Resources for the Mentally Retarded Citizen: A Bibliographic Essay

FRED D. STRIDER FRANK J. MENOLASCINO

ESSENTIALLY, THE TERM mental retardation refers to impaired intellectual functioning. Implicit in this definition is disordered development, impaired learning ability, and consequences of intellectual functioning below what is ordinarily considered to be normative for the culture in which the individual lives. A definition on mental retardation was adopted by the American Association of Mental Deficiency in 1961 and reaffirmed in 1973: "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and is manifested during the developmental period."¹ This definition specifies three vectors in the diagnosis of mental retardation: (1) general intellectual functioning which falls below that of 97 percent of the population (usually defined by scores on standard psychological tests of intelligence), (2) impaired ability to adapt to and control one's environment (usually defined in terms of ability to learn, delayed or arrested maturation, and impaired social skills), and (3) impairment of development (impairment occurring in the period from conception to about sixteen years of age).

Levels of retardation are usually assessed on the basis of psychological tests of intelligence, such as the Stanford-Binet Intelligence Scale, the Wechsler Intelligence Scale for Children, and the Wechsler Adult

Fred D. Strider is Chief, Clinical Psychology Section, and Director, Allied Professional Services, Nebraska Psychiatric Institute, University of Nebraska Medical Center, Omaha; and Frank J. Menolascino is Associate Director, Nebraska Psychiatric Institute, and Vice-Chairman, Department of Psychiatry, University of Nebraska Medical Center, Omaha.

Intelligence Scale. Until the recent adaptation of the latest revision of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM III) by the American Psychiatric Association, a border line level of mental retardation was assigned to individuals who achieved intelligence quotient (IQ) scores between 68 and 85 on standard tests of intellectual functioning. Mild mental retardation is now related to IQs in the 50-70 range; moderate mental retardation to the 35-49 range; severe mental retardation refers to IQs between 20 and 34. IQ scores below 20 are associated with the classification of profound mental retardation.

The second vector in the diagnosis of mental retardation is impaired social-adaptive behavior, ordinarily manifested by difficulty in coping with the educational, vocational and social demands of the environment. In infancy and early childhood, maturational difficulties are observed in impaired motor development; impaired development in socialization and communication skills; and in limited acquisition of such self-help skills as dressing, toileting and feeding. Retarded children of school age show impaired learning ability. In adulthood, difficulties in interpersonal relationships, limited vocational skills, problems in social conformity, and limitations in socioeconomic independence reveal impaired social adjustment.

Historical Aspects of Mental Retardation

We find no evidence that the physicians of the ancient world, with the exception of Hippocrates and some of his contemporaries, had any interest in mental retardation. The first 1800 years of the Christian Era were a time when the nature of the mind was regarded as the province of theology and philosophy. The Catholic Church provided refuges and almshouses for the mentally ill and the retarded; the entire town of Geel, Belgium, was the first sheltered community provided for the mentally impaired. The Middle Ages, however, were characterized by extremes of rejection, ostracism and cruelty; retardation was an attribute to be ridiculed, or was viewed as evidence of possession and dealt with by exorcism and torture. This view of retardation persisted until the early seventeenth century, when Paracelsus described "cretinous idiocy" as an illness and discussed its frequency of occurrence.

Itard, Jean-Marc G. *The Wild Boy of Aveyron*. Translated by George Humphrey and Muriel Humphrey. New York: Appleton-Century-Crofts, 1962.

Lane, Harlan L. The Wild Boy of Aveyron. Cambridge, Mass.: Harvard University Press, 1976.

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Seguin, E. The Moral Treatment, Hygiene, and Education of Idiots and Other Backward Children. New York: Columbia University Press, 1846.

Binet, Alfred. "La perception des longueurs et des nombres chez quelques petits enfants." *Revue Philosophique* 50(1890):68-91.

______. "Nouvelles recherches sur la mesure du niveau intellectuel chez les enfants d'école." *L'Année Psychologique* 17(1911):145-201.

, and Simon, T. "Sur la nécessité d'établir un diagnostic scientifique des états inférieurs de l'intelligence." *L'Année Psychologique* 11(1905): 163-90.

. "Méthodes nouvelles pour le diagnostic du niveau intellectuel des arnormaux." *L'Année Psychologique* 11(1905):191-244.

