

RESIDENTIAL PROGRAMMING:

Position Statements by the National Association
of Superintendents of Public Residential Facilities
for the Mentally Retarded



**PRESIDENT'S COMMITTEE
ON MENTAL
RETARDATION**

May 1974

FOREWORD

This policy statement was developed by the National Association of Superintendents of Public Residential Facilities at a meeting sponsored by the President's Committee on Mental Retardation and the Rehabilitation Services Administration.

Although it does not necessarily reflect in every detail the views of the President's Committee on Mental Retardation, it does represent a progressive approach to the Committee's goal of improvement in residential services for retarded persons. The Committee highlighted this need with its publication in 1970 of "Residential Services for the Mentally Retarded: An Action Policy Proposal."

The superintendents of public institutions are in a strategic position to improve the quality of residential services and to facilitate the movement of many residents to the community. Their interest in playing such a role is forcefully expressed in this statement. As such, it has the support of the Committee.

Fred J. Krause
Executive Director

In November, 1973, sixteen superintendents representing the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded met in Washington, D.C., to draft position statements concerning five contemporary issues affecting residential services. These involve: (1) recent emphasis upon community programming, (2) future role of residential services, (3) role of residential staff in deinstitutionalization and community programming, (4) standards of the Joint Commission on Accreditation of Mental Retardation Facilities, and (5) Federal participation.

The sixteen superintendents represented a cross section of varying viewpoints, years' experience in residential programming, professional backgrounds, populations served, and geographical distribution. In addition to the superintendents, a university administrator and staff representatives from the President's Committee on Mental Retardation and the Division of Developmental Disabilities participated.

Basic Premise

All retarded persons have the same basic civil and human rights as other citizens, including the right to live in the least restrictive environment. As stated in the "Declaration of General and Special Rights of the Mentally Retarded" (1968):

The mentally retarded person has a right to live with his family or with foster parents; to participate in all aspects of community life and to be provided with appropriate leisure time activities. If care in another institution becomes necessary, it should be in surroundings and other circumstances as close to normal living as possible.

The basic positions advocated by the Association all reflect a vital concern for the rights of the retarded, the desirability of community programming, and upgrading residential services.

Definitions

The definition of residential facility for the mentally retarded and its purpose as promulgated by the President's Committee on Mental Retardation (1970, p. 1) were used in developing the position statements:

A residential facility for the mentally retarded is any housing facility, other than the individual's natural home, which provides (24-hour) supervised living with appropriate services related to the individual's needs.

The prime purpose of residential services for the mentally retarded is to protect and nurture the mental, physical, emotional, and social development of each individual requiring full-time residential services. Inherent in this commitment is responsibility to provide those experiences which will enable the individual (1) to develop his physical, intellectual and social capabilities to the fullest extent possible; (2) to develop emotional maturity commensurate with social and intellectual growth; (3) whenever possible, to develop skills, habits and attitudes essential for return to contemporary society; and (4) to live a personally satisfying life within the residential environment.

Position Statements

The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded thoroughly supports the recent emphasis upon community programming for the mentally retarded.

While the Association advocates without reservation the rights of the retarded to live in the least restrictive environment and to enjoy fully the benefits of a free and open society whenever possible, it does express concern over the manner in which this goal is being realized. First, the quality of community programs and services being offered to the mentally retarded and other developmentally disabled persons in many parts of the country is inadequate. All too often, "community back wards" and "closeting" are being substituted for institutional "warehousing". Neither community nor residential back wards or "closeting" are justified; the rights of the retarded must be respected wherever they reside. In essence, the Association calls attention to the need not only for continued upgrading of residential facilities toward becoming decent, viable, and responsive environments reflecting normalization for those who, for some time, will require specialized residential care, but also calls for a greater interest in quality control for developing community programs.

In this context, the Association strongly supports advocacy programs which, once developed, will lead to a system accountable to retarded people and their parents, and will insure a quality of life compatible to the needs of all people. The Association encourages its members and all others interested in the care and treatment of the mentally retarded to advocate especially for the profoundly and severely, multiply handicapped who often see "good and new things" drift away from them. The Association also urges that greater emphasis be placed on maintaining the child in his natural home, and that parents receive greater and more timely support in terms of both services and financial assistance to attain this goal.

Secondly, the development of community programming should not be accomplished by sacrificing quality of services for retarded persons requiring residential care. It is not a question of residential *or* nonresidential programming. Both are essential, and both, in reality, constitute community services.

Thirdly, in many parts of the country today, a dichotomy exists between "community" and "residential" programming. This polarization of persons with a common dedication to meeting the needs of the mentally retarded is unwarranted and should be resolved as rapidly as possible to insure maximum services for the retarded, both within the community and within a residential environment. Residential programming must be viewed as part of the complete range of community services which may be required by some retarded persons.

The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded fully supports efforts toward deinstitutionalization, institutional reform, and acceptance of a changing role.

Deinstitutionalization encompasses three inter-related processes: (1) prevention of admission by finding and developing alternative community methods of care and training; (2) return to the community of all residents who have been prepared through programs of habilitation and training to function adequately in appropriate local settings; and (3) establishment and maintenance of a responsive residential environment which protects human and civil rights and which contributes to the expeditious return of the individual to normal community living, when-

ever possible. The success of deinstitutionalization is dependent upon the availability of an array of quality community programs and services.

Institutional reform, in contrast, involves a modification or improvement in attitudes, philosophies, policies, effective utilization of all available resources, and increased financing to provide adequate programs to motivate and assist individuals to reach their maximum level of functioning in the least restrictive environment possible. Institutional reform will occur only through an increased effort on the part of all professional, nonprofessional, and lay persons concerned with the mentally retarded.

The emphasis on deinstitutionalization, institutional reform, and the need to provide support to developing community programs demands a changing role among residential facilities. Publicly sponsored residential facilities will continue to be a necessary and important part of the continuum of services required by some mentally retarded individuals at some time during their life.

Residential populations will continue to undergo significant change. With few exceptions, only the most severely and profoundly, multiply handicapped mentally retarded will require extended residential service. Programs developed for these individuals will include an interdisciplinary approach to facilitate whatever developmental potential exists. Evidence to date in those facilities which have had an opportunity to concentrate on the more seriously affected have demonstrated unequivocally that even the most severely involved child has considerably more potential than previously believed. Many of the severely and profoundly, multiply handicapped retarded can live in a sheltered foster home-type setting in the community.

A number of short-term programs will be established with the intent of ameliorating specific problems and returning the child to his home community as soon as possible. Such services will be for the socially inadequate retarded child who can not participate in a formal education program or day services and whose needs can not be met locally. Another such program may involve physical restoration in which a retarded person with a severe orthopedic problem receives appropriate surgery, therapy, and follow-up home services, including parental training

and guidance. In a few instances, very young multiply handicapped children or infants might be admitted for a brief period of time in order to develop a program which can be implemented by parents and/or representatives from a community agency. Genetic counseling and specialized dental services for mentally retarded persons from the community will become readily available.

Comprehensive developmental programs for several long neglected groups of retarded persons — the sensorially handicapped (i.e., blind and/or deaf) and emotionally disturbed — will be developed. These programs will utilize the contributions of specialized institutes, university personnel, and representatives from a variety of community agencies.

Most residential facilities already offer a most welcome service to parents of the retarded — respite care. Most residential facilities also provide comprehensive diagnostic, evaluation and planning services for retarded persons (infants, children, and adults) referred from other community agencies. It is anticipated that these will be extended to individuals with a variety of developmental disabilities.

Residential facilities in the future will not function in an isolated capacity. All services will involve the active participation of parents, foster parents, or guardians and staff of appropriate community agencies. It can not be over-emphasized that intensive training and treatment programs of residential facilities will represent only highly technical back-up services. In other words, short-term programs will be available only when a local agency is unable to provide them. Duplication of services will be avoided.

Further, programming will be a shared responsibility between residential facility and community. Services of both shall be used simultaneously. For example, while the child may be receiving some specialized medical treatment requiring short-term residential care, he also may be attending a local school.

It naturally follows that as communities begin to provide a continuum of care for retarded persons and their families, technical assistance and training will be required. This is especially true **when** agencies attempt to design

programs for the more severely and profoundly, multiply handicapped retarded and for those who are making the transition from residential to community living.

The net effect of these trends is very positive. The majority of retarded persons who can function in a community environment with or without supervision will be able to do so, and those requiring intensive, highly specialized services in a residential environment will find them readily available.

The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded fully supports the utilization of residential staff services and facilities to aid and support the development of community programs essential to deinstitutionalization.

The Association restates its basic position that residential facilities should be considered as one community service. Subsequently, residential personnel should, and will assume an active professional interest and role in aiding communities to develop appropriate programs for the retarded.

In many instances, residential staff can provide valuable technical assistance and consultancy to other agencies or organizations dealing with the developmentally disabled, including local community programs, policy boards, planning commissions, generic practitioners, and legislative bodies.

A number of technical consultancy programs requiring expertise of residential staff will be established. Such programs may involve diagnosis and evaluation; education and training; language, speech, and hearing therapy; activity therapy and recreation; nutrition; and domiciliary care. In essence, any aspect of residential services (administrative or clinical) may become involved in technical consultancy, depending upon evident needs. In some areas, technical consultancy services will be transitory, existing only until the community has had an opportunity to develop its own cadre of well-experienced personnel and appropriate standards.

Residential facilities will expand training programs for persons from the community. An example of such training programs are preparation of parents, aides, and

other personnel working in foster family, groups, or nursing homes. Parental training for home care and development of the retarded also will be offered. Many residential facilities have established specialized programs to train babysitters for the more severely and profoundly retarded. Seminars and training sessions are, or will be offered to students in any health or behavioral field concerned with the mentally retarded and developmentally disabled.

