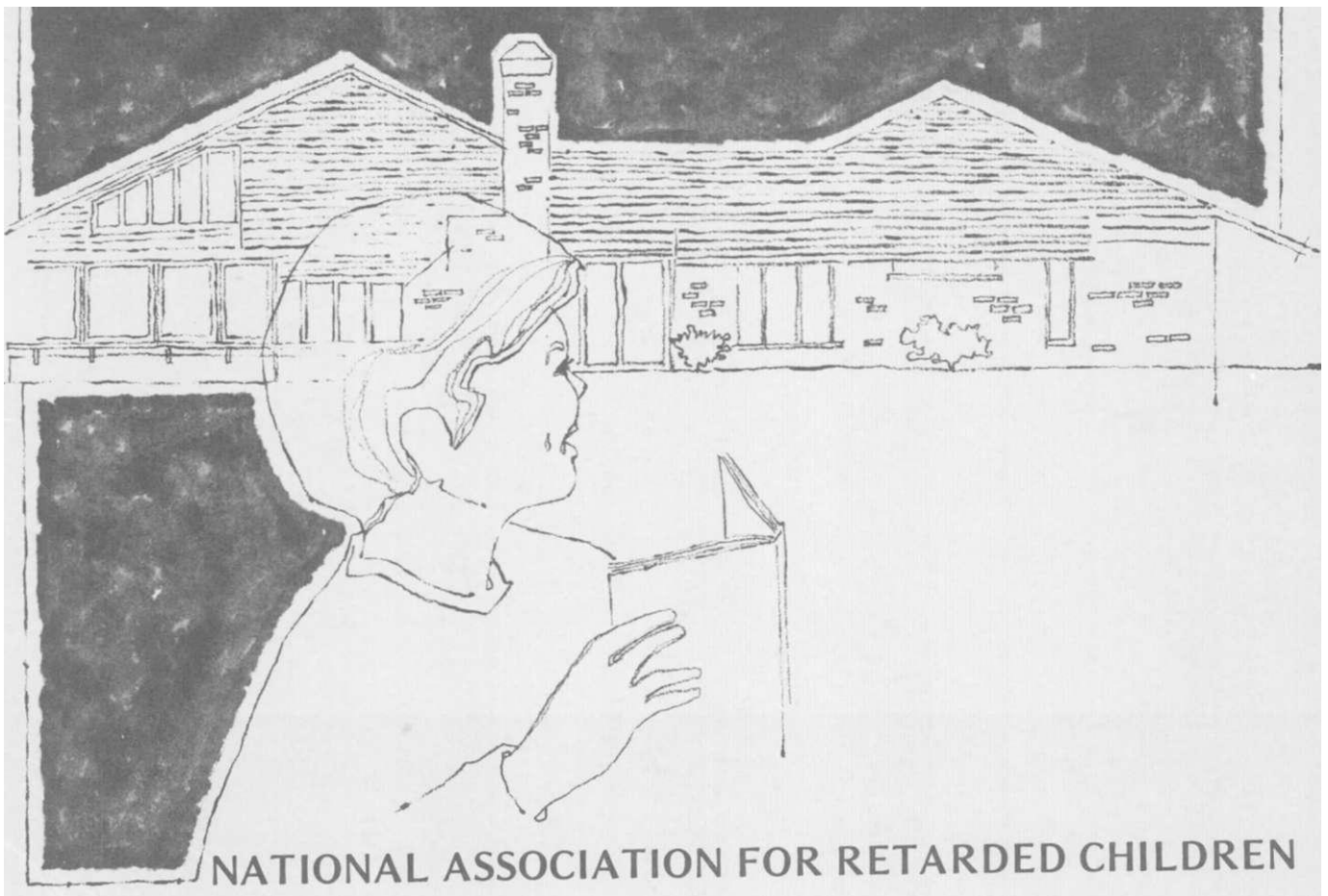


handbook for residential services committees





HANDBOOK FOR RESIDENTIAL SERVICES COMMITTEES

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INTRODUCTION

A Residential Service is any service which is primarily concerned with the acquisition, provision or supervision of housing other than the individual's natural home.

As indicated in the preamble of NARC's **Policy Statements on Residential Services**, the Association continues to regard residential programs and services as a critical issue in the field of mental retardation:

"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 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." **Policy Statements on Residential Services**, p.1.

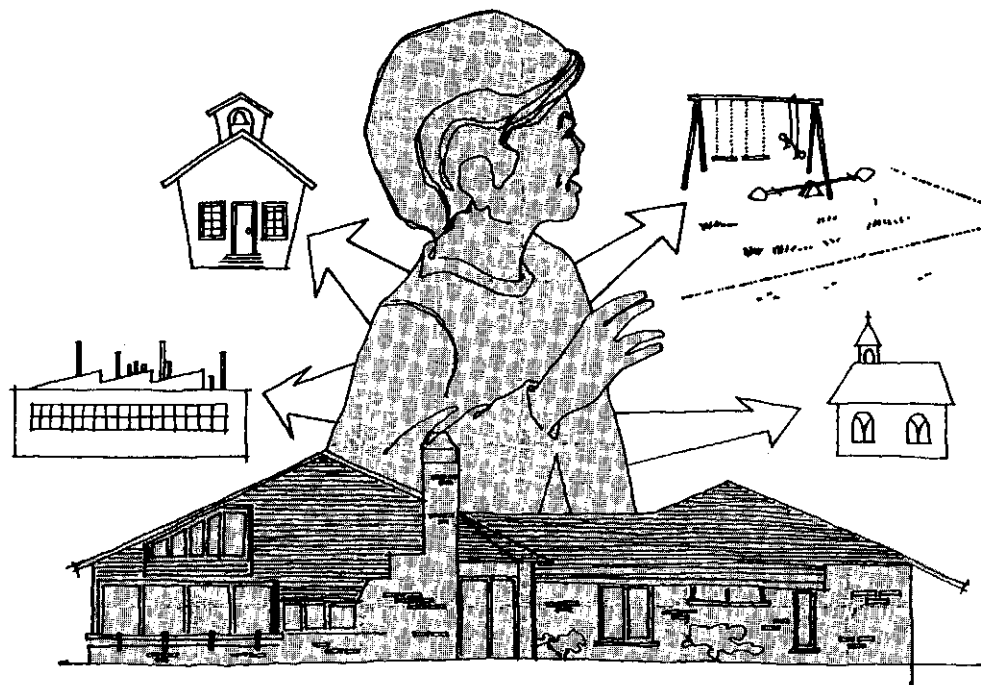
Available data suggest that many, if not most, of our nation's public institutions for the mentally retarded are severely overcrowded, badly under-staffed, archaic, and non-functional in design. With respect to programming, it is still possible to walk into a dormitory in some of these facilities and find residents pacing aimlessly about the room, sitting on benches and rocking or staring vacuously at malfunctioning TV sets. Appropriate programming within residential facilities has been seriously hampered in spite of the often heroic efforts by institutional administrators and other personnel within the facility. The causes for the continued dehumanizing atmospheres which exist in many public and private facilities are far too complex to be assigned to any one problem. In some instances it is the parents themselves who prevent administrators from making significant changes in programs. The uniformed and overprotective attitudes of some parents and professionals have sometimes resulted in a continuation of custodial programming to the detriment of individual development.