Goddard, Henry H. *The Kallikak Family*. New York: MacMillan, 1912. Davenport, Charles B. *Heredity in Relation to Eugenics*. New York: Holt, 1913.

Itard's work, published at the turn of the nineteenth century, is perhaps the first description of the beneficial effects of a structured, creative, enriching environment on the effects of retardation. Victor, the "wild boy of Aveyron," was most likely a severely retarded child who had been abandoned by his family. Jean-Marc Gaspard Itard devoted five years to a demonstration of his conviction that Victor could be educated by a carefully designed system of sensory input and habit training. Aspects of Itard's work also reveal recognition of motivation, needs and transference, so that parts of his program with Victor contain elements of modern psychotherapeutic practice. Seguin's work is a landmark in the literature of mental retardation because of its influence in bringing recognition of mental retardation and its presentation of a systematic program for the education of the retarded. A more recent reference is the book by Lane. Seguin's system was introduced in America by Samuel G. Howe, who became director of the first state-supported school for the retarded in South Boston, Massachusetts, in the midnineteenth century.

In 1867 a group of American psychiatrists founded the American Association on Mental Deficiency, an organization devoted to the principle that mentally retarded children ("idiots" and "imbeciles") could be significantly improved by psychotherapy and dynamically oriented education. This emphasis on psychological and behavioral approaches to mental retardation was significantly slowed by a trend to investigate the basic nature and cause of mental retardation and the apparent causal relationship between mental retardation and brain pathology, or neurological defect, which emerged from such investigations. At the beginning of the twentieth century, the discovery of brain pathology in

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mental retardation brought an end to attempts to educate the retarded. In a few short years, although attitudes of benevolence and human kindness remained in professional approaches to the retarded, custodial care came to replace all other professional approaches. Over the years even these attitudes faded away, and the view of the retarded as defective came to be expressed in programs designed to protect society from the retarded. Institutional models of care, characterized by low budgets, patient labor as an important means of institutional support, penal facilities, incarceration, and neglect, became the standard for treatment of the retarded.

In the early 1900s, the involvement of American psychiatrists in the treatment of mental retardation was essentially ended by the convergence of three events: (1) the development of a rationale for the measurement of intellectual ability, and the application of this rationale in a standardized procedure by Binet; (2) the introduction of the theory and methods of psychoanalysis to American psychiatry; and (3) publication of Goddard's monograph on his genetic study of the Kallikak family. The Binet test quickly became the essential procedure for the diagnosis of mental retardation, the guide for educational programs for retarded persons, and the index of prognosis for social effectiveness. Psychometric procedures replaced psychiatric ones, and use of Binet's test revealed far greater numbers of mentally retarded among populations of prisoners and social misfits. These events led to withdrawal of psychiatry from the field of mental retardation and the conceptualization of the retarded as criminal and dangerous to the social order. Goddard's work related mental retardation to genetic defect, and the belief that heredity was the major cause of mental retardation was established by other researchers. Psychoanalytic successes with neurotic individuals, and limited applications to the retarded, completed the retreat of psychiatry from the field of mental retardation. A new policy demanding immediate institutionalization of the retarded arose from the menacing statistics of psychometric research and the "genetic alarm" first sounded by Goddard and reinforced by Davenport and others.

Blatt, Burton, and Kaplan, Fred. Christmas in Purgatory. Boston: Allyn and Bacon, 1966.

Vail, David J. Dehumanization and the Institutional Career. Springfield, Ill.: Charles C. Thomas, 1966.

The period from the early 1900s to the 1960s marks an era of incarceration of the retarded in order to "protect society from the deviant." *Christmas in Purgatory* by Blatt and Kaplan documents in graphic form the institutional world of the retarded citizen, characterized by warehousing, enforced labor and mass sterilization. Vail's work documents this tragic era and aptly refers to the period as one of dehumanization.

The National Association for Retarded Citizens was formed in the mid-1950s. Since that time, the association, parents of the retarded, and persons committed to humanitarian and social justice ideals have brought to the attention of the public the plight of the retarded. The past thirty years have brought about renewed interest in the causes, treatment and amelioration of syndromes of mental retardation. We shall review later these advances in education, training and delivery of services.

Causes of Mental Retardation

Menolascino, Frank J., and Egger, Michael L. Medical Dimensions of Mental Retardation. Lincoln: University of Nebraska Press, 1978.

- Menolascino, Frank J., and Strider, Fred D. "Advances in the Prevention and Treatment of Mental Retardation." In *American Handbook of Psychiatry*, 2d ed., edited by Silvano Arieti and H.K. Brodie, vol. 7, pp. 614-48. New York: Basic Books, 1981.
- Hilliard, L.T., and Kirman, Brian H. Mental Deficiency, 2d ed. Boston: Little, Brown, 1965.

Over 350 causes of mental retardation have been identified. Menolascino and Egger review these syndromes as they are related to genetic factors; prenatal, perinatal, and postnatal factors; hypothyroidism; disorders of brain and skull formation; spinal column disorders; epilepsy; and other disorders of the central nervous system. Detailed information on the specific causes of these disease processes which produce the symptoms of mental retardation are found in texts such as that by Hilliard and Kirman. Modern approaches to the prevention and treatment of mental retardation are presented as models of primary (prevention of the appearance of a disorder), secondary (early diagnosis, effective treatment and return of the person to a normative state), and tertiary (minimization of the remaining handicaps and return of the person to as high a level of functioning as possible) prevention, and detailed in Menolascino and Strider's chapter of *American Handbook of Psychiatry*.

Masland, Richard L., et al. Mental Subnormality. New York: Basic Books, 1958. Robinson, Halbert B., and Robinson, Nancy M. The Mentally Retarded Child: A Psychsocial Approach, 2d ed. New York: McGraw-Hill, 1976. Mercer, Jane R. Labeling the Mentally Retarded: Clinical and Social System Perspectives on Mental Retardation. Berkeley: University of California Press, 1973.

In addition to reviewing the biological and physiological causes of mental retardation, social and cultural determinants are included in the reference by Masland, Sarason and Gladwin, and are stressed in Robinson and Robinson. Lastly, the diagnostic problems which psychosocial factors can cause in mislabeling a person who is mentally retarded are cogently reviewed by Mercer.

Solomons, G. "Counseling Parents of the Retarded: The Interpretation Interview." In Psychiatric Approaches to Mental Retardation, edited by Frank J. Menolascino, pp. 455-75. New York: Basic Books, 1970.

Interpretation of the diagnosis of mental retardation to a child's parents is a cornerstone for future helpful therapeutic intervention. If clinicians fail at this point to help parents understand their child's problems, the parents may shop for further diagnostic services rather than focus upon effective treatment and intervention. The interpretation interview is reviewed by Solomons and Menolascino.

Noland, Robert L. Counseling Parents of the Mentally Retarded: A Sourcebook. Springfield, Ill.: Charles C. Thomas, 1970.

Menolascino, Frank J., and Egger, Michael L. Medical Dimensions of Mental Retardation. Lincoln: University of Nebraska Press, 1978, pp. 423-30.

Helping parents to accept the diagnosis of mental retardation in their child requires an awareness of the family dynamics. Such concerns are discussed by Noland and by Menolascino and Egger as constituting a necessary step toward actively involving the family in modern treatment programs for the child.

Delivery of Services to the Mentally Retarded

- Stedman, D.J. "Important Considerations in the Review and Evaluation of Educational Intervention Programs." In Research to Practice in Mental Retardation: IASSMD Proceedings, vol. 1: Care and Prevention, edited by Peter Mittler and Jean M. de Jong, pp. 99-108. Baltimore, Md.: University Park Press, 1977.
- Barber, H. "Intervention in Infancy: A Developmental Approach." In The Mentally Retarded and Society: A Social Science Perspective, edited by Michael J. Begab and Stephen A. Richardson, pp. 287-303. Baltimore, Md.: University Park Press, 1975.

- Hayden, A.H., and Haring, N.G. "The Acceleration and Maintenance of Developmental Gains in Down's Syndrome School Age Children." In IASSMD Proceedings, vol. 1, pp. 129-41.
- Hayden, A.H., and Pious, C.G. "A Case for Early Intervention." In *Teaching* the Severely Handicapped, vol. 4, edited by E.B. Edgar and R. York, pp. 265-87. Seattle, Wash.: American Association for the Education of the Severely/Profoundly Handicapped, 1979.

Early childhood education has been increasingly viewed as a key treatment intervention program for the mentally retarded. The rationale and need for such early intervention is well presented by Stedman. The value of such early intervention programs has also been documented by the experimental study of the Milwaukee Project. In the longitudinal follow-up studies by Hayden and Haring, the effectiveness and cost efficiency of early intervention programs for the mentally retarded are clearly demonstrated and documented.

Education for the Mentally Retarded

- Robinson, Halbert B., and Robinson, Nancy M. The Mentally Retarded Child: A Psychosocial Approach, 2d ed. New York: McGraw-Hill, 1976.
- Hutt, Max L., and Gibby, Robert G. The Mentally Retarded Child: Development, Education and Guidance. Boston: Allyn and Bacon, 1958.
- MacMillan, Donald L. *Behavior Modification in Education*. Edited by Patrick T. McConahay. New York: Macmillan, 1973.
- Hardy, Richard E., and Cull, John G., eds. Mental Retardation and Physical Disability. Springfield, Ill.: Charles C. Thomas, 1974.
- Freeman, Stephen W. The Epileptic in Home, School, and Society: Coping with the Invisible Handicap. Springfield, Ill.: Charles C. Thomas, 1979.
- Bernstein, Norman R., and Menolascino, Frank J. "Apparent and Relative Mental Retardation: Their Challenges to Psychiatric Treatment." In Psychiatric Approaches to Mental Retardation, edited by Frank J. Menolascino, pp. 91-114. New York: Basic Books, 1970.
- Michaelis, Carol T. Home and School Partnerships in Exceptional Education. Rockville, Md.: Aspen Systems Corp., 1980.

Special education services for retarded children and adolescents have been greatly enhanced by the passage of national legislation (Public Law 94-142) which mandates these services for all. There has followed a plethora of basic special education programs, as presented by Robinson and Robinson, Hutt and Gibby, and MacMillan. Further, these special education approaches have also focused on retarded persons with allied handicaps such as a physical disability (Hardy and Cull), seizures (Freeman), and emotional disorders (Bernstein and Menolascino). Lastly, the closely allied roles of professionals and parents in special education has been underscored by Michaelis.

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- Baumeister, Alfred A., ed. Mental Retardation: Appraisal, Education and Rehabilitation. Chicago: Aldine, 1967.
- Bellamy, G. Thomas, et al. Vocational Habilitation of Severely Retarded Adults. Baltimore, Md.: University Park Press, 1979.

Vocational habilitation with focus on the world of work has been reviewed as to basic concepts by Baumeister and, more recently, refined by Bellamy.

- Menolascino, Frank J., ed. *Psychiatric Approaches to Mental Retardation*. New York: Basic Books, 1970.
- Szymanski, Ludwik S., and Tanguay, Peter E., eds. Emotional Disorders of Mentally Retarded Persons: Assessment, Treatment and Consultation. Baltimore, Md.: University Park Press, 1980.
- Group for the Advancement of Psychiatry, Committee on Mental Retardation. *Psychiatric Consultation in Mental Retardation*, vol. 10. Pittsburgh, Pa.: Group for the Advancement of Psychiatry, 1979.

Emotional problems often plague the lives of the mentally retarded and present major stumbling blocks to their education and habilitation. Scientific study of the types of emotional disorders was delineated by Menolascino in 1970. Treatment aspects have been reviewed by Szymanski and Tanguay. Effective psychiatric consultation modalities have been presented by the Group for the Advancement of Psychiatry.

New Approaches to the Problem

Wolfensberger, Wolf. "The Origin and Nature of Our Institutional Models." In Changing Patterns in the Residential Services for the Mentally Retarded, edited by Robert B. Kugel and Wolf Wolfensberger, pp. 59-171b. Washington, D.C.: USGPO, 1969.

The past decade has witnessed significant changes in attitudes toward mental retardation. A major advance has been the erosion of the once-prevalent "deterioration" model of mental retardation in favor of a more positive view. The modern positive attitude views the mentally retarded individual, even if severely retarded, as capable of growth, development and learning. This point of view is termed the "developmental model," as noted by Wolfensberger.

Nirje, Bengt. "The Normalization Principle and its Human Management Implications." In Changing Patterns in the Residential Services for the Mentally Retarded, edited by Robert B. Kugel and Wolf Wolfensberger, p. 181. Washington, D.C.: USGPO, 1969.

