Policy Statements on Residential Care

Adopted by
The Board of Directors of the National
Association for Retarded Children
October 1968

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PREAMBLE

The failure to eliminate dehumanization in state institutions throughout the United States is testimony that the work of the National Association for Retarded Children is far from finished. Despite an increasing vocal concern for retarded persons, the problems related to care, training and living conditions of the institutionalized retarded children and adults continue to exist. The combined efforts of professionals, parents and interested citizens to eliminate dehumanizing conditions which presently exist in great numbers of residential care facilities have undoubtedly been responsible for what progress has been made. However, it is obvious that a more concentrated, all-encompassing approach must be developed if the humane conditions we are seeking for retarded persons are to become realities. This will require a systematic and on-going critical analysis of those practices, systems and policies which contribute to the dehumanization of persons in institutions for the mentally retarded. Such practices result in such things as (1) over-dependency, (2) lack of personal identity, (3) lack of privacy, (4) lack of meaningful relationships, (5) lack of self-esteem, (6) cultural and sensory deprivation, and (7) lack of individual programming.

In order to focus on the dehumanizing aspects of institutional care, the Ad Hoc Committee on Residential Care of the NARC used a problem defining-problem solving approach. Although the NARC is primarily concerned with those aspects of institutional life which deprive the resident of his basic civil and human rights, it nevertheless recognizes that there are many experiences outside the residential facilities which also have a dehumanizing effect and deprive retarded persons of their rights and dignity. The NARC hopes that local and state associations for the mentally retarded will be aware of these practices wherever they exist, and explore methods of combating them. The Ad Hoc Committee on Residential Care wishes to go on record as recognizing that additional funds are necessary if we are to achieve the kinds and quality of program services, facility, staff and training we hope to have in our residential care facilities. However, it also recognizes that there are many improvements which can take place and which can and will have a profound effect on the mentally retarded residents which does not require large expenditure of funds. The excuse of "too little and too late" can often be

a handy alibi for doing nothing. Therefore the committee strongly recommends that local and state chapters take on the challenge of bringing about a measure of change and improvement in spite of the usual shortages of funds, staff, facilities, etc.

The Ad Hoc Committee on Residential Care feels strongly that policy statements are meaningless unless they are followed by a vigorous plan of action. Therefore the committee strongly recommends that a program or plan for implementing the policies be initiated as soon as possible.

Problem: Denial of Civil Rights

All human beings are entitled to certain basic rights; however, the rights of the mentally retarded have not always been recognized or protected and are too often ignored or violated. Whether the retarded individual is in the community, in his home, or in a residential facility, consideration must be given to his civil and legal rights. Some persons may be able to exercise all of their civil rights, in due course, even though they are or may have been at one time or another identified as mentally retarded. Others may, as a result of a serious degree of mental retardation, be unable to exercise any of these rights in a meaningful way. There are some retarded persons for whom modification of all legal rights might be appropriate. However, there are large numbers of less severely retarded persons who are capable of exercising their full legal rights who have never been given the opportunity to do so.

Policy:

The mentally retarded person is entitled to the same civil rights as any other citizen unless a specific individual determination has been made, by appropriate procedures, that his exercise of some or all of such rights will place his own rights or those of others in undue jeopardy. Among the rights to which this general principle may apply are:

the right to choose a place to live,

to acquire and dispose of property,

to marry and have children,

to be given a fair trial for any alleged offense,

the right to engage in leisure time activities and to receive such special training, rehabilitation, guidance, counseling, education, and special education, as may strengthen his ability to exercise these rights with a minimum of abridgement.

When modification or denial of rights is necessary, certain compensating special or alternative rights should be acquired. In respect to any right which it is proposed to deny or modify, whether by administrative or judicial action, the retarded person is entitled to the benefit of special procedures in accordance with the general code of his state, which will insure that:

(1) An evaluation of social capabilities to exercise the rights in question has been made by persons specially qualified to do so;

(2) He, and members of his family or other interested persons, are advised in advance of the process;

(3) Rights of appeal to higher authorities, and especially the courts, are kept open;

(4) The benefits of these and related legal provisions are not limited by the economic status of the retarded person;

(5) There is provision for periodic review of the necessity to restrict rights;

(6) The possibility remains of restoring at a later date any right that has been denied, should the circumstances later justify restoration;

(7) Physical and psychological integrity of his person is preserved.