The National Association for Retarded Children continues to regard residential services as an integral and important part of the total spectrum of services within a community. Residential programs should be emphasized in comprehensive state and local community planning for mentally retarded citizens. As a corollary, it is stressed that persons in residential facilities should have available to them the full range of education, rehabilitation, health, social, and other services to at least the same extent as would be considered adequate for similarly handicapped individuals living at home. When considering the availability of comprehensive services, it is important to remember that sheltered domiciles should be separate from other sheltered activities. It is developmentally inappropriate for an individual to sleep, work, play, study and receive all services in the same physical setting. Such arrangements, which are common in the traditional institution, do not provide the resident with the

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environmental stimulation and demands necessary for fostering his continued development.

Federal legislation which made possible comprehensive planning for the retarded and improvement of residential facilities has caused governmental officials to regard retardation as a public concern. This, plus the creation of the President's Committee on Mental Retardation and a greater interest on the part of the public has contributed to a changing pattern of activity for Associations for Retarded Children throughout the nation.



The mentally retarded person should live, work, play and learn in different settings.

In the early years of the Association, the main emphases of State and Local Residential Services Committees was often to establish close liaison with state institutions, and to provide them with funds and equipment. The development of mutual respect and a sound working relationship between institutional personnel and the ARC's, as well as improvements of the institutions themselves are still important goals for State Committees. However, their scope of operations now should be considerably broadened and additional goals emphasized. Citizen action directed towards changes in basic public policies affecting all varieties of service is now a major concern.

In view of these redirections of a national concern, the NARC Residential Services Committee has prepared this **Handbook for A.R.C. Residential Services Committees** to offer suggestions that may be helpful to those who are in the process of establishing or evaluating their committee organization and activities. Many of the suggestions contained in earlier guidelines have been retained because they are still sound and apply to the current level of activity.

With marked differences in geography, population, number and types of residential facilities and programs in the various states, each Residential Services Committee must consider these guide-

INTRODUCTION

lines in light of its own particular needs. Each should feel free to modify, limit, or expand as the situation warrants. However, the suggestions incorporated in this Handbook represent workable experiences of committees in the various states and should be given careful consideration.

It should also be noted that the basic principles upon which services for the mentally retarded citizens are based should never be compromised, no matter how unusual the current local situation may appear to be.

BASIC PRINCIPLES

The following principles are summarized from the International League of Societies for the Mentally Handicapped, Symposium on Residential Care for the Mentally Handicapped, Frankfurt, Germany, September, 1969.

- Efforts must be directed toward eradicating "dehumanizing" conditions which still exist in some residential facilities. Conditions may be considered as dehumanizing to the degree to which they foster behavior which departs from the cultural norm. Such conditions frequently violate the dignity of the retarded residents.
- Retarded individuals should be treated so as to promote emotional maturity. They should not be treated as children throughout their lifetime, lest childishness become fixed rather than replaced by adult patterns of behavior.
- Most programs for retarded persons have paid little attention to the goals of the individuals themselves, and typically few opportunities are provided for encouraging them to participate in decision-making or goal setting. Yet, most retarded men and women are capable of setting life goals and communicating their desires and aspirations. Even non-verbal retarded children and profoundly retarded adults can often select among alternatives if given the opportunity.
- A sound basis for programming may be utilized by paralleling the normal patterns of the culture and drawing the retarded person into the mainstream of society. Such "normalization" approaches aim at maximizing the individual's human qualities, as defined by his particular culture. Retarded children and adults should, therefore, be helped to live as normal a life as possible. The structuring of routines, the life style and the nature of the physical environment should approximate the normal cultural pattern as much as possible.
- The most appropriate model of mental retardation programming is a developmental model, according to which retarded children and adults are considered capable of growth, learning and development. Each individual has potentials for some progress, no matter how severely impaired he might be.
- The basic goal of programming for retarded individuals consists of maximizing their human qualities, and as such is identical with the goal of educating and socializing all children and young adults. The adequacy of programs as well as of physical and psychological

BASIC PRINCIPLES



environments can be evaluated in terms of the degree to which they fulfill this goal.

In general this goal is best reached by including the retarded individual within the mainstream of society or replicating the patterns and physical characteristics of the prevailing culture when it is necessary to withdraw the retarded individual from society for a greater or lesser time period. However, to the extent that departure from cultural norms in either programming or physical environment enhances the retarded person's human qualities, such departures do not violate the basic intent of the "Principle of Normalization," although they might lead to practices or physical settings which differ markedly from the cultural norm. Even profoundly retarded persons who may remain institutionalized should be stimulated to reach their optimal level of functioning.

- Specific program goals must be tailored to meet the needs of each individual, and they will differ for different degrees of impairment. The most feasible and humane approach, in view of current limitations of knowledge, is to assume that all retarded persons have the potential for discharge from an institution until their response to appropriate programs clearly reveals the inappropriateness of this goal.

The Developmental Model has been expanded (Roos, Patterson, and McCann, 1971) to include two additional criteria for the development of program goals. Thus, programs may be considered

appropriate to the extent to which they contribute to:

- increasing the complexity of the resident's behavior;
- increasing the resident's control over his environment; and
- maximizing in the resident those qualities which have been
- culturally designated as "normal" or "human".

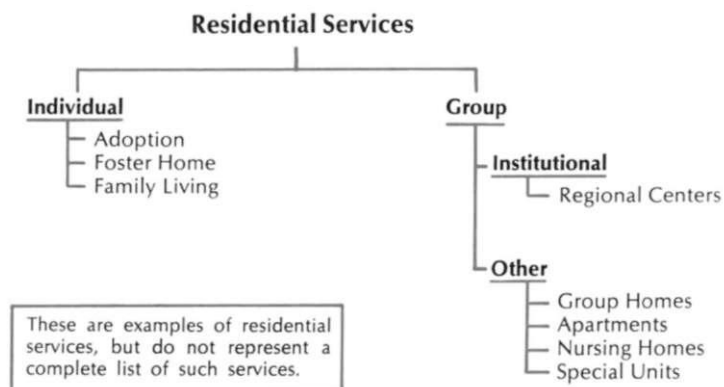
BASIC PRINCIPLES

Essentially, the functions of state and local Residential Services Committees are twofold: (1) catalyzing the development of new and innovative approaches to residential programming for the mentally retarded; and (2) monitoring, through appropriate mechanisms, the quality of existing Residential Services so as to ensure that they meet nationally established standards of excellence. With regard to the latter point, in 1971 the Accreditation Council for Facilities for the Mentally Retarded published a document entitled *Standards for Residential Facilities for the Mentally Retarded*. An overview of the standards and their development is presented in Appendix II.

GOALS OF THE COMMITTEE

The following are basic goals for state and local Residential Services Committees:

1. To bring about improvements in all existing institutions and community residential programs, in accordance with the NARC ideology, including Policy Statements (Appendix I) and nationally established standards for accreditation of residential facilities, in order to ensure the protection of these basic rights to which all people are entitled.
2. To develop, on the basis of 1 above, a long-range policy position and general principles on which the ARC will base its recommendations and efforts.
3. To obtain and disseminate information to the ARC members and others, about programs, needs, developments, and trends in residential services. This would include any type of Residential Service for the mentally retarded, whether a large institution or a regional residential center, foster home, nursing home, halfway house,



GOALS OF THE COMMITTEE

farm, hostel, apartment, etc., under public, private, or religious auspices.

4. To help plan and encourage the development of appropriate new public and private Residential Services, taking into account geographic needs, as part of the comprehensive state and/or community plan.

5. To help develop close working relationships between residential facilities and universities or other organizations concerned with either research in mental retardation or the education of personnel in the various disciplines concerned with mental retardation as a means of fostering better residential programs.

6. To provide information and guidance to relatives of retarded individuals in residential facilities or on waiting lists for admission.

7. To enlist the aid of all Associations for Retarded Children, their members, the public, professionals, agencies, legislators and governmental bodies to accomplish the goals of the committee.



COMMITTEE STRUCTURE

The Residential Services Committee should be structured so as to be the representative of the ARC membership as ARC membership itself should be representative of a concerned public. Other voluntary agencies and service organizations should be considered in Committee representation. Representatives of the state departments responsible for residential programs, as well as persons involved in the provision of private Residential Services, may be asked to serve in a consultant capacity to the Committee. (See Appendix V for a listing of agencies and organizations.)

The Committee should be appointed in the manner designated by the particular ARC constitution and by-laws. The selection of committee requires careful consideration of the goals of the committee and the types of activities which are involved in reaching those goals. Selection should, of course, always be made on the basis of individual ability, interest, and the willingness to devote time and energy to the work of the committee.

At the state level, some committee members should be selected from the list of local unit chairmen who can contribute significantly to the work of the committee. A committee which has a broad representation in its membership is more likely to avoid problems stemming from feelings of individual vulnerability which may result when the committee is largely composed of parents whose children are currently residents in public institutions.

These suggestions for committee membership are intended to provide the most objective and effective voice for the committee. Any other criteria for committee membership should be related to the specific goals and problems of the committee. A staff member from the state ARC office should act as consultant to the state level committee. When available, local staff should likewise serve in a consultant capacity to the local committee.

Recognizing the problems of meeting and communicating, a central state level committee of five to twelve members is suggested and, if necessitated by the size of the state and number of residential facilities, regional sub-committees may be established as needed. Regional sub-committees may be made up of local chairmen and should include at least one member from the state committee. In establishing regional sub-committees, the following considerations should be kept in mind:

- Overall size of the state in relation to the number and location of residential facilities, both public and private, now in operation or planned for the future.
- Geographical boundaries or barriers which may exist in the state and may present difficulties for a centralized committee to make regular visits to areas of activity.
- Locations of local units within the state in relation to residential facilities. All ARC units should have an active Residential Services Committee to ensure the development of appropriate residential services within the community.
- In sparsely populated states, it may be more practical to have action sub-committees commissioned to carry out the recommendations made by the state Residential Services Committee.
- Where there is no regional sub-committee, an ad hoc committee may be appointed by the chairman of the state committee if an

COMMITTEE STRUCTURE

unusual situation arises in a geographical location difficult for the main committee to service.

It is suggested that the full committee meet as a body at least twice a year (one meeting can be held during the state convention if desired). Since a viable committee requires more frequent meetings, it is suggested that consideration be given to a small group of the committee acting as an "executive" body between meetings.

THE JOB OF THE COMMITTEE CHAIRMAN

The job of the chairman is essentially that of bringing order and sequence to the activities of the committee. Planning will be easier if the chairman recognizes and accepts his leadership role and the responsibilities inherent in it.

Leadership involves the dynamic process of change. Thus, a leader is not fulfilling his responsibilities when things remain the same or simply drift in a state of inertia. The chairman is responsible for sustaining an initiated action rather than pointing in a direction and just letting things happen.

One of the greatest pitfalls for the leader is to feel or act as though he were all alone. The quickest way for the chairman to fall into this pit is to decide, by himself, the problem to be solved and the action necessary by the committee. Through this approach, other committee members obviously do not feel involved and will most likely find themselves only partially dedicated to the committee's work. If committee action is to be successful, it must involve other committee members at all stages of its activity.

Since action on any issue begins with defining the problem, the entire committee should be involved in problem definition rather than merely trying to solve the problem as the chairman has diagnosed it. It is, of course, equally unrealistic for the chairman to prescribe the remedies to the problem without the ideas and advice of the committee. NARC has developed a number of training programs (e.g., the Leadership Training Seminar and the Organization Development Workshop) which may be used by state and local ARC's to increase their effectiveness on behalf of the mentally retarded. Chairmen should ensure that they and the members of their Committee have participated in these training programs and that an ongoing effort is made to **apply** the techniques learned in training to the everyday activities of the Committee. A brief description of these training programs is included in Appendix VII.

The chairman should, at the beginning of his term, seek answers to the following questions:

- 1. What records should be kept?**
- 2. What reports should be submitted and when?**
 - a. to the Board**
 - b. to the Membership**
 - c. to the state or national office**
 - d. to others**
- 3. What is the budget for the committee?**
- 4. How are funds obtained for committee expenses?**

THE JOB OF THE COMMITTEE CHAIRMAN

5. **What expenses are allowed?**
6. **How is coordination accomplished with other committee chairmen?**
7. **With what community agencies should the committee have contact?**

As the chairman plans for the year's activities it is especially helpful to construct a committee calendar which indicates the dates for every activity of the committee.

In addition to the committee calendar, the chairman will find that a few minutes spent in preparing a project "count-down" sheet for each task or committee activity will make his job easier and will more likely assure a successful year for the committee. Examples of the project count-down format and more detailed instructions for their use are given in Appendix III.

RESPONSIBILITIES OF THE COMMITTEE

Generally speaking, a national, state or local committee is a group of ARC members appointed to take action or to study some matter of concern to the Association. A particular committee may be authorized by the Board of Directors or the membership to take a specific action (e.g., to conduct a fund raising campaign or to negotiate for the establishment of a summer camp), but often the committee is an investigating and recommending body. It studies a situation, assembles facts and agrees on a policy or project, and suggests to the Board or the membership the action which appears most desirable and appropriate. The Association may then accept, modify or reject the recommendations, or may request additional study.

The major responsibilities of the committee are: (1) to promote the development of a wide range of appropriate residential services to meet the individual needs of the retarded children and adults who require such service; and (2) to promote improvements in existing public and private facilities through expanded and varied programs, adequate and competent staffing arrangements, appropriate training and utilization of staff, volunteers, and community resources. See for example the array of direct services suggested on page 10.

A primary responsibility of the committee is to encourage every residential facility serving retarded individuals to achieve full accreditation of their services and programs. The Accreditation Council for Facilities for the Mentally Retarded is the national accrediting body within the Joint Commission on the Accreditation of Hospitals. The National Association for Retarded Children has long been interested in the development of standards and has taken a leadership role in the establishment of the Accreditation Council and its program. A more detailed discussion of the accreditation program is contained in Appendix II.

ARRAY OF DIRECT SERVICES FOR THE RETARDED*

LIFE STAGE	Components of special need						
	Physical & mental health	Shelter nurture protection	Intellectual development	Social development	Recreation	Work	Economic Security
Infant	Specialized medical follow-up Special diets, drugs or surgery	Residential nursery	Sensory stimulation				
Toddler	Home nursing	Child welfare services	Home training				
	Correction of physical defects Physical therapy	Foster care Trained baby sitter	Nursery school	Environmental enrichment			
Child	Psychiatric care	Homemaker service	Classes for slow learners Special classes—educable Special classes—trainable		Playground programs		
	Dental care	Day care	Religious education		Scouting Swimming		
Youth		Short stay home	Work-school programs	Day camps Residential camps			"Disabled child's" benefits
	Psychotherapy	Boarding school	Speech training Occupational training	Youth groups			Health Insurance
Young adult		Half-way house	Vocational counseling—Personal adjustment training	Social clubs		Selective job placement	
	Facilities for retarded in conflict	Guardianship of person	Marriage counseling			Sheltered employment	
Adult		Long-term residential care				Total disability assistance	
		Group homes	Evening school	Bowling	Sheltered workshops	Guardianship of property	
Older Adult				Social supervision		Life annuity or trust	
		Boarding homes		Evening recreation			
	Medical attention to chronic conditions						Old age assistance OASI benefits

*Not included are diagnostic and evaluation services, or services to the family; the array is set forth in an irregular pattern in order to represent the overlapping of areas of need and the interdigitation of services. Duration of services along the life span has not been indicated here.

A state's institutions and other residential facilities for its retarded citizens will be only as good as the public insists they be. The ARC, therefore, as the "informed" public on mental retardation has a specific responsibility to be informed in order to:

- (1) educate, counsel, guide and inform its members, professionals and **the general public** about the program needs of the mentally retarded;
- (2) provide leadership in bringing about improvements in present services;
- (3) take the initiative in planning for adequate and appropriate community-based residential programs and other services in the community necessary to meet the developmental needs of the mentally retarded citizen; and
- (4) publicize and implement NARC policy statements regarding residential programming.

The Residential Services Committee should assist the ARC to be informed about residential programs. Every Residential Services committee chairman should be provided with (and the whole committee should have access to) copies of the publications listed in Appendix I.

A study of these and other materials will help provide the necessary background which committee members need to inform others and solicit support for residential programs and facilities.

It is also the responsibility of the committee to help develop effective support for, or resistance to, existing and proposed plans, programs and projects for residential facilities (construction, location, program goals and methodologies, budgets, etc.). This requires extensive familiarization with such facilities. The committee should never "rubber stamp" proposals suggested by state departments or handed down from program administrators. On the other hand, blind and irrational opposition to everything "they" proposed will produce stalemates. Study, observation, and experience are the watchwords to make committee operations effective and more rewarding.

In order to improve the flow of information between local, state and national committees, it is suggested that local units name an individual (usually the local Residential Services Committee Chairman) to report on a regular basis to the state committee chairman, who in turn reports to the national chairman. This proposed flow of information must work in both directions if the substance of our rapidly expanding knowledge and techniques are to become available at all levels. A suggested form (Form LRS-1) is found in Appendix IV, which should be completed on a quarterly basis and forwarded to the state chairman who in turn completes Form SRS-1 for use by the national committee. When issues arise at the local or state, level which require immediate action or information distribution, the chairman should not wait for the quarterly report, but should communicate these matters at once to the state or national committee chairman. It is only through a dynamic process such as the one suggested here, that action can be coordinated in positive and beneficial ways.

RESPONSIBILITIES OF THE COMMITTEE

COORDINATION OF COMMITTEE ACTIVITIES

SOME MAJOR COMMITTEE FUNCTIONS

The functions of the Residential Services Committee should involve activities such as:

- Coordination with state agencies and other groups
- Providing information
- Public education
- Legislative activities
- Fostering the development of protective services

Some activities may require sub-committee or ad hoc task force action and some may require cooperation and coordination with other agencies. The division of responsibility is a matter to be determined by the committee chairman in consultation with his committee members, officers and staff personnel. Often, division of responsibility is best held in abeyance until the committee as a whole makes an initial study of Residential Service needs to determine precisely the areas to which the committee will give priority.

COORDINATION WITH OTHER GROUPS

Coordination with State Agencies. — The Residential Services Committee chairman should establish an on-going contact with state departments directly concerned with the administration and financial support of the state's residential facilities. The chairman should arrange to have key administrative personnel meet with the committee at appropriate times during the year. Appointments and correspondence with state officials should be channeled through the state ARC office to establish and maintain a fixed point of reference for state department personnel.

Contact should be made with administrators of all residential facilities to explain the committee's interest and desire to be of service and to explain the committee's objectives. Where there are many residential centers and regional sub-committees are expected to maintain contact with a facility, it is advisable for the state chairman to attend the sub-committee meetings when administrators are invited. Subsequent meetings can then be arranged by the sub-committee chairman who will be responsible for making full reports to the state committee.

Coordination with Other Organizations. — It is also important for the committee to arrange meetings with other state and local groups or agencies which may share some of the committee's concerns. In initiating any action program it is important for the committee to know its friends, that is, to know the kinds of support it can expect from whom. It is equally important, of course, to know the kinds of opposition it can expect, and from what quarters. In determining the kinds of collaboration possible between the committee and other organizations, it is wise to examine a number of strategies. Typical patterns of collaborative efforts which may occur between ARC committees and other organizations may be summarized as follows:

- Joint programming with other groups;
Sending official representatives to joint councils or committees, either as observers or as full participants;
- Parallel programs with other organizations;

Endorsement and sponsorship of non-political campaigns of other organizations which seek to improve the delivery of human services.

SOME MAJOR COMMITTEE FUNCTIONS

The chairman may be well advised to construct a map of organizational potentials which indicates the name of each organization, its probable or possible relation to specific projects and what it can be expected to do, either in support of or in opposition to committee objectives.



The Residential Services Committee has a strong obligation as part of its activities to interpret to others the appropriate use of Residential Services in the total pattern of services for the mentally retarded, and to be able to present to parents and relatives who are seeking advice an objective, nonprejudiced appraisal of the advantages and disadvantages of residential programs and other alternatives.

PROVIDING INFORMATION

Informing Parents. — Parents of the mentally retarded, including those who are not members of the Association, should be a major target group for the committee's informational efforts.

- NARC's parent training project is designed to provide ARC members with increased sophistication in the basics of sound residential programming. Regional, state and local representatives may be trained to conduct workshops and seminars designed to help parents become discriminating consumer representatives of Residential Services for retarded persons. Through this program parents

SOME MAJOR COMMITTEE FUNCTIONS



and others should become knowledgeable participants in the evaluation of Residential Services. State and local Residential Services Committees should ensure that this training is provided for all members of their association. Thus, it will be necessary to periodically repeat the training program for new members.

Administrators of residential facilities should be encouraged to arrange for staff members to hold periodic (perhaps quarterly) meetings for parent education or group counseling. Relatives of those on the waiting list should be invited to attend.

Staff members of Residential Service programs should be encouraged to routinely provide relatives and guardians with information about state and local ARC's. This means, of course, that the ARC will furnish literature and brochures which include names and addresses of ARC officers and committee chairmen. Relatives of residents should be encouraged to become active and involved participants in local and state ARC's so that all concerned individuals may work together for the total program of services to retarded persons.

In order that parents and guardians can make informed decisions and choose among alternative programs, it is necessary to provide sufficient information to them. To achieve this purpose, the committee should encourage facilities in cooperation with ARC groups to prepare attractive, realistic, readable brochures, films and slide presentations, describing the facility, its programs, policies and admission procedures, for the use of relatives of present and prospective residents, for visiting groups, local units, etc.

The state Residential Services Committee chairmen should develop a complete file, with pictures and program descriptions of

SOME MAJOR COMMITTEE FUNCTIONS

all public and private Residential Services in the state as a resource for helping parents and as a baseline for continuing evaluation of progress toward effecting change. The file should be kept in the state ARC office in order that it does not become lost with the change of chairmen and committee members.

- Assistance should be given relatives of those on waiting lists during the preadmission period as well as to those whose children are leaving residential placement. If relatives wish to talk about procedures and conditions, they should be directed to someone (possibly a committee member) who is experienced, knowledgeable and objective.
- Members of the committee may serve as a contact between relatives of residents and residential facilities' staff if problems arise which cannot be resolved by relatives alone and assistance is required.

Informing Professionals. — Residential Services Committees, and ARC's in general, often overlook the important role which they can play in informing professionals who are involved actively or to some extent in the field of mental retardation.

- State and local workshops, conference programs, etc., on Residential Services and residential programming should be planned for professional groups. These workshops should be tailored to the specific profession involved — the interests of lawyers for instance will differ from those of physicians or clergymen. Attempts should be made to involve representatives of the profession itself in developing the program. Schedule workshops and seminars for the convenience of the participants — avoid conflicting with professional meetings. In planning such seminars, do not overlook the professional of tomorrow, i.e., the college student.
- Professionals in the community or on the staff of residential facilities may be encouraged to become involved in services to the region or the community, such as diagnostic and evaluation clinics and counseling services.
- Encourage administrators of residential programs to subscribe to **Mental Retardation News** and **The Record** for key personnel if they are not already receiving it regularly. The ARC may wish to consider sending them gift subscriptions.

Informing Your Committee. — It is critical that the Residential Services Committee be involved in an ongoing and systematic program of self-education.

- Every Residential Services Committee should have available to it a copy of the Accreditation Standards published by the Accreditation Council for Facilities for the Mentally Retarded. Every facility, both public and private, should be working toward full accreditation, and the ARC should play an important role in assisting the facility's administration to meet the Standards. Thus, members of the Residential Services Committee should be thoroughly familiar with the Accreditation Standards and program.
- The committee should review NARC's **Policy Statements on Residential Services** and compare them, item by item, with the current conditions in each residential facility or service. Using this data, a

SOME MAJOR COMMITTEE FUNCTIONS

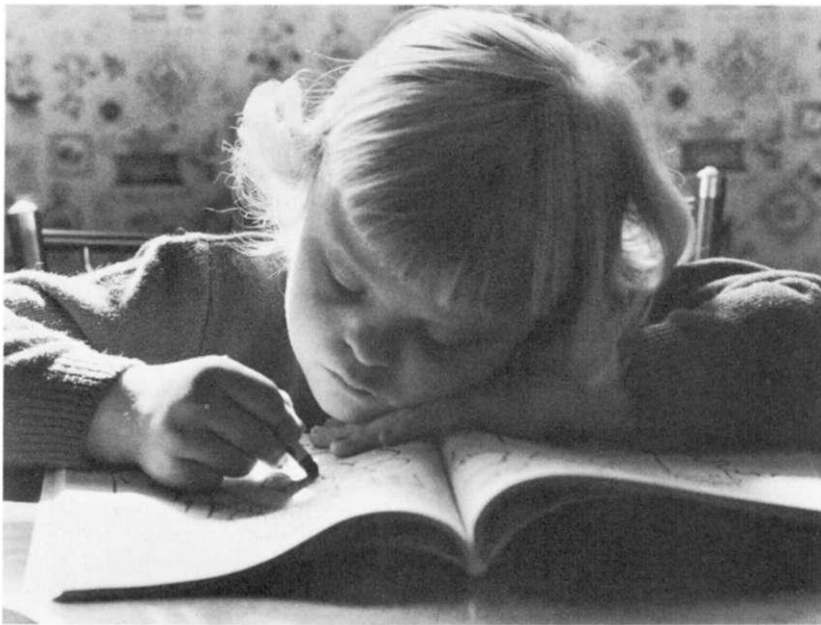
written proposal for meeting the criteria set forth in the policy statements may be prepared. When possible, it is desirable to involve staff of the residential facility in preparing such a proposal.

- State governments and departments of mental retardation should be encouraged to officially endorse the NARC policy statements.
- State and local licensing requirements and program guidelines for Residential Services should be studied. If they are inadequate, develop a plan for making appropriate changes. In some instances, this may require more demanding standards. In other cases, it may simply require modifications designed to create a more normalized living setting.
- Be aware of working conditions of staff, particularly noting those working most directly with the residents, to determine the factors relating to job satisfaction, morale and continued employment.
- It is important that the committee develop a specific mechanism for keeping abreast of changing trends in the area of residential programming. Thus, specific members of the committee should be assigned to read, on a regular basis, relevant professional journals and publications. Representatives of the state committee (and where possible local committees as well) should attend meetings of professional and sister organizations which devote portions of the program to residential services. Sound procedures should be developed to ensure that the committee provides ongoing feedback on new developments and trends in the field of the Association's broad and general membership.
- Check periodically to assure that the newsletter published by facilities in the state are received by all members of the Residential Services Committee, including sub-committee members. In order to assure an uninterrupted flow of information, it may be more suitable to arrange for all newsletters to be sent, in bulk, to the state or local ARC office where they can be distributed to each committee member. Such a system is more easily controlled when committee membership change and does not require the constant changing of addresses which always results in new members missing issues of important newsletters. (The NARC Residential Services Committee Chairman, the Editor of **The Record**, the NARC Regional Representative and the national headquarters should also receive the mailings.)

PUBLIC EDUCATION

In this age of mass communication, when a multitude of agencies and organizations are vying for support, it's difficult to overestimate the importance of an effective public education program. Before the public can respond to the needs in the area of residential programming, they must be made aware that such needs exist.

- Nearly every meeting, institutional visit, etc., can generate some kind of beneficial publicity. Prior to each event, ask this question: what public information efforts would best apply here? Sometimes, only a press release is called for. And, on occasion, there may be reasons why **no** publicity should be generated. Ordinarily, though,



SOME MAJOR COMMITTEE FUNCTIONS

some activity is called for. Here are a few ideas and points to remember:

Keep everyone in your group informed. Communications promote interest and help assure participation. You cannot expect your members to generate much enthusiasm about an upcoming meeting, visit or event, if they are not aware of its existence.

See that editors of local unit newsletters are provided with items about residential programs such as special events, new staff members, building plans, volunteer service opportunities and needs, etc. If the State ARC has a regular newsletter or bulletin, be certain that it includes regular reports on residential services and programs.

Regional sub-committee chairmen should provide news about facilities in their regions to the state chairman, who, in turn, shares the information with the state publicity chairman or staff person for dissemination to the local units and the news media.

Both state and local committees should develop a speakers list of knowledgeable persons not limited to institutional personnel, who can speak on a variety of approaches to residential living. The speakers list should be available to unit program chairmen. For example, some local units have arranged for personnel from all types of residential programs to speak at ARC unit meetings and to bring with them movies or slides of their facility. The general public should be invited to attend these meetings in order that information may be disseminated as widely as possible.

Encourage residential facility personnel to attend State and National ARC conferences and conventions. Every effort should be made to involve the influential forces of the state and community in the development and progress of Residential

SOME MAJOR FUNCTIONS COMMITTEE

Services. Where appropriate, these individuals may be invited to participate in the programs.

State and local committees should encourage and assist their members and the general public to visit residential facilities, both public and private. Such visits may be general tours of the facility, although in-depth visits with special intent should be planned on a regular basis to gain an understanding of the current programs and to support the development of new programs. The catalytic and monitoring function of the committee should be emphasized during visits to facilities. Specialized visits should also be made to residential programs operated in connection with sheltered workshops, nursing homes, community group homes, special schools, etc.

Work with the state publicity chairman and unit publicity chairmen in planning for "high visibility" of open house programs at residential facilities during National Retarded Children's Month (November). Remember that it is always to the institution's advantage to have both the best and worst on view for the public. It is through these approaches that the public becomes aware of the needs for programs and is more likely to support efforts to upgrade services.

Encourage professional groups and other key people (physicians, social workers, special education teachers, lawyers,



legislators, clergymen, etc.) to become acquainted with residential facilities and their programs. In cooperation with administrators it is suggested that special days be set aside for these visits. Arrange for transportation to ensure attendance.

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The legislative, or governmental affairs, area is particularly critical to the attainment of sound residential programming. It is frequently desirable for a member of the Residential Services Committee to serve on the Governmental Affairs Committee. ARC members should have full knowledge of their legal and rightful power to work for the welfare of the state's retarded citizens.

LEGISLATIVE ACTIVITIES

- Work in close liaison with ARC Governmental Affairs Committee to make recommendations to the state ARC for endorsement of, or resistance to legislation, not only to budget requests but also legislation pertaining to admission policies, commitment procedures, charges for services, parental responsibility, special education, etc.
- Study statutes and legislative proposals pertaining to Residential Services including state and local plans for capital outlays, personnel policies and public facilities budgets and formulate recommendations on legislation.
- Encourage public support or resistance to legislation, as the situation warrants, after careful assessment of its potential benefit or detriment to the needs of the mentally retarded. Efforts must, of course, be coordinated with the State Governmental Affairs Committee. Have available at all times a list of legislators, particularly those involved on committees concerned with appropriations, mental retardation, mental health, education, public health, children's services, and judiciary committees.
- Review state laws as they relate to the NARC and ARC policy statements with particular regard to civil and human rights.
- In some states, the Residential Services Committee (or sub-committees) meet with the residential facilities' budget committees to review budget requests. In this way the committee has a better understanding of needs and is in a better position to work for adoption of budget requests. The committee should work to assure access to budget proposals in order to provide an informed position in support of or opposition to such proposals. Budget requests should be reviewed with a concern for appropriate programming rather than assuming that more money will automatically result in better service.
- Cultivate a relationship with state government executive officers so that you will be consulted when administration budgets and legislation are being drafted. A regular and on-going contact with state legislators will more likely result in the positive consideration of the ARC's advice.
- Residential Services Committee members who are knowledgeable should, in cooperation with the Governmental Affairs Committee, arrange to meet with or appear before legislative committees, councils or commissions to answer questions or present testimony

SOME MAJOR COMMITTEE FUNCTIONS

on matters pertaining to residential programming.

- Reports, projects, ideas and materials developed or received by the Residential Services Committee should be shared with the ARC Governmental Affairs Committee in order that they can use it to educate and persuade key legislators who serve on committees which consider residential services legislation.
- Timely newspaper, TV and radio coverage of state ARC endorsement of or opposition to legislation is often most effective in getting legislation acted upon. Be sure that such coverage is planned with staff or state Publicity Committees in order to present a united front to the public.
- Encourage specific legislative measures in the following areas:
 - Each state should assume responsibility in law to provide for appropriate residential services.
 - Provision of funding for different types of Residential Services which can be independent from the funding of existing institutions.
 - Creation of local or regional service bodies and administrative structures which can provide community Residential Services.
 - Consider the development of state-local funding partnerships.

FOSTERING THE DEVELOPMENT OF PROTECTIVE SERVICES

An important role which the Residential Services Committee can perform is to promote the development of protective and advocacy services for those residents who may require this type of program. A number of strategies have been devised to aid in safeguarding handicapped persons against abandonment, neglect, abuse and exploitation. Generally, the services that have arisen from these efforts have been classified under the general heading of "protective services." These include guardianship, adoptive parenthood, conservatorship and trusts. Citizen's advocacy is a viable and exciting concept to the field of mental retardation. Wolfensberger has defined citizen advocacy as:

"A mature, competent citizen representing, as if they were his own, the interests of another citizen who is impaired in his instrumental capacity, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention."

Thus, citizen advocacy is concerned with providing the individual with support in coping with the practical problems of every day life as well as support in the area of his emotional and social needs. The advocacy role should not be exercised by governmental agencies or professionals functioning in their professional capacity, but rather by competent and suitable citizens who are free of relationships which might result in a conflict of interests between the needs of the retarded person being served and the agency providing services to that person.

- There is often a great need for citizen advocates in the traditional institutional setting. The residents of an institution do not,

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in many cases, develop meaningful personal relationships with the institutional staff. Occasional visits, telephone calls, letters, gifts and periodic trips to the advocate's home can help meet many of the developmental needs of these residents and enable them to maintain some degree of contact with the outside world. In addition, the advocate's role would involve safeguarding the rights and dignity of the mentally retarded resident within the institution.

- There is a similar need for advocates to assist semi-independent mentally retarded persons who reside in hostels or group homes in the community. These citizens, although physically integrated into the community, are sometimes afforded few opportunities to form long-lasting personal relationships with non-retarded friends.

In short, the citizen advocacy model, which was endorsed in principle by the NARC Board of Directors in April of 1971, is one example of the viable approaches which may be developed to ensure the rights of mentally retarded persons participating in Residential Services programs.



SUMMARY AND CONCLUSIONS

Persons labeled as mentally retarded have for many years been viewed by large segments of the general public as something less than human. This may explain society's long-standing indifference to the lot of these people and to the intolerable conditions under which many of them live.

Today, however, we are seeing an increased interest in massive attacks upon dehumanization in our residential institutions. Professionals in our own Associations for Retarded Children and in government agencies, together with parents of retarded children, have now demanded a radical departure from dehumanizing custodial care. The results are encouraging, although there are still too many institutions operating as human warehouses. Some administrators have already adopted new approaches and others are seeking to make such changes.

This new philosophy calls for a variety of decentralized services, and a recognition of the human and civil rights of the retarded in such basic areas as programming according to the nature and degree of the individual's handicap. Among the major causes of failure to provide proper housing and programs are public apathy to the problem, misunderstanding of the condition, overcrowding, understaffing and inadequate financial support. Despite the enlightened concepts of many leaders in the field of mental retardation, the inherited philosophy is too often one of isolation, coupled with disease-oriented treatment. The result has been mass housing, built and administered on an outmoded model and usually removed from community life and society.

In most cases, the administrative personnel of residential facilities are the first to welcome the enthusiasm and guidance of those who are working on the outside toward the establishment of more acceptable living conditions for the mentally retarded. It strengthens their efforts toward attacking the same problems from the inside. In other words, voluntary agencies and the general public can often do more to improve existing conditions than the administrators themselves, because volunteers are seldom hampered by political and economic restraints.

We seem to be on the edge of remarkable innovations, but there continue to be dangers. If programs embodying developmental approaches are not provided in residential facilities for the mentally retarded, we will be faced with an ever-growing number of individuals who will require increasingly expensive and difficult-to-staff custodial services, merely to sustain life. In view of the high degree of affluence in our society, something must be done within our residential facilities to create a better climate and to reduce the dehumanizing situations which result in such a waste of human potential.

If the humane conditions we are seeking for retarded persons are to become realities, it will require systematic and on-going critical analyses of those practices, systems and policies which contribute to the dehumanization of persons in institutions — those which result in overdependency, lack of self-esteem, cultural and sensory deprivation — all reflected in the lack of individual programming.

In order to focus on the dehumanizing aspects of institutional care, the Committee on Residential Services of the National Association for Retarded Children used a problem defining/problem solving approach in the development of its **Policy Statements on**

Residential Services. Although the NARC Policy Statements are primarily concerned with those aspects of institutional life which deprive the individual of his basic civil and human rights, the Association 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 Committee knows that additional funds are necessary if state and local Associations for the Retarded are to achieve the kinds and quality of program services, environment, staff and training we hope to have in our residential facilities. It also recognizes that there are many strategies which can dramatically improve the lives of retarded residents but which do not require large expenditures of money.

In each of our 50 states, we must initiate and/or intensify a movement to improve our Residential Services for the mentally retarded. We must make residential facilities and their programs effective not only in terms of cost, but in terms of human lives salvaged from the limbo of neglect and given, to the fullest degree possible, the dignity of place and value in daily life and work.

The trend is toward normalization, a principle emerging as a significant new approach to management and programming for the retarded. The normalization concept refers to allowing the retarded individual to obtain an existence as close to the normal way of life as possible in a residential setting ... to serve all degrees of retardation in helping the individual to continue his development by enhancing his basic drive to understand and control his environment.

The Residential Services Committees at the state and local levels face a tremendous and exciting task — to assist the society to improve the quality of life for those citizens who require an extra measure of concern.



APPENDIX I
POLICY
STATEMENTS ON
RESIDENTIAL
SERVICES

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

October 1968

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 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 ongoing 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 Services 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 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 Services wishes to go on record as recognizing that additional funds are necessary if we are to achieve the kinds and quality of program services, facilities, staff and training we hope to have in our residential 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 Services 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,

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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.

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:

POLICY:

- 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 engaged 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

APPENDIX I 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 expenditures 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 of placement. Even today, in our so called enlightened society, there remains a tendency to think of residential care as the

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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.

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.

POLICY:

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.

PROBLEM:

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.

POLICY:

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 explanation and inadequate counselling all contribute to widening the gap between the retarded person and his family.

PROBLEM:

The residential facility should extend its services beyond the traditional boundaries of its own campus and reach out to assist the

POLICY:

APPENDIX I resident and his family. Administrative policies should maximize relationships between the resident and his family. Any major changes in program or residential 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 programs 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 as 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 for the most part sub-standard conditions. Some state and private residential facilities unfortunately can best be described as economically 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

** The National Planning Committee on Accreditation has evolved into the Accreditation Council for Facilities for the Mentally Retarded.*

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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.

Dehumanizing Facilities

PROBLEM:

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.

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 inter-personal 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.

POLICY:

Staff Shortages and Staff Attitudes

PROBLEM:

The shortages 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

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who lack maturity and understanding to work with handicapped persons.

POLICY:

Since work with the mentally retarded is extremely 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, suppor-

tive, 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.

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

PROBLEM:

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.

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. Where 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. Restraints or seclusion should not be used for the convenience of staff, as punishment for residents, or as a substitute for program.

POLICY:

Segregation of Sexes

PROBLEM:

Segregation of sexes which has become a traditional practice in residential facilities for the retarded over the years has resulted in an unnatural way of life and has mitigated against the interests of the retarded and 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.

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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 commensurate with normal restraints, not only in day centers and workshops but also in leisuretime activities. The NARC endorses and advocates 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, correctional institutions and more recently, hospitals for the mentally ill. One of the problems we have faced over the years in most state-operated programs 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 conditions which we are now trying to change. The problem of a mentally retarded person is not exclusively a medical problem—it requires a multi-disciplinary approach. Without appropriate recognition of the specific 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.

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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.

Resident Work

PROBLEM:

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.

POLICY:

Residents performing jobs related to maintaining and operating the residential facility should receive pay commensurate with their ability for work performed. In addition the resident should also be entitled to the same working conditions as other paid staff — including coffee breaks, 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 programs should have built in safeguards to insure that they do not become free labor.

Volunteer Services

PROBLEM:

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

POLICY:

Residential care facilities should encourage and expand volunteer services — particularly emphasizing the one-to-one relationship between a volunteer and a resident.

The following policy statements were developed by the Education Committee of NARC with the assistance of NARC headquarters staff and other resource people.

NARC Education Committee

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The following individuals also contributed significantly to the formulation of the policy statements: Mr. Bertram Katz, Mr. David Rosen, and Mr. Marion P. Smith.

Special thanks go to the following NARC staff members who worked long hours on finalizing this report: Mr. Robert E. Luckey, and Dr. Brian M. McCann.

Dr. Walter J. Cegelka, Chairman
NARC Education Committee

APPENDIX I

POLICY STATEMENTS

Policy Statements on the Education of Mentally Retarded Children

Since its inception, the National Association for Retarded Children (NARC) has remained deeply concerned with the marked inequities which exist within the public school systems of this nation with respect to the education and training of mentally retarded persons. As early as 1953, the NARC Board of Directors adopted an Educational Bill of Rights for retarded children. This Bill of Rights was followed in 1964 by a set of guidelines in the form of policy statements intended to assist local communities in obtaining adequate educational services.

The education policy statements that follow represent a further attempt on the part of NARC to clarify its position regarding the education of all retarded persons. The present statements are prompted by the fact that large segments of the retarded population continue to be denied appropriate educational services. This denial of basic educational rights is found among persons functioning at all levels of mental retardation, but is particularly acute among severely and profoundly retarded persons.

NARC will attempt in the present document to delineate persisting problems in the education of America's mentally retarded children, as well as to provide policy statements regarding these problems. The policy statements will be consistent with the philosophy of education for all children to which this nation is committed.

Denial of the right to education in the public schools

PROBLEM:

Many mentally retarded children are frequently denied education in the public schools because of their projected inability to contribute tangibly to society, while others are excluded because they do not possess sufficient behavioral controls and/or self-care and verbal skills to make them readily amenable to traditional school curricula, physical facilities, and competencies of teaching personnel.

Public school education must be provided for all mentally retarded persons, including the severely and profoundly retarded. There should be no dividing line which excludes children from public education services. If current educative technologies and facilities are inappropriate for the education of some retarded persons, then these existing educational regimes should be modified.

POLICY:

Mandatory provision of education services and compulsory attendance

PROBLEM:

Many states do not require local school systems to provide education services for mentally retarded individuals, and those states which do have mandated services do not necessarily have compulsory attendance rules.

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POLICY: Our nation guarantees education for all. This concept is based on the fundamental belief in society's responsibility to educate every individual to the fullest extent of his capacities, whatever they may be or however attenuated by special circumstances. To this end, laws which mandate public school services and specify compulsory attendance for all children do by definition include all mentally retarded persons. Excuse from compulsory attendance should be allowed only when a suitable alternate plan of education is available and is clearly advantageous for the student in question and meets with the approval of his parents or guardian.

PROBLEM: Administration of services

Education of mentally retarded persons is frequently the responsibility of agencies or organizations other than the state education agency which is responsible for the education of non-retarded persons.

POLICY: All education services for retarded persons must be the responsibility of the state education agency and the public schools, regardless of the pupil's level of retardation. Present facilities and curricula must be modified as necessary, and cooperative educational programs (two or more school districts) should be implemented, where necessary, to provide more appropriate services to retarded persons. These cooperative programs should be particularly encouraged in sparsely populated school districts.

PROBLEM: Locus of responsibility

In many instances, mentally retarded students are excluded or expelled from special education because of their inability to adapt to traditional curricula, or by virtue of their manifesting behavior problems.

POLICY: The responsibility for developing appropriate educational techniques and/or modifying disruptive classroom behavior patterns rests with the school system. Failure to adapt to traditional educational models should thus not be viewed as a legitimate basis for exclusion or expulsion. Failure to learn at a level commensurate with intellectual potential is not caused by something within the child, but rather, results from the use of inappropriate educational technologies.

PROBLEM: Educational rights of the retarded in residential institutions

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

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The public educational agency charged with overseeing community education programs should have the responsibility for the education of mentally retarded persons who are in residential care settings. Teachers within these facilities should be certified in their field of competency according to the same criteria employed in public schools. Serious consideration should be given to providing their education within community-based school facilities.

POLICY:

Classification and placement in special education classes¹

Children are sometimes incorrectly classified as mentally retarded and assigned to special education classes because of problems which are essentially behavioral, cultural, or linguistic in nature. Other children who are mentally retarded do not necessarily require special class placement for optimal educational benefit.

PROBLEM:

Placement in special classes should be based upon the child's special educational needs, regardless of his diagnosis or type of disability. Special class placement for mentally retarded students may be appropriate when, in the considered opinion of an interdisciplinary evaluation team, the special curriculum of regular school class composed of age mates will not optimize the child's potential for learning and achievement as effectively as a modified curriculum directed by a teacher especially trained to work with children with impairment of learning potential. When special class placement is determined to be the appropriate course there should remain daily opportunities for the special class child to interact with regular class students in non-academic situations and in those academic areas where he can compete on an equal basis.

POLICY:

The integration-segregation issue

There remains considerable controversy and confusion regarding the relative educational value of integrating or segregating retarded children from their age peers in regular school classes.

PROBLEM:

Whenever possible the retarded child should be integrated into the mainstream of regