

PART

4

**SERVICES
AND
COMMUNITIES**

CHAPTER IX

A SYSTEM OF SERVICES

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From the discussion in the preceding chapters it should be clear that the diverse needs of mentally retarded citizens approximate the varied needs of others in society. Rich or poor, mentally retarded or non-retarded, urbanite or resident of a rural area, we all strive to fulfill our common yet distinctive needs. The ease with which one accomplishes this depends on a variety of resources (i.e., family, schools, community, human service agencies) designed by society to assist individuals in developing their potential as human beings. A person must have access to a continuum of care which permits "fluidity of movement of the individual from one type of service to another while maintaining a sharp focus on his unique requirements"

The existing or expanding framework of generic services should provide for the majority of needs expressed by mentally retarded individuals. This does not imply the immediate dissolution of specialized services or a marked expansion of generic agencies, but rather a commitment to include in generic services those previously denied entry. A generic approach to service delivery, based on an accurate assessment of individual needs, helps to reduce the effects of mental retardation on human development and expand the potentials of every human being.

Given the foregoing emphasis, what are the goals of a service delivery system designed to meet the range of needs expressed by mentally retarded persons? The following series of goals can serve as a prototype in identifying the components which will enable a retarded citizen to live and function within his community.²

¹ President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation*. (Washington, D. C.: Superintendent of Documents, 1962.) pp. 73-74.

² Special thanks for assistance in the development of the following section belong to Paul Pearson, M.D., C. Lewis Meyer, Children's Rehabilitation Center, University of Nebraska Medical Center, and Gunnar Dybwad, Professor of Human Development, Heller School, Brandeis University.

GOALS OF THE SERVICE SYSTEM

- *The system should identify and register needs of persons.* The person in need should be the focal point of the system; the initial and continual evaluation and assessment of needs would allow for the appropriate match of the individual to an array of services.
- *The continuum of services should meet these identified needs.* A sufficient range of service components must exist to meet the variety of known needs. Services should be accessible to persons of all ages and all degrees of disability. Services must be comprehensive and appropriate to the needs of individuals. "The various services that should be available in this array must be marshaled in different ways and for different people in accordance with their needs at different times."³ This may entail developing different forms and modes of service delivery, including outreach, mobile teams, resource centers, and new funding sources.
- *The continuum of services should be provided where possible through generic service systems, to which parents and clients have guaranteed access.* No specialized service should be developed to meet the identified needs of an individual when existing agencies could address such needs. "The 'richer' and more easily available all general services become, the less need for special services for the retarded."⁴ The system should stress the importance of the family in planning and decision making. Such an effort will have to view parents as potential resources rather than as obstacles to be overcome.
- *Coordinating mechanisms should exist among agencies and service systems ensuring the goals of the individualized habilitation plan.* All services, generic and specialized, must be linked together to facilitate coordination in line with the specified needs of the individual. An absence of linkages among the various elements in the total system results in a non-system.
- *Service settings must reflect geographic dispersal at the community, area, and regional levels.* The component parts of the service system should be located at levels where clients can obtain them readily. Services should be combined in ways which will ease interdisciplinary approaches to common and

³ The President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation*. (Washington, D. C: Superintendent of Documents, 1962), p. 75.

⁴ *Ibid.*, p. 73.

special needs. Some services should be highly mobile so that distant clients can use them.

¹ *Service settings should strive to integrate the individual into the mainstream of community life.* The service system must strive to create new and more appropriate living patterns for mentally retarded citizens, including participation in the activities of the community appropriate to people of the same age. Such social opportunities pertain to both children and adults.

A normal range of options should be available for parents and clients among an array of services. This includes the right to enter and leave the system as the need occurs. This range of options refers to the continuum of care previously discussed. Individuals may move into or out of the service system as needs arise. Access to and egress from the system must be guaranteed. The system must recognize that some individuals may need combinations of services for a long time, while the majority may "only" require specific services for a relatively short time.

Services should be instituted at the appropriate time. Appropriately timed interventions lead to an improved level of functioning. The effectiveness of late interventions is minimal. Age obviously is a crucial factor in this process. Age is important not only regarding the initiation of a service but also regarding the kind and duration of service. *The human and civil rights of all persons should continuously be observed and served, including appropriate habilitation within the least restrictive setting, regardless of the severity or combination of disabilities.* The various recent statements regarding rights and the impact of class action proceedings have opened many new avenues for mentally retarded persons. In Chapter IV, Donald Freedman examines the issues raised by this goal.