Another major force in the ideological shift that began in the late 1960s was the normalization principle. It was first systematically elabo-

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rated by Nirje in 1969, who defined the concept as "making available to the mentally retarded the patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society."

Menolascino, Frank J. Challenges in Mental Retardation: Progressive Ideology and Services. New York: Human Sciences Press, 1977.

Both the developmental model and the concept of normalization have become the cornerstones for minimizing the mental and physical handicaps of the retarded via modern program methods, so that their handicaps become less pronounced. Further, these twin concepts have stressed that the retarded person has the same rights for selfactualization in the world as do all other citizens. Further, these concepts have become the basis for moving away from the dehumanization of traditional care. Indeed, they have become the basis for the deinstitutionalization movement.

- Eastern Nebraska Community Office of Retardation. *Five Year Plan*. Omaha, Neb.: ENCOR, 1980.
- Dybwad, Gunner, ed. New Neighbors: The Retarded Citizen in Quest of a Home (President's Committee on Mental Retardation, Report to the President MR79). Washington, D.C.: USGPO, 1980.
- Elliott, Ian, ed. Mental Retardation: The Leading Edge. Service Programs that Work (President's Committee on Mental Retardation, Report to the President MR78). Washington, D.C.: USGPO, 1979.

Concurrently, there has gradually arisen across the country a number of community-based programs and systems of services for the mentally retarded which embrace educational, vocational, social, and residential services for the retarded citizen from birth until death. These systems are reviewed in the ENCOR report and in the 1978 report to the president by the President's Committee on Mental Retardation.

Rights of the Mentally Retarded

- Basic Rights of the Mentally Handicapped. Washington, D.C.: Mental Health Law Project, 1973.
- Friedman, Paul R. "Human and Legal Rights of Mentally Retarded Persons." International Journal of Health 6(Spring 1977):50-72.

The rights of the mentally retarded have been a major theme in the current work in the field of mental retardation. As noted by the Mental Health Law Project, initial thrusts were on the right to treatment, right to compensation for institution-maintaining labor, and right to education. As noted by Friedman, the advocacy of human and legal rights for the retarded began to encompass due process protection in civil commitment and guardianship proceedings, legal limitations on hazardous research procedures, employment rights, right to a barrier-free environment, sexual and marital rights, etc.

- Mason, Bruce G., and Menolascino, Frank J. "The Right to Treatment for Mentally Retarded Citizens: An Evolving Legal and Scientific Interface." *Creighton Law Review* 10(Oct. 1976):124-69.
- Pennhurst State School and Hospital v. Haldeman, Civil Act No. 74-135, U.S. District Court, Eastern District, Penn., 1977.
- American Psychiatric Association. "Position Statement on the Right to Adequate Care and Treatment for the Mentally Ill and Mentally Retarded." *American Journal of Psychiatry* 134(March 1977):354-55.

The most dramatic advocacy as to rights of the mentally retarded has been the thrust for right to treatment. The initial seminal formulation of a constitutional right to habilitation for mentally retarded citizens involuntarily confined in state institutions appeared in *Wyatt v. Stickney*. This particular Federal Court Decision, reviewed by Mason and Menolascino, has not only set the tone for dramatic improvement in institutional care for the retarded, but has also raised the issue of whether institutions are a viable treatment modality for the mentally retarded. This evolving legal and scientific interface has spawned rightto-treatment cases in virtually every state, and was recently the subject of a Supreme Court decision. (See *Pennhurst State School and Hospital v. Haldeman*, and the position statement on the right to adequate care and treatment for the mentally ill and mentally retarded of the American Psychiatric Association.)

Research and Prevention of Mental Retardation

Mittler, Peter, and de Jong, Jean M., eds. Research to Practice in Mental Retardation: IASSMD Proceedings. 3 vols. Baltimore, Md.: University Park Press, 1977.

Research to elucidate the multiple causes of the symptom of mental retardation must, by necessity, cover a broad range of activity. As noted in the excellent international overview of research in mental retardation by Mittler and de Jong, there is much activity in biochemical, metabolic, genetic, pharmacological, and developmental areas. Research activities range from prenatal nutrition to maximizing the daily activity schedules of the elderly retarded citizen.

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- Preventing Mental Retardation—More Can Be Done (Report of the U.S. Comptroller General). Washington, D.C.: USGPO, 1977.
- Menolascino, Frank J., and Strider, Fred D. "Advances in the Prevention and Treatment of Mental Retardation." In American Handbook of Psychiatry, 2d ed., edited by Silvano Arieti and H.K. Brodie, vol. 7, pp. 614-48. New York: Basic Books, 1981.

Closely allied to research are the ongoing efforts to apply the fruits of such endeavors. Specifically, there are a wide variety of primary, secondary and tertiary prevention activities underway, as reviewed in a 1977 report to Congress by the Government Accounting Office and in the review by Strider and Menolascino.

Resources for Parents of the Mentally Retarded

The major organized advocacy group for the mentally retarded is the Association for Retarded Citizens (ARC), which has its national offices in Arlington, Texas.* Each state has an office of this national advocacy group. In New York state, an allied group is the New York Association for Retarded Children. Beyond the national and state organizational format, there are over 2000 local ARC units in our country, whose addresses and phone numbers are obtainable from local telephone directories. These local/state/national ARC offices are an excellent first step for parents seeking information or services for their retarded child. Other major resources include a developmental disabilities office, which can be reached by contacting the governor's office in any state. Information and services can also be obtained, in many states, by contacting the local university-affiliated program, a national network of twenty-four major programs in mental retardation which provide information, training and services for mentally retarded citizens. Each state government has a department of mental health/mental retardation which can be contacted for specific and general information.

Dybwad, Rosemary F. International Directory of Mental Retardation Sources, 2d rev. ed. Washington, D.C.: USGPO, 1978.

Professional organizations, which can also be a source of information, include the American Association on Mental Deficiency, (5101 Wisconsin Ave. NW, Washington, D.C. 20016), the American Psychological Association, and the National Association of Social Workers. These national organizations also publish excellent journals concern-

^{*}Association for Retarded Citizens, 2501 Avenue J, Arlington, TX 76011. (tel.: 817-640-0204)

ing research and service activity in the field of mental retardation: American Journal of Mental Deficiency, Mental Retardation Journal, and the journals of the professional organizations. Information as to international programs has been provided by Rosemary Dybwad.

Library Resources for the Mentally Retarded

Although some library resources have been noted above with regard to professional journals, a number of specific library resources are available. Each of the twenty-four university-affiliated programs noted above has both general and specific library resources concerning mental retardation. Similarly, there are a number of regional medical libraries which have extensive collections on this topic. In particular, there are national library resources at the headquarters of the Association for Retarded Citizens in Arlington, Texas, the headquarters of the Canadian Association for the Retarded in Toronto, Canada, and the offices of the President's Committee on Mental Retardation in Washington, D.C.

- American Library Association. Standards for Libraries at Institutions for the Mentally Retarded. Chicago: ALA, 1981.
- Matthews, Geraldine. Library Information Service Programs in Residential Facilities for the Mentally Retarded. Madison: Wisconsin Department of Public Instruction, 1974.

The American Library Association has prepared a draft "Standards for Libraries at Institutions for the Mentally Retarded." Matthews has also surveyed library information service programs in facilities for the mentally retarded.

An exciting trend in the utilization of library resources has been that of "living library resources," which over the last six or seven years has provided special toy libraries for the parents of the handicapped, packaged behavioral analysis programs (with or without videotape components), and a variety of manual aids for helping the parent to interact directly and more effectively with a retarded son or daughter. The use of mobile vans which travel to community neighborhoods, high levels of personal contact, and the packaging of highly technological information into everyday language are remarkable features of this new trend. Indeed, reaching out to the handicapped citizen and his parents via the specific library resources of the community signifies the direct delivery of library services where the consumer needs them most.

Summary

The role of the librarian in providing up-to-date informational resources on a topic as diverse as mental retardation is difficult to accomplish. In this article we have reviewed different types of resources that are available, sources for obtaining more specific information, and a wide variety of resources which must be orchestrated for delivery of information to retarded citizens and their parents. It is hoped that this article has helped to clarify how significantly needed services can best be delivered, in view of the state of modern library practices and technology, and the library's active involvement in community problems.

Reference

1. American Association on Mental Deficiency. Manual on Terminology and Classification in Mental Retardation (AAMR Special Publication Series No. 2), rev. ed., edited by Herbert J. Grossman. Baltimore, Md.: Garamond/Pridemark Press, 1973, p. 5. This Page Intentionally Left Blank