Finally, residential staff can provide leadership in developing a precise interagency plan for deinstitutionalization of specific individuals and participate in the overall development of a comprehensive state plan for deinstitutionalization and institutional reform.

The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded fully accepts, approves, and supports accreditation standards for residential and community services and facilities.

The realization of acceptable standards of programming in both community and residential settings is imperative to meeting the needs of the retarded and other developmentally disabled persons. In order to realize these standards, most facilities and programs will require increased financial assistance. Further, once standards have been realized, incentives must be available to satisfy and maintain future, upgraded expectancies. Without such support, accreditation standards, which in many respects are minimal, may impede progress and programming.

Administrators and staff associated with programs affected by standards should have a continuous dialogue with agencies preparing and setting such standards. The Association should have input not only to the accreditation standards as developed by the Joint Commission on Accreditation of Hospitals, but also into Federal and state agencies concerned with levels of care, treatment, and programming. The Association recommends that each state develop a plan for achieving accreditation.

Any standards governing programming for developmentally disabled persons should be evaluated in a rigorous, scientifically acceptable manner. To date, the majority of standards reflect professional judgment. Their validity now needs to be established. Further, many questions have been raised about the reliability of assess-

ment instruments and raters. Reliability studies are most essential to increasing acceptability of the standards and related procedures established by many agencies.

The Association and its members are most willing to cooperate with any agency attempting to design, implement, or evaluate standards relevant to the developmentally disabled.

The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded strongly encourages the Federal government to establish and maintain a constant, flexible system of financial assistance to community and residential services providing for developmentally disabled persons.

While the prime responsibility for any public residential facility remains with the state, continued Federal interest and financial assistance is critical. The Association believes that block grants should be available to states which, in accordance with a state plan, will be distributed to community and residential programs on a competitive, state-wide basis. Granting agencies should award all funds solely on the basis of the needs of the developmentally disabled, taking into consideration the state's plan for meeting accreditation standards.

Categorical grants should be available to residential facilities in order to accomplish broad goals of deinstitutionalization, institutional reform, and the provision of back-up services. Federal controls should exist only to the extent of insuring that funds are being used: (1) to accomplish deinstitutionalization and institutional reform; (2) to guarantee that human and civil rights of the retarded are being met; and (3) to insure that funds are being used for increased programmatic effectiveness.

Purchase-of-service funds should be used by the individual to acquire services from any agency of his choice, and any such monies spent should remain with the provider. The latter is essential to guarantee maintenance of effort and to insure that service dollars are being used to enhance levels of programming. In other words, developmentally disabled persons, rather than any establishment, should benefit from Federal funds.

Funds should be available for purposes of maintaining

and expanding research and staff training efforts in residential facilities. Care, treatment, and training of the developmentally disabled, especially the more severely and profound mentally retarded, are complex. Much remains to be learned. Many residential facilities are staffed and equipped to do research into these vital areas of human development and related services. Research of this nature should be encouraged.

As residential populations become more multiply handicapped and seriously affected, intensive inservice training programs will need to be developed and delivered to staff. In addition, increasing commitments to provide extensive training to parents and representatives from both specialized and generic community agencies will require supplemental financial assistance. Appropriate inservice training programs are a key to the development of community services as well as deinstitutionalization and institutional reform.

In conclusion, the Association contends that the primary goal of providing more acceptable residential and nonresidential services can be accomplished only through the enactment of appropriate legislation (e.g., mandatory education); through greater cooperation among residential staff, state coordinators, and representatives from developmental disabilities councils and local agencies; through modification of residential roles; through development of standards appropriate to residential and community programming; and through elicitation of greater public and political support. The Association firmly believes that national priorities must be reassessed to bring the needs of retarded citizens much closer to the national conscience than currently evidenced.

References

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Statement of Purpose

National Association of Superintendents of Public Residential Facilities for the Mentally Retarded

The purposes of the Association are:

1. To promote continuous improvement of residential programs and encourage all facilities to satisfy requirements of accreditation.
2. To promote the interests of severely and profoundly as well as the multiply handicapped retarded and to foster the development of appropriate programs.
3. To promote the development of community service programs for all developmentally disabled persons.
4. To promote increased communication between all persons interested in the mentally retarded.
5. To promote the professional development of superintendents through regularly scheduled meetings to be held in conjunction with the regional and national convention of the American Association on Mental Deficiency.
6. To promote public awareness of the role and significance of residential services within comprehensive programming.
7. To collaborate with other professional agencies, associations, and national organizations in the development and implementation of comprehensive community and residential services for the mental retarded, including the National Association for Retarded Citizens, the American Association on Mental Deficiency, Council for Exceptional Children, and the President's Committee on Mental Retardation.

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