Record systems should be designed and maintained which facilitate program efficiency and effective service analysis. Record systems must maintain the continuity of individual program planning, document a client's progress, store reliable information, and assess the program's effectiveness. The records system must guarantee appropriate confidentiality. *Program evaluation should be integral to all service systems and reflect the involvement of consumers, system staffs, and the public.* The input and involvement of persons not directly involved in providing service is crucial. A provider of a service is not an impartial and objective evaluator of his own interventions. The agency and the service system of which

it is a part must have built in and ongoing mechanisms for monitoring the quality of its operations.

- *All service systems should be accredited or have plans for achieving accreditation within three years.* This goal will become a reality soon. Mechanisms now exist for all systems, both residential and non-residential, to achieve the standards set forth by the Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals.
- *To assure effective implementation and functioning of the service system, qualified specialists should hold positions of leadership in the system.* Without this prerequisite, effectively meeting the diverse needs of mentally retarded individuals becomes an exercise in futility.
- *Mechanisms should be established between Education/Training Programs and the service delivery systems to assure the continuous availability of enough appropriately trained personnel to meet the goals of the service system.* The relationship between education and training facilities (i.e., colleges, universities, University Affiliated Facilities) must be refined to meet the needs of the service systems. Such an arrangement can lead to new methods which may more appropriately meet the needs of mentally retarded persons.
- *Laws should be recodified to facilitate the development of services and facilities to fulfill the goals of the service system.* Legislation has received a great deal of attention in recent years because of the perception that new legislation can answer a long standing problem. The need very clearly is one for good, adequate, and implementable legislation, not legislation which creates additional confusion.
- *Prevention should be an integral component of the service system, and measures should be planned and implemented to reduce the incidence and severity of mental retardation.* This goal, so well articulated by the President's Panel, is a continuing concern. Preventive services must reflect present knowledge and effectively use private and public resources. The potentials that exist through new medical advances (e.g., amniocentesis) and new screening techniques for PKU and sickle cell anemia must be continued. Prevention must be
 - an ongoing part of all components of the service system. In many instances appropriately timed intervention may prevent the need for other services. One man's prevention is another man's cure.
- *An effective means for educating the public and generating public awareness and support should be implemented.* The

need for an adequate and appropriate program of education and awareness must be conducted on several levels (i.e., professionals, the public, and the legislature). This chapter will further elaborate on this goal.

(The above listing of requisite goals is not rank-ordered and may be expanded to reflect the specific characteristics of a community.)

NOW, WHERE TO:

In a chapter like this, one is tempted to set forth an ideal or model service system, with potential universal applicability. However, this is neither practical nor desirable, given the diverse geographic, political, and economic circumstances throughout the country. Nevertheless, the chapter can describe a systematic way of interrelating the functional components of a service delivery system. If one chooses to refer to this exercise as systems design or model-building, he should do so within the context of Kugel's description of a model service delivery system.⁵ According to Kugel, a model must consist of a clearly circumscribed, currently functioning entity that can be identified and described. Such a model must contain a range of services. The model must be evolving and have its foundation in a formally defined planning scheme. Its existence is predicated on legislation and is associated with a well-defined geo-political unit.

