Mental Health in the Rural Community," Human Services in Rural Environment, 1 (2), 3-8, July, 1976.

²⁴Kirk and Therrien

²⁵Kirk and Therrien

D. *Quality of Care*

The issue of quality care is continually re-emerging. The usual questions are whether health and welfare services are appropriate and acceptable to the needs of the client, and whether they are effective and efficient. In short, is the expected benefit achieved at a reasonable cost and in an acceptable manner? However, hidden behind these obvious questions are more subtle considerations. Quality is a relative matter depending upon: (1) who is asked to define it and when, (2) the level of technology, and (3) the commitment of resources. In addition, fundamental value issues about whether care is a right or a privilege and whether it should be equally distributed or distributed according to need have yet to be resolved in our society. The hard fact remains that at the beginning of this century the limits to the provision of care were primarily knowledge and technology. In the decade of the 70s the limit is resources. We know more and can do far more than existing resources will allow. As a result, some are deprived of services and for some quality is lower. This is seen in limitations on range of services, inaccessibility, fragmentation, and the like. The fundamental questions are who will receive services, who will be deprived of services, and on what basis will these decisions be made and by whom.

III. Community Resistance

Our society has difficulty in dealing with the presence of the disabled and inform elderly in the community. Bases for opposition

range from unfounded beliefs that their disability is contagious to the more legitimate concerns that concentrations of these types of individuals may either lead to diminished real estate values and tax base, or that they may pose threats to others. The release of "unattractive," "misbehaved," or "undesirable" elements into the community is typically not welcomed.

At the opposite end of the scale is the discussion encountered when consideration is given to closing a hospital or nursing home.

Forces commonly encountered include:

1. Resistance by institutional personnel. Concern focuses only partly around the protection of jobs. Staff morale may decline which in turn could affect the quality of patient care provided during the period when the institution is preparing to close. Frequently, there is also real concern for the welfare of patients and ambivalence about the ability of patients to live in the community.
2. Resistance of patients and families. Patients may respond with worsening illness and family members may fear the burden of caring for the older or emotionally disturbed person at home.
3. Resistance by agencies who may serve patients. Resentment may emerge over the prospect of receiving chronic patients with "low rehabilitation" potential.²⁶ Frequently community

²⁶Leona L. Bachrach, Deinstitutionalization: An Analytical Review and Sociological Perspective. DHEW Alcohol, Drug Abuse, and Mental Health Administration, Stock No. 017-024-00530-4, (Washington: U.S. Government Printing Office, 1976).

agencies are already over-extended and underbudgeted and the prospect of an enlarging caseload is not encouraging.

IV. Effects on Significant Others

Serious crises may emerge in the lives of those families and friends who become responsible for the care and rehabilitation of a mentally disabled or elderly person. The individual's presence may put severe emotional, social, and economic strains on the attending family. A point can be reached when it has to be decided whose rights will take precedence. In fact, there is evidence that families do not "dump" relatives into institutions but rather care for them as long as they can cope. Community support services must also deal, then, with the needs of these family members, too.

V. Financial Issues

A. *Cost*

The data required to make accurate cost assessments of community care which has a positive effect on health (such as improved health status) are not available. In short, no one really knows the "hidden" costs of community care and how they compare with the costs of institutionalization. Some of the "hidden expenses" of community care are the costs incurred by agencies in dealing with the mentally disabled or inform elderly-- such as emergency rooms, police, courts, etc.²⁷ Indeed, community-based care may not be as inexpensive as many once believed,

²⁷Kirk and Therrien

especially if the complete array of needed and appropriate services is provided. Whereas the state and federal governments typically absorb the financial costs associated with institutionalization, many of these direct and indirect costs shift to local government with community-based care and as a result many communities are not not eager to absorb these costs.