No retarded person should be legally committed to a residential facility without his consent or that of his parent or guardian unless it has been demonstrated that his behavior constitutes a danger to himself or to others, or that he is in need of special care and attention, and that such restriction of his activities is required in his own or in the public interest. In such a case he should be committed only to such a facility as has a program adapted to his treatment and needs. Indefinite commitments without provision for an appropriate program and periodic review should not be permitted.

Guardianship:

Each state should establish a protective service for the retarded in an appropriate state agency. A retarded person, whether he is an adult or a child, who has a general inability to manage his life has a right to the appropriate degree of protective supervision and of services needed to protect his interests and promote his welfare. Where a guardianship procedure is deemed appropriate it should state the form of guardianship: personal or property, plenary or limited. There should be provision for continuity of guardianship and in particular for the appointment of a

suitable successor guardian when no member of the family remains available.

Problem: Dehumanization and Lack of Human Rights

Much of the dehumanization which occurs in residential facilities involves the kinds of practices or procedures which adversely affect the dignity and the self-esteem of the individual. It is in this area of human rights that so much can be done without the involvement of great expenditure of funds. Lack of privacy, lack of personal possessions, lack of involvement in decisions affecting oneself, lack of praise for a job well done, lack of feeling that someone cares, lack of being recognized as an individual with ability and potential for growth, enforced and unnecessary regimentation, being ignored, living in crowded unattractive wards—these are but a few of the many kinds of conditions which can and do exist in residential facilities and which contribute greatly to dehumanization.

Policy:

On-going assessment and review of practices and policies which adversely affect the dignity and human rights of mentally retarded persons should be established. The identification of the problems, as well as the methods for solving them, should be the joint responsibility of staff, parents, legislators, governmental agencies and interested citizens. All internal practices which tend to dehumanize a resident should be eliminated. This applies to living conditions, working conditions, recreation, training and treatment. The atmosphere should be such that it recognizes the individual's worth and dignity, and makes provision for appropriate care, treatment and programming.

Problem: Unnecessary, Inappropriate and Prolonged Institutionalization

The needs of retarded persons vary with the individual and change at different times of their lives. Not too long ago residential placement was the first and often the only consideration given in planning for the care of mentally retarded persons, and often this meant a lifetime placement. Even today, in our so called enlightened society, there remains a tendency to think of residential care as the only appropriate place for retarded persons. Communities should offer a variety of alternatives which can be investigated in the development of the retarded person's life plan, with residential care considered as but one facet in the continuum of care.

Policy:

Every effort should be made to satisfy the retarded person's needs through

a variety of available resources rather than resorting in a routine fashion to residential care. Residential placement should be restricted to those whose specific needs can best be met by this type of service. No child or adult should remain in residential care any longer than necessary, and regular and frequent reevaluations must be scheduled to reveal any possibilities which have been developed in his community and to determine whether the individual himself has reached the point where he may profit by some other form of care.

Problem: Community Placement Can Also Be Dehumanizing

The problem of dehumanization can occur in a community facility as well as in residential facilities. Too often, in an attempt to remove an individual from the residential facility back into a community setting, the safeguards necessary to insure that the needs of the mentally retarded are in fact being adequately met have not always been established.

Policy:

If and when a resident is ready for another type of community placement adequate resources and services for meeting his needs should be available. Responsibility for the care of persons who have returned to the community should not be relinquished by the residential facility until assistance is assured from some other source. The community placement should guarantee at least as much if not more in the way of services and programs as the residential facility from which the individual came.

Problem: Lack of Family Involvement

Far too many residential facilities continue to operate in isolation from the community, parents, and other resources. This often presents a barrier between the resident and his family— and to the development of adequate planning and arrangements for his return to the community when this is possible and appropriate. Parents are not always informed of the changes in situations affecting their child, nor are they encouraged to become involved. Many rules and regulations tend to discourage parent interest and stifle rather than foster normal parent-child relationships. Unnecessary red tape, out-dated rules and regulations, lack of explanations and inadequate counselling all contribute to widening the gap between the retarded person and his family.

Policy:

The residential facility should extend its services beyond the traditional boundaries of its own campus and reach out to assist the resident and his family. Administrative policies should maximize relationships between the resident and his family. Any major changes in program or residen-

tial setting, including the legal, financial and program aspects, should be. discussed with both the resident and his relatives or guardian.

Problem:

Most residential facilities are still custodial-oriented and lack program; based on individual needs. Most residential facilities for the retarded throughout the country are large, overcrowded, and impersonal.

Policy:

A. Every residential facility, including those that care for the seriously
retarded, should be basically habilitative in character and emphasis and closely linked to appropriate medical, educational and welfare programs in the community. No residential facility should be merely custodial.
B. Each resident should have an individually designed and recorded program, written down and planned by a multidisciplinary staff, and regularly reevaluated and redirected.

Problem: Educational Rights

Large numbers of children in residential facilities for the retarded are deprived of the educational rights guaranteed to all other children.

Policy:

The regular public educational agency should have the responsibility for the education of the mentally retarded who are in residential care The teachers should be certified in their field of competency the same a in other public schools. For those retarded with potential for return to the community, serious consideration should be given to providing their education with their community peers.

Problem: Lack of Maintaining Standards

Living conditions in residential facilities throughout the country represent sent for the most part sub-standard conditions. Some state and private residential facilities unfortunately can best be described as economic cally and culturally deprived areas. Oftentimes, basic health and safety standards are not met, to say nothing of humane standards.

Policy:

The NARC endorses the standards set forth by the National Planning Committee on Accreditation.* Mentally retarded residential facilities shall be licensed in accordance with the state and local laws for similar

facilities, including all applicable laws pertaining to staff, licensing, registration, fire, safety, communicable diseases, etc. It must meet the standards of national accreditation groups and it must be open for inspection and suggestions for further improvement by parent and public groups.

The National Planning Committee on Accreditation is composed of representatives appointed by six national voluntary associations with recognized interests in the field of mental retardation. They are the American Association on Mental Deficiency, American Medical Association, American Psychiatric Association, Council for Exceptional Children, National Association for Retarded Children and United Cerebral Palsy Associations.

Its objectives are (1) to determine the nature and level of standards required for accreditation; (2) to develop policies and procedures for the accreditation processes; (3) to establish an accreditation agency ready to begin functioning on or before January 1, 1969.

Problem: Dehumanizing Facilities

It has been established and recognized that physical surroundings can and do produce a humanizing or dehumanizing effect. The physical atmosphere of a building or a room—the colors, the furnishings, the lighting, the ventilation, the temperature control, the equipment, the degree of privacy it will allow, can and does have a very direct, profound effect on the individual residing in that facility. In addition, the utilization of space is a very important factor in the development of programs, supervision, and social relationships. Sensory deprivation can and does result in the lack of growth and development.

Policy:

Residential care facilities should provide (a) a homelike and therapeutic environment which uses space, color, form and textures effectively; (b) adequate artistic and sensory stimulation; (c) space for each resident to have some privacy; (d) space that lends itself to group activities and programming needs and allows for the possibility of easy movement from one space to another; (e) barrier-free space throughout so that movement and programming for semi and non-ambulatory residents is not limited. While there are differences of opinion as to the optimum size of multi-purpose residential facilities, there is general agreement that the size should be small enough to insure that the humane and individual needs of the residents are met, and to be able to offer appropriate programming space located as close to the family as possible. The living units, including dining, sleeping and leisure time activity units,

should be small enough to insure the development of meaningful interpersonal relationships among residents and between residents and personnel rendering direct care. Architectural environment should take into consideration such factors as the need for privacy in toileting and bathing, the need for facilities for storing personal belongings, the elimination of unnecessary restrictive devices (bars on windows, nets over cribs, etc.) and create an atmosphere which is conducive to sensory and visual stimulation.

Problem: Staff Shortages and Staff Attitudes

The shortage of staff in residential facilities is a chronic problem. It makes little or no difference how many fine residential facilities are built if there are not enough qualified persons to take care of the people living there. Qualified personnel means people with both the education or training *and* the disposition to take care of retarded persons. Every person employed at a residential facility is in a position to contribute to or take away from the dignity and self-esteem of the retarded person. Yet many are currently hired who lack maturity and understanding to work with handicapped persons.

Policy:

Since work with the mentally retarded is extemely demanding and the responsibility is great for those employed in this field the recruitment and training of personnel is a most essential consideration. The attitude and understanding of staff is as important as their formal training and should be assessed at the time of hiring.

The accepting or rejecting staff member, the rewarding or punitive type of employee, the criticism or praise given to the resident, help to determine how he sees himself. Appropriate screening of new employees should be conducted.

No staff should be assigned the responsibility for the care and training of a retarded resident without having proper orientation and preservice training in the area of mental retardation.

Every effort should be made to maintain continuation of adult-child relationships by staffing policies which not only make possible individual attention to residents by care personnel, but also minimize turn-over and inter unit transfers among care personnel. NARC supports the standards included in the standards prepared by the National Planning Committee On Accreditation under "personnel policies and staffing for resident care'.' Only trained persons should be used to provide direct resident care. If mentally retarded residents are involved in direct care of other residents, it should be only with direct visual supervision by a regularly trained staff person and on a highly selective basis.

Adequate salaries (above the poverty level) should be paid to employees rendering direct care to residents.

Problem: Lack of Adequate and Appropriate Medical and Psychological Services

Residential placement of an individual without providing medical and treatment services is tantamount to incarceration. Unfortunately, many residents in our state residential facilities are rarely seen by a physician. Drugs are prescribed and changed without a medical examination by a doctor. Abuse, neglect, accidents and questionable deaths are not adequately investigated or reported. Appropriate measures to safeguard the health of a retarded resident through concern with such things as sanitation, availability of drinking fountains to prevent dehydration, methods of feeding and intake of food, abuse of the use of seclusion and restraints, are but a few of the medical and health concerns which contribute to dehumanization.

Policy:

Every residential facility should have a basic requirement that each individual resident receive a physical examination by a qualified doctor at least once a year. Medical standards that apply in the community should apply within the institution. Cosmetic, supportive, corrective and prosthetic devices should be prescribed, made available, and used. Drug prescriptions should be controlled by the same rules that apply in the community. The public health and welfare laws and regulations that serve and protect people in the community should also apply to residents in an institution, e.g., laws regarding child abuse, inoculation, etc.

Problem: Inappropriate Use of Seclusion and Restraints (Mechanical and Drugs).

Too often seclusion and restraints are used for the convenience of the staff or as a means of punishing the residents, and more often than not, represent a lack of appropriate programming. It has been proved that with proper programming and attention, the kinds of behavior which very often result in the use of seclusion or restraint, can be eliminated. The dehumanizing aspects of seclusion and restraint are many, including the fact that very often the resident doesn't even understand why he is put into seclusion or restraint; while he is in seclusion or restraint there is no attempt to offer any type of rehabilitative service or program; the resident is often not seen by a staff member except at those times when food is provided; the condition of the resident while he is in seclusion is often dehumanizing in that he may be in a room without furniture, equipment, clothing, etc. (even though his condition may not be destructive).

The isolation usually does not provide anything therapeutic for the resident in terms of constructively changing the behavior which brought about the seclusion or restraint.

Policy:

Restraint should be used only on an individually prescribed basis and should be signed by a physician. Periods of restraint should be recorded and reported to the superintendent on at least a weekly basis. When seclusion or restraints are used, there should be ongoing observation by staff, explanation to the resident, and more active programming developed so as to eliminate the necessity for restraint or seclusion. Re straints or seclusion should not be used for the convenience of staff as punishment for residents, or as a substitute for program.

Problem: Segregation of Sexes

Segregation of sexes which has become a traditional practice in residen tial facilities for the retarded over the years has resulted in an unnatura way of life and has mitigated against the interests of the retarded an< their proper development. The dangers involved have been greatly exaggerated, and normal heterosexual relationships have been frowned upon and prohibited. This has resulted in an unnatural situation in the residential facilities and does little to prepare the resident for life in the community.

Policy:

The NARC endorses the conclusions recorded in the Stockholm Symposium of 1967 with regard to the mixing of the sexes. The symposium strongly advocates the mixing of the sexes in a manner as free as is correct mensurate with normal restraints, not only in day centers and workshop but also in leisuretime activities. The NARC endorses and advocate the mixing of the sexes in a manner which is consistent with the normally accepted standards of any home or community.

Problem: Mixing of the Mentally Ill and the Mentally Retarded

Over the years there has been a trend to move the mentally retarded into any vacant facility that has space, e.g., TB hospitals, correction; institutions and more recently, hospitals for the mentally ill. One of the problems we have faced over the years in most state-operated program has been a lack of attention to many of the needs of the mentally retarded—a lack which has resulted in neglect and the resultant condition which we are now trying to change. The problem of a mentally retarded person is not exclusively a medical problem—it requires a mult disciplinary approach. Without appropriate recognition of the specif:

and unique needs that retarded persons have according to their degree of retardation, and their life needs, additional problems can be imposed in the way of competition, frustration, abuse, failures, being taken advantage of by other residents, and a general lack of program aimed at helping the retarded individual reach and achieve his maximum potential.

Policy:

The NARC does not favor moving mentally retarded persons into facilities for the mentally ill except when clinically appropriate and based on individual needs where the movement of groups of retarded persons does occur. The mentally retarded residents should have programs specifically designed to meet their needs. There should be separate staff to carry out those programs. When transfer from a residential facility for the mentally retarded takes place, it should be only on the basis of the fact that the receiving facility is equipped to better meet the particular needs of the retarded individual.

Problem: Lack of Funds

In order to carry out the kinds of services and programs which are necessary to enhance the dignity of residents in residential facilities and in order to insure desirable staff-ratios, properly trained personnel, adequate and appropriate facilities, and sufficient and proper equipment, more money will be required than is presently appropriated. Unfortunately, we are not making use of the knowledge we have at the present time in educating and treating the mentally retarded, because of lack of funds.

Policy:

The financing of programs for retarded persons should continue to be the prime responsibility of the state. Maximum utilization of federal and local funds, combined with reasonable and effective service arrangements, will help to meet the cost of retardation programs. It is the responsibility of the state to insure that financial support will be adequate to meet the needs of the retarded and their families and support all needed services. The NARC strongly endorses and supports the development of new programs and the continuance and expansion of programs initiated and currently under way through federal funds.

Problem: Resident Work

Under the label of 'industrial therapy,' residents in facilities across the country are providing free labor to help run residential facilities. Work performed without pay is tantamount to peonage.

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dential facility should receive pay commensurate with their ability work performed. In addition the resident should also be entitled to same working conditions as other paid staff—including coffee break days off, vacation periods, and a work week not to exceed forty hours. Working for the benefit of the institution should not be confused with training programs designed to benefit the resident. 'Training' program should have built in safeguards to insure that they do not become 'free labor.'

Problem: Volunteer Services

All human beings respond to and benefit from a meaningful relation-ship with another human being. Such a relationship is particularly i portant to those in residential facilities—where size and staff ratio minimize the possibilities of individualizing the resident and providing him with a feeling that someone cares. Unfortunately many residents state facilities rarely, if ever, have visitors, receive mail, or have opportunity to leave the institution grounds.

Policy:

Residentia l care facilities should encourage and expand volunteer service —particularly emphasizing the 'one-to-one' relationship between volunteer and a resident.

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