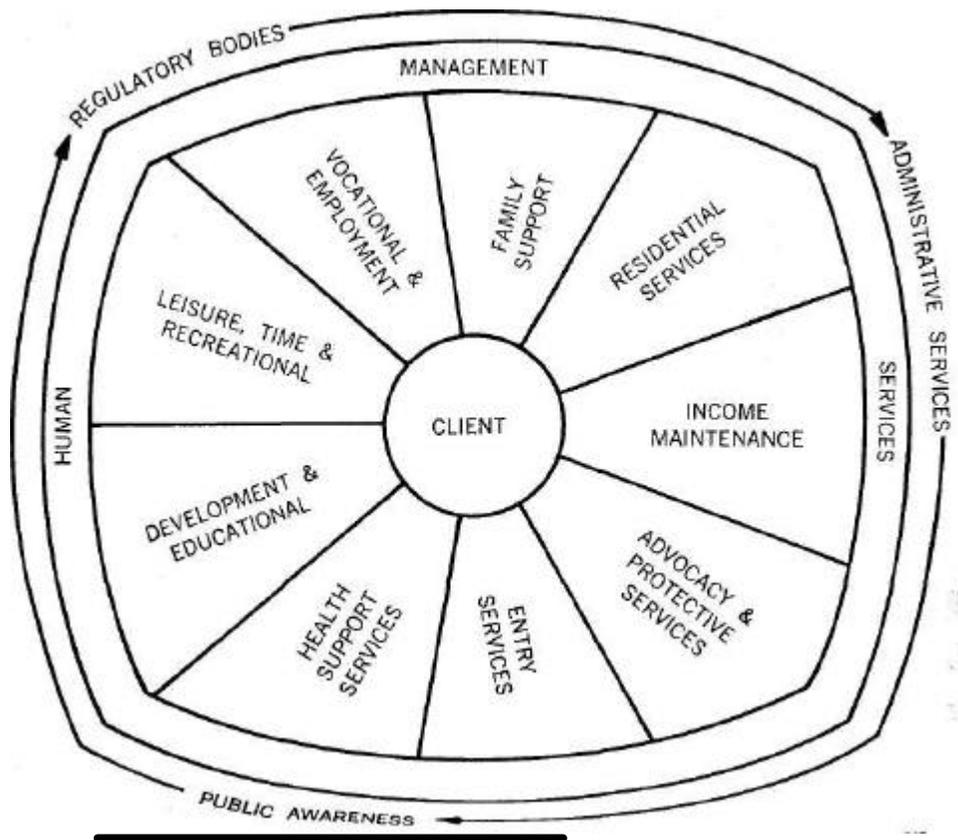
One may chart the components of a service system to illustrate the range of services which an individual may require to achieve his potential. Such a scheme, presented in the accompanying chart, does not show a totally complete system. It serves rather as a technique to describe various types of services which may be required in an integrated continuum of services. A description of the working parts of existing service systems follows the chart.

HUMAN MANAGEMENT SERVICES

In the inner ring of the chart, a series of nine service headings have been grouped and designated as Human Manage-

⁵ Robert B. Kugel, "Why Innovative Action?" *Changing Patterns in Residential Services for the Mentally Retarded*, ed. Robert B. Kugel and Wold Wolfensberger (Washington, D. C.: Superintendent of Documents, 1969), p. 11.

FUNCTIONAL COMPONENTS OF A SERVICE DELIVERY SYSTEM



ment Services.⁶ All of these assess needs or provide direct or indirect services. Although all of these services should be available, given the specific needs and age of the individual, they will be utilized only when required. The service components are not distinct entities but should be integrated and flow together; they are not hard and fast categories.

Entry Services

Entry services include case finding, information and referral, intake, fixed point of entry, and registration. They include the service contract functions as well as the assignment of a case manager or expediter. At the local or area level, agencies designated as Base Service Units, Mental Health/Mental Retardation Centers, or Human Service Centers can best provide these services. Actual location can vary from a storefront to a mobile unit touring the countryside. Available and appropriate services are a prerequisite for prevention. The system, however, requires adequately and appropriately trained staff to carry out these functions. *Health Support Services*

Health Support falls into at least two major areas, specific and general services. Specific services include diagnostic and evaluative procedures, necessary medical and surgical interventions, various therapies (i.e., speech, occupational, physical), genetic counseling, and public health nursing. General Services include health screening and preventative activities (e.g., PKU, lead poisoning, sickle cell), health supervision (prenatal and postnatal care, nutritional services), and basic medical research.

Any number of existing private or public resources can provide these services. Private physicians, hospitals and clinics, and Departments of Public Health have the resources, facilities, and expertise to offer a range of needed services in this area. Physicians, medical social workers, public health nurses, or organizations such as Planned Parenthood have or are developing programs on genetic counseling.

Public Health and visiting nurses can provide needed services in health supervision and nutrition and can assist in establishing and carrying through screening programs. Prevention as a goal must remain a prime concern and is essential to all service elements. Support for basic medical research must be continued within hospital and/or university based facilities. Both preventive as well as health support services must move out beyond the existing boundaries of such agencies.

⁶ Gunnar Dybwad, "Action Implications, U.S.A. Today" *Changing Patterns in Residential Services for the Mentally Retarded*, ed. Robert B. Kugel and Wolf Wolfensberger (Washington, D. C.: Superintendent of Documents, 1969), p. 403.

Developmental Educational Services

Developmental and educational services can be discussed as two major categories: Developmental Services for Infants and Toddlers, and School Services. Both broad areas have their own specialized diagnostic and evaluative procedures. Early assessment and intervention in both areas are important preventative tools. Developmental services would provide for intervention and assistance in motor, cognitive, and communication skills as well as in socialization activities. School Services would encompass early childhood education, elementary school programs, secondary school programs including pre-vocational services and the possible use of five-day residential boarding programs, and post high-school programs.