B. *Third Party Payments*

Insurance company and government payments, e.g., Medicare and Medicaid are another impediment to greater use of community-based support services. Current third party reimbursement policies encourage hospitalization rather than outpatient or home health care.²⁸ Another problem is that frequently third party insurers have defined home health care as a rehabilitation program--with the implicit expectation that all patients/clients will improve. This type of policy makes it difficult to continue providing home health care to certain persons who might not be expected to improve. It also excludes preventive services from home care. In the end, these types of policies discourage the delivery of comprehensive care. Many providers simply provide those services that are reimbursable.

Not only is the excessive paperwork required by third party payors for reimbursement a problem; long delays in payment and reimbursement rates below actual cost further aggravate the

²⁸J. Bermon and Morris Ostroff, "Care for the Homebound Aged," Annals of Internal Medicine, 82 (5), pp. 717-8, May, 1975.

situation. Agencies need to learn how to use third party payments efficiently and effectively.

VI. Legal Issues

A. *Rights of Treatment and Education*

The courts have made a host of decisions regarding the rights of the mentally disabled, including declarations on the rights of treatment, protection, decent living conditions, exercise, and public education. Even if an individual is declared by a court of law as being incompetent, he or she will have these rights.

Some communities find they have to spend additional monies to provide the necessary treatment for the disabled in publicly run institutions (hospitals, nursing homes, schools, etc.).²⁹

B. *Diagnosis and Prognosis*

The state of the art is such that we do not have accurate and reliable criteria for determining mental illness or dangerousness.³⁰

This shortcoming makes it very difficult to determine who belongs in the community and who belongs in the hospital for emotional disturbances.

VII. Evaluation

What kind of impact or outcome have the community support services had? Did the client's physical and/or emotional functioning improve or decline? What factors were related to improvement? Evaluating

²⁹ Bruce Ennis and Loren Siegel, The Rights of Mental Patients, (New York: Avon Books, 1973).

³⁰ Leonard P. Ullman and Leonard Krasner, A Psychological Approach to Abnormal Behavior, (New York: Prentice Hall, 1969).

community support services is frequently difficult to do because of limited funds. However, rigorous evaluation is crucial in order to know where and how public monies are spent, but even more important; in order to assess ways to improve individual health status and health services. Findings from such evaluations will enable other communities to benefit. Thus, those responsible for initiating and administering alternatives to institutionalization have a professional and social obligation to evaluate their program the best way they can and to make known what they have done.

SOME APPROACHES TO COMMUNITY CARE

Community care services are designed to maximize residential choice for the mentally disabled and elderly. The goals of such services are to (a) decrease inappropriate institutionalization, (b) extend as much as possible the capacity of the elderly and disabled to function in the housing and neighborhoods of their preference, and (c) provide access to appropriate services, including institutions as needed.

While no universally agreed-upon guidelines exist, the programs highlighted in Figure 1, and briefly described below, are considered as typical components to community care services for the elderly and emotionally disabled.³¹ Services vary according to their sponsorship, organization, source of financing, and service delivery pattern. Because the elderly and emotionally disturbed commonly have multiple problems (health, economic, social, etc.) they frequently receive services from many sources. Therefore, it is essential, regardless of the administrative structures used to deliver the services, that communication, flexibility, and continuity of care prevail so that the range of services delivered to an individual are coordinated.³²⁻³³

³¹An excellent work, which covers among other things the objectives of each desirable service component for long-term care alternatives for the elderly is the North Puget Sound Health Council's Long-Term Care Alternatives: A Development Guide for Services for Senior Citizens, (Mount Vernon, WA: North Puget Sound Health Council, November, 1976).

³²F. Van Dyke and V. Brown, "Organized Home Care: An Alternative to Institutions," Inquiry 9 (2), 3-16, June, 1972.

³³Harold M. Visotsky and Barbara A. Kay, Deinstitutionalization: A Community Mental Health Process, (Chicago: Northeastern University, November 19, 1975).

FIGURE I
INGREDIENTS TO A COMMUNITY SUPPORT SYSTEM FOR THE
EMOTIONALLY DISABLED AND ELDERLY

HOME DELIVERED SERVICE FOCUS

Home Care

Health Maintenance
Homemaker Health Aids
Home Delivered Meals
Chore Services
Transportation

Information and Referral

Information
Advice
Outreach
Referral
Crisis Line

Telephone Reassurance

Friendly Visitor

GROUP SETTING SERVICE FOCUS

Outpatient Care

24-Hour Acute Crisis Care
Hospital Based Outpatient Care
Mini-Mental Health Center
Community Mental Health Center
Day Care Center

Ambulatory Supportive Services

Congregate Meals Program
Employment Services
Legal Aid
Health Screening
Recreation and Socialization
Support Groups

Domiciliary Care

Foster Home
Half Way House
Residential Hotels
Boarding Home or Rooming House

I. Home Delivered Service Focus

A. Home Care

Home care refers to a combination of health treatment and social services provided in the home. The goal of home care is to prevent, support, or improve the quality of life for individuals or families when health and safety are threatened, either by illness or short-or-long-term duration or by emotional crises or by a combination of these. Whereas medical care services are provided under a home care arrangement, the most needed services to the aged and disabled are intermittent home helpers who provide assistance with food shopping, meal preparation, laundry, dressing, personal care, etc.³⁴ Although there have been instances where hospitals and public health departments have sponsored health maintenance services for the chronically ill, typically these services are made available by an organized home health agency which uses employed staff and contractual arrangements with other agencies to deliver needed services.

1. Health Maintenance. This involves delivery of medical-related services (including equipment and supplies) which are designed to maintain, or if possible promote, an acceptable standard of personal health care to individuals living at home or confined there. Frequently, these services can cut down on hospitalization by the early detection and treatment of the problem(s). Essential

³⁴Special Committee on Aging, Alternatives.

services are those provided by registered nurses, physical therapists, speech therapists, nutritionists, social workers, occupational therapists, and homemaker health aide (see below). In most instances health maintenance services are delivered under the direction of, or in consultation with, a physician or registered nurse. Other services which are considered essential but which are typically arranged for by the home health agency and facilitated by the availability of patient transportation services are audiological, dental, laboratory, ophthalmological, medical, podiatric, prosthetic/orthopedic, respiratory therapy, and X-ray services.³⁵

2. Homemaker Health Aide. Services are provided principally by a paraprofessional homemaker to assist individuals or families with tasks related to daily personal maintenance such as grooming, dressing, meal preparation, and housecleaning, and care of children.³⁶
3. Home-Delivered Meals. Food which may or may not be prepared under a registered dietician's supervision is delivered regularly to individuals unable to prepare their own meals or to attend congregate meal programs (see congregate meals program below).

³⁵ National League for Nursing, Proposed Model for the Delivery of Home Health Services, (New York: National League for Nursing, 1974).

³⁶ The National Council for Homemaker-Home Health Aide Services estimates that one home service worker is needed for every 1,000 Americans under age 65 and one worker for every 100 aged 65 and over. See Anne R. Somers and Florene M. Moore, "Homemaker Services: Option for the Elderly," Public Health Reports, 91 (4), 354-359, July-August, 1976.

4. Chore Services. These services are designed to maintain or upgrade the physical structure in which the individual lives. Examples of these services are: winterproofing, carpeting, securing of handrails and steps, lawn maintenance, and to help with minor chores such as changing light bulbs, washers in the faucets, etc.
5. Transportation Service. A whole host of approaches to transportation services have been tried. These include: mass transit fixed route, reduced fare approach for the elderly riding mass transit, transportation cooperatives operated by private or senior citizens groups, subsidized use of taxis, use of school buses during off-school hours, and special buses supplied, without charge, by merchants offering transportation to shopping centers. Other experiments have dealt with providing transportation to the impaired from their home to some point and back to their home again for trip purposes limited to essential needs--such as to a supermarket, physician's office, clinic, or other needed health and social services. This type of service has also been delivered through the use of station wagons or small buses provided by health and social agencies transporting selected clientele, and by volunteer-operated transportation.

B. *Information and Referral*

The services provided under this umbrella can range from the simple to the complex. Some are commonly provided by volunteers while others necessitate delivery by social workers or psychologists. This type of service can be subdivided to include one, some, or all of

the following:

1. Information. This service involves answering questions of a general nature concerning program/service availability.
2. Advice. Individualized interpretation is provided on how a given program may be applied to an individual; for instance, after determining the eligibility of the person for a specific service, the suggestion is made that he/she seek that particular program or service.
3. Outreach. This includes search-and-find activities which seek out and identify hard-to-reach individuals and assist them in gaining access to needed services.
4. Referral. This is a specific form of advice involving the suggestion that the person believed to be in need of the service or information go to a specific agency or facility. It is not unusual for the individual making this suggestion to set up an initial appointment or send a background report to the referral agency.
5. Crisis-Line. A crisis line provides counseling over the phone in times of emergencies or crisis.
6. Telephone Reassurance. This involves friendly "chats," which may be initiated by the community resident and/or the telephone reassurance operator. In the latter case, it is not uncommon for such calls to be routinely scheduled for one time of day in order to "check-in" with an individual. If the call goes unanswered, a follow-up usually is undertaken.

7. Friendly Visitor. This service is similar to telephone reassurance. Routinely, an individual (such as a neighbor or visiting nurse), in order to help reduce isolation, "stops in" at someone's residence. Such a visitor may observe the need for a variety of other services in the home served. Thus, close ties frequently evolve with information and referral services.

Just about all the home delivered services may be provided by either a formal or informal (e.g., family member or friend) resource.

II. Group Setting Focus

A. *Outpatient Care*

1. 24-Hour Acute Crisis Care. Some hospitals and community mental health centers (described below) have established a small number of short-term beds for individuals experiencing an emotional crisis or emergency. It is believed that the use of this sort of unit plays an important part in preventing prolonged hospitalization.³⁷⁻³⁸
2. Hospital-Based Outpatient Care. One model for hospital-based outpatient care is the After-Care Program, the first hospital-based home-care program, designed by Montefiore Hospital.³⁹

³⁷ P. Ruiz and G. Saiger, "Partial Hospitalization within an Urban Slum," American Journal of Psychiatry, 24 (7), 467-472, 1973.

³⁸ R. L. Pearlman et al. "An Acute Treatment Unit in a Psychiatric Emergency Service," Hospital and Community Psychiatry, 24 (7), 489-491, 1973.

³⁹ Isadore Rossman, "Alternatives to Institutional Care," Bull N.Y. Acad. Med. 49 (12), 1084-1092, December, 1973.

Several individuals with a similar disorder are transported to the hospital for a few hours each day. While at the facility they receive physical, occupational, and recreational therapies, and if needed, have access to care delivered by physicians, nurses, and social workers. This alternative is more cost effective, when compared to a home-care program, in cases where the individual is not too sick to be transported to the outpatient facility. For instance, the Montefiore Hospital schedules a physical therapist on a home-care program for six patient visits per working day. In contrast, six patients can be treated at the hospital's physical therapy department by the same physical therapist, plus an aide, in one hour's time.

3. Mini-Mental Health Center. Under this type of program, a single hospital sets up a mini-mental health center to provide multiple services including inpatient and outpatient services, partial hospitalization, and sometimes home visits. Frequently the same treatment team continually serves the patient as the individual moves from an inpatient to an outpatient status.⁴⁰⁻⁴¹
4. Community Mental Health Center (CMHC). The Centers program was established by Congress in 1963. Centers, in order to receive

⁴⁰P. R. A. May, "Adopting New Models for Continuity of Care: What Are the Needs," Hospital and Community Psychiatry, 26 (9), 599-601, 1975.

⁴¹E. Johnson et al. "Adopting New Models of Continuity of Care: The Ward as a Mini-Mental Health Center," Hospital and Community Psychiatry, 24 (10), 675-679, 1975.

federal grant dollars, must develop a full range of accessible mental health services, or ensure that such services are available in the community through other agencies which affiliate and cooperate with the CMHC. These services include emergency and early intervention services, outpatient care, transitional living arrangements, 24-hour inpatient services, and consultation services to human service agencies (such as schools, police, welfare departments, and health care providers) on how to (a) deal with emotional problems and (b) refer individuals in need of treatment to the CMHC. CMHCs have had a dramatic effect on providing alternative community services for individuals who might otherwise have been institutionalized. In 1973, these centers treated 25 percent of all mental health care episodes.⁴²

5. Day Hospital. Day hospitals are relatively new on the American scene. These are facilities providing therapy, predominantly physical rehabilitation and physical maintenance therapies. Follow-up studies of rehabilitated geriatric patients show a relapse rate of close to 75 percent in the year after hospital discharge.⁴³ This may occur because of a complete loss of hospital support upon discharge. Observers feel that day

⁴²U.S., Congress House, Subcommittee on Health and the Environment of the Committee on Interstate and Foreign Commerce, National Health Insurance: Major Issues, Vol. II, Serial No. 94-90 (Washington: U.S. Government Printing Office, 1976).

⁴³O. K. Timm, "Rehabilitation - to What?," Journal of the American Geriatrics Society, 15 (709-716), 1967.

hospitals would help reduce this problem, especially if psychiatric care was provided.⁴⁴ Some day hospitals provide psychiatric care. Whether or not psychiatric or nonpsychiatric care is provided, past experience indicates that most day hospitals are run on a small-scale basis (between 30 to 50 patients daily) and that the average patient uses the day hospital only once a week for a short period of time (4 to 8 hours).⁴⁵ A midday meal is provided, and when the patient is not involved in treatment, (s)he is provided with social and recreational activities. Custodial care is not provided at night.

6. Day Care Center. As is true with the definition of a day hospital, there is no total agreement over what constitutes a day care center. Day care centers frequently provide social facilities, a midday meal, and a variety of amenities such as hairdressing, bathing, chiropody, arts and crafts, and sheltered workshops. Typically, transportation to and from the center also is provided. Depending upon who one reads, day care centers are or are not part of a hospital's services; its staff does or does not include doctors, nurses, and therapists; and medical investigation or treatment is or is not provided.⁴⁴⁻⁴⁶ The day care center is

⁴⁴David R. Matlack, "The Case for Geriatric Day Hospitals," Gerontologist, 15 (2), 109-113, April, 1975.

⁴⁵J. C. Brocklehurst, "Geriatric Services and the Day Hospital," ed. J. C. Brocklehurst, Textbook of Geriatric Medicine and Gerontology, (Edinburgh: Churchill Livingstone, 1973).

⁴⁶Eloise Rathbone and Julia Levenson, "Impact of Socialization Therapy in a Geriatric Day Care Setting," The Gerontologist 15 (4), 338-342, August, 1975.

primarily a social program for the frail, moderately handicapped, or slightly confused person who needs care during the day for some part of the week either because (s)he lives alone and cannot manage on his/her own, or because his/her family needs relief at times in order to keep him/her at home.⁴⁷ The goal of a day care program is to meet the health maintenance and restoration needs of participants. These programs also have a socialization element, helping individuals overcome the isolation associated with disability and aging. Some day care centers also arrange for home nursing and shopping services when indicated.⁴⁸ Day care centers may be institution based, church based, or free standing. Ideally, the center should have linkage or access to health-related organizations.

B. *Ambulatory Supportive Services.*

1. Congregate Meals Program. Since the 60s Congress has funded the congregate feeding program for people age 60 and over (and their spouses), particularly for those with low incomes, minorities, and people who are socially isolated. The intent of the program is to promote better health through improved nutrition and through a reduction of the isolation of old age. In addition to meals, mandated supportive services include

⁴⁷ H. Padula, Developing Day Care and Older People. Senior Opportunities and Services, Terminal Assistance Monograph #11 (Washington: National Council on Aging, 1977)

⁴⁸ Rossman

recreation, health and welfare counseling, nutrition education, transportation to the meal site, information and referral, and an outreach component to locate persons most in need.

2. Employment Services. Individuals are provided information about available job opportunities and preparatory counseling for referral to prospective employers.
3. Legal Aid. These services provide legal advice and counseling; as well as ombudsman or advocacy services--bringing the concerns and needs of the elderly and mentally disabled before the public and/or appropriate authorities. Advocacy works toward the passage of pertinent legislation as well as the alleviation of injustice.
4. Health Screening. These services identify individual health problems. The screens are typically performed by voluntary health organizations or public health departments in local health offices, senior centers, or other settings. Usually, detected problems are interpreted to the person concerned, and resources are recommended to correct the problem(s).
5. Recreation and Socialization. Recreation services aim to foster the health and social well-being of individuals through satisfying use of leisure time. Hosts of recreation services are varied and include public recreation departments, public schools, universities (through their adult education efforts), libraries, and Congregate Meals Programs. In addition, there are senior centers. A senior center is a physical facility open to senior citizens the year around, at least five days a week

and four hours a day, operated by a public agency (e.g., school, recreation agency) or nonprofit private agency (e.g., church). It provides, under the direction of paid professional leadership, three or more of the following services: recreation, adult education, health services, counseling, information and referral, and opportunities for community and volunteer service.⁴⁹

Senior centers have been developed in conjunction with a day care center and extended care facilities.

6. Support Groups. These programs concentrate on helping older persons who are living in the community to become less agitated and more communicative, to increase their independence and feelings of self-worth, and to utilize problem-solving skills in making new adjustments.⁵⁰ The primary goals of support groups are (a) to present objective information about normal changes in old age and (b) to assist the individual develop more affective interpersonal skills to cope with these changes.

C. *Domiciliary or Supportive Living-Care Arrangements*

These arrangements are for individuals who cannot carry out essential activities of daily living and, therefore, require care beyond that available in their own homes or in ordinary boarding homes, but who require less than 24-hour medical and nursing care.

⁴⁹ Subcommittee on Senior Citizens Centers, The Senior Center - Its Goals, Functions and Programs, (Washington: President's Council on Aging, 1964).

⁵⁰ Beryl J. Petty et al. "Support Group for Elderly Persons in the Community," Gerontologist, 15 (6) 522-528, December, 1975.

1. Foster Home Care. Foster homes are one of the oldest forms of care for the emotionally disturbed. It is used as an alternative to prolonged hospitalization; that is, the individuals entering foster homes have been discharged from a hospital. When it is deemed unwise to send a patient back to his/her own home because the home setting is too stressful or the family fails to offer support, the individual is placed in a foster home. Foster homes are designed to assist in adjustment of those undergoing physical deterioration, emotional problems, or convalescence.⁵¹ They are also used in the placement of retarded individuals. Under a foster home arrangement a sponsor-family is paid by a welfare department to provide a custodial care setting for a "guest." At the same time the individual is receiving other types of services in the community--such as vocational rehabilitation, physical therapy, etc. Professional supervision (usually by a social worker) of the foster home resident varies.⁵²
2. Half-Way House. Halfway houses are relatively new in the United States. Generally the facility is set up to serve

⁵¹Margaret Linn and Eugene M. Caffey, Jr., "Foster Placement for the Older Psychiatric Patient," Journal of Gerontology, 32 (3), 340-345, May, 1977.

⁵²Walter Alwin, "Adult Foster Care - An Alternative to Nursing Home Care in Marathon County," 2nd Annual Northern Wisconsin Symposium on Human Services in the Rural Environment; Reader, eds. David Bust and Julie Schmidt, (Milwaukee: University of Wisconsin-Extension, 1977), pp. 56-68.

the emotionally disturbed, alcoholics, or the elderly.

Most residents of psychiatric half-way houses enter the facility upon discharge from a hospital, whereas the prior residence of a majority of residents of half-way houses for alcoholics is the community. A wide variety of services, ranging from counseling, vocational rehabilitation, job placement, and recreation, can be found in half-way houses. Some half-way houses for the elderly are set up so older people can either cook for themselves or, as an alternative, go to a common dining room.

3. Residential Hotels. Hotels and apartment complexes which serve predominantly the elderly have been labeled residential hotels. The two major categories of residential hotels are (1) those which provide communal dining but no housekeeping services and (2) those which provide housekeeping services but do not offer meal service. Some residential hotels offer social programs for their guests.
4. Boarding Home or Rooming House (includes apartment group living). By and large these facilities are operated by lay persons who are seeking ways to supplement their income. Considerable variation is found in the ways these places are operated. Some are set up solely to deliver food, clothing, and shelter. In others, trained operators take part in patient rehabilitation.

CONCLUSION

The economic costs of long-term institutionalization, the physical, social, and psychological costs to those who have been institutionalized, and the uncertain quality of care in long-term institutions are sufficient and compelling reasons to seek alternative methods of caring for the mentally disabled and infirm elderly, and of helping them to care for themselves. But the road from recognizing the need for alternatives to successfully realizing them must be paved with something more than community concern and good intentions.

To design and implement effective alternatives to institutionalization, a community must determine what its needs are and who is to be served. It must evolve a comprehensive plan suited to its own population. Resources to meet these needs may be found either in one's own community and/or by sharing services with neighboring communities.

A workable plan should address questions of how deinstitutionalization will occur and how community-based services will be delivered. It also should make some provision for supportive services that allow those who have been institutionalized to make the transition to living in the community and to thrive there. The quality of the deinstitutionalized person's life in the community, the community's resistance to deinstitutionalization, and the effect on the lives of significant others should all be assessed and incorporated in the planning effort.

The best-designed plan will not amount to anything, however, if it is inconsistent with the financial resources at the community's disposal and what the community can realistically be expected to appropriate in money and

energies for alternatives to institutionalization. For this reason, studies of a number of service alternatives are a clear necessity. In the initial stages of planning, it is also wise to build in a way to evaluate how well the alternative services design is working after it is implemented. Whether services are being delivered effectively and efficiently, whether additional services are needed, and whether existing services should be discontinued, should be recurring questions. The scope of existing community-based services has been suggested in the section on approaches to community care. That section will not have fulfilled its purpose, however, if it leads the reader to be intimidated by the sheer variety of service options or to think it may be used indiscriminately as a shopping list for community health services. Again, the important consideration is, what is viable and appropriate given the characteristics of the individual community?

Alternatives to institutionalization have and will work where a community has the advantage of self-knowledge, foresight, and careful planning.

SOME SUGGESTED READINGS.

President's Commission on Mental Health, Report to the President from the Commission on Mental Health, Volumes I-IV (Washington, D.C.: U.S. Government Printing Office, 1978), Stock No. 040-000-00390-8, 040-000-00391-6, 040-000-00392-4, and 040-000-00393-2.

Among other things the report details a variety of alternative community support services.

National Economic Development Law Project, "Home Health: A Need You May Be Able to Fill," Economic Development Law Project Report, May/June, 1978.

Outlines the steps to the planning and development of home health services; plus identifies funding sources for such services.

Norman, Alison. Transport and the Elderly--Problems and Possible Action, (London: National Corporation for the Care of Old People). Available from National Corporation for the Care of Old People, Nuffield Lodge, Regent's Park, London, NW1 4RS.

Covers: (dis)advantages of different modes of travel; various types of voluntary transport; and actions that can be taken through legislation, governmental departments, local authorities, community health councils, bus companies, and individuals to improve transportation for the elderly.