At the local community level, day care, pre-school nursery programs, and Head Start can and do offer developmental programs. Early education programs exist under both the public (Head Start, Home Start) and private (ARC) auspices. Elementary, secondary, and post high-school programs should be provided under the public school system. The entire area of developmental and educational services will expand under the influence of the recent Right of Education court decisions.

Leisure Time and Recreational Activities

Such activities may include craft activities, sports, outings, social clubs, vacations, and adult education. The focal point for these activities may be the local Department of Parks and Recreation, the Community Center, Scouts, neighborhood groups, service organizations, ARC's, Y-ARC's, and the public schools. Activities such as those developed by such organizations as the Nippon Society of Philadelphia can serve as prototypes.

Vocational and Employment Services

This service component encompasses activities ranging from an ongoing evaluation and assessment of needs and service requirements to follow-up-services. It may include assessment, vocational and technical training, social and vocational counseling, job placement, employment support, follow-up, provisions for sheltered employment, and adult education.

The public school system or vocational training centers can provide these services. The emerging Regional Vocational Training Centers are a valuable resource for those needing specialized training. Linkages must be established between these programs and existing or potential manpower programs, private contractors, unions, and the State employment service. Since mentally retarded individuals spend far more years of their lives as adults than as children in need of academic services, programs and efforts in this area must expand. The successes

of the federal government should serve as both a prototype and as an inspiration.⁷ Follow-up services are integral to the continuum.

Family Support Services

A wide range of available services and service options lie within this broad category. Services may include Home Start Programs, homemaker services, home sitter, home management, health visitor, dietary assistance, individual and family counseling, respite care, transportation services, crisis intervention, and religious nurture.

Responsibility for coordinating these services should rest with the area center or base service unit, with both public and private agencies actually providing services through a wide range of in-house and outreach programs. The in-home services can be provided on a contract basis with a Homemaker or Home Health Aide Service, Visiting Nurse Association, or public or private Child Welfare Agencies. The center can provide Social Services, including various forms of counseling, or contract for these services with public or private family service agencies. The area center should also coordinate Respite and Crisis services (i.e., 24-hour hot-line) and link them into the residential service component. Transportation services will require coordination with school authorities, regional transportation systems, and private contractors. Religious activities will range from a highly individualized approach observing familial allegiances to the provision of services by ministerial associations. *Income Maintenance Programs*⁸

Income maintenance programs include Social Security, Survivors Health Insurance (OASDHI), Social Security Disability Insurance (SSDI), General Assistance (GA) and the Supplemental Security Income Program (SSI). The importance of these programs lies in their potential versatility. Coordination between funding agencies and services dealing with potential recipients is mandatory. These various forms of funding may someday follow the individual and thus facilitate the purchase of necessary services rather than exclude individuals from services because of eligibility requirements or service gaps.

⁷Ronald W. Conley, *The Economics of Mental Retardation*. (Baltimore: John Hopkins Press, 1973).

⁸Gunnar Dybwad, *Challenges in Mental Retardation* (New York: Columbia University Press, 1964), pp. 85-194; U. S. Department of Health, Education and Welfare, *Mental Retardation Financial Assistance Programs*. (Washington, D. C.: Superintendent of Documents, 1971); National Association of Coordinators of State Programs for the Mentally Retarded, 92nd Congress: *Federal Legislation Affecting the Mentally Retarded and Other Handicapped Persons* (Arlington, Virginia: National Association of Coordinators of State Programs for the Mentally Retarded, 1973).

Residential Services

Residential services encompass a full range of age-appropriate domiciliary options which may include residence with one's own family, respite homes, individual and group foster homes, community residences, boarding homes, nursing homes, intermediate care facilities, apartments, independent living arrangements, and multipurpose (regional) institutional settings.

Funds for placing individuals in most of these settings are available through reimbursement or existing income maintenance programs. Residential services are one component in the continuum of services which enables an individual to reside in his community. *Advocacy and Protective Services*

Protective Services can be either specific or generalized. Specific protective services may include casework services (available from any number of agencies), individual advocacy (i.e., Fellowship Plan, Big Brother/Big Sister, One-to-One, other advocacy programs), Legal Services, Ombudsman, Guardianship, Citizen Advisory Boards, and Periodic Review (periodic review is a joint responsibility of public and private agencies, providers of service, consumers, and interested citizens).⁹ Generalized Services include institutional monitoring, advocacy by or for organizations, and the volunteer services of religious or civic groups. Some roles and functions of advocacy are discussed in detail by Robert Perske in Chapter XIII and by Thomas Graf in Chapter XII.

As stated previously, the foregoing service components comprise the Human Management portion of a generic service system. It is *not* an all-inclusive account of possible service options. Services have been grouped in what appears to be a logical order.

REGULATORY SERVICES

Regulatory services entail the various aspects of licensing, zoning, Life Safety Codes (fire-building codes), health and sanitation codes, and wage and hour laws. A state usually mandates and regulates licensing of facilities, personnel, and services. Licensing should guarantee appropriate programs, staffed by certified or approved personnel, which meet the

⁹ Sheldon R. Gelman, *Social Policy Implications, of Statutory Periodic Review of Residents in State Institutions for the Mentally Retarded*. Unpublished Ph.D. dissertation, The Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, 1973.

accepted standards in the field. Local ordinances concerning zoning, fire, and health must reflect standards consistent with a normalizing environment. A state must use codes and regulations to *include* mentally retarded individuals in the community, not to *exclude* them or set them apart.

ADMINISTRATIVE SERVICES

This chapter has stressed the importance of planning, coordination, and cooperation. Without them, no continuum of service can exist. Appropriate research and evaluative procedures are crucial for effective planning and coordination. Only skilled personnel and adequate budgetary provisions can generate the range of services required. Citizen advisory boards must share in planning and policy development. Without effective and efficient Administrative Services the Human Management Component of the system lacks the dynamic quality necessary for meeting individual needs.

PUBLIC AWARENESS ACTIVITIES

A public awareness of the scope and content needed for mental retardation cannot and should not be the responsibility of any single existing organization, but should become the joint responsibility of several.

No one agency working in this field is in a position to discharge the full responsibility for this important work, because each is concerned only with special aspects of this program; and broad public awareness, as well as an effective approach to professional groups and other organizations, requires a broader concept and the use of different although related techniques.¹⁰

The above mandate of the President's Panel explicitly sets out the needed actions in public education and information. Public attitudes resist change and can withstand extraordinary pressure for change on certain issues. In recent years we have made great strides with a variety of media to generate public awareness and acceptance of individuals and groups who in the past have been relegated to a special status. The efforts of

¹⁰ The President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation*. Washington, D. C.: Superintendent of Documents, 1962.

the President's Committee on Mental Retardation, the National Association for Retarded Citizens, the American Association on Mental Deficiency, and the Council for Exceptional Children have brought facts about mental retardation to the living room of almost every American home. Public awareness can also be accomplished through agency consultation services to reach both **lay** and professional attitudes.

The message has also traveled other avenues, including the exposure of a variety of dehumanizing situations. These exposes have generated both concern and fear. To avoid resurrecting the stereotypes and prejudices of the past, extreme caution and restraint must be exercised. One case may serve as a guide in this area. Although intended to generate concern and more appropriate habilitative programs for mentally retarded individuals, a series of events in Pennsylvania during 1972-73 may have served to reinforce the perception of these individuals as "deviants." Newspaper and television accounts of conditions in a private licensed facility showed residents "wantering aimlessly in a semi-clad condition around the grounds." A parallel series of newspaper accounts of the same situation as well as conditions in state-operated facilities linked deaths of residents to the activities of other residents. If you add the spectacular disclosure of "wooden cages" as a means of controlling aggressive residents, many cannot avoid a conclusion which emphasizes the "animal-like" qualities of individuals labeled as mentally retarded. The damage of this type of publicity far exceeds the very noticeable gains made through appropriate and constructive media coverage.

ONWARD!

This chapter has no conclusion; it is merely a starting point for what must follow. The mandate and requisites have been set out; the goals and components have been described.

However, let me close this discussion with a few words of caution. A service system without a firm administrative base, without adequate funds for staffing and support systems needed for implementation, without the necessary comprehensive planning and coordination, and without effective linkages to other service systems cannot go far toward improving services to **mentally** retarded citizens. A well designed and executed service system, geared to the needs of its clientele, sees its service gaps **and** continually takes the necessary actions to improve the com-

pleteness of its services. Effective and appropriately designed monitoring procedures, integral to every service system, can assure this continual upgrading.

If then we should discover what is to be done and who is to do it we may slowly come to recognize that we need no oracles—only dedication, wisdom, and above all, common sense.¹¹

¹¹ Philip Klein, *From Philanthropy to Social Welfare*. Jossey-Bass, San Francisco, 1971. p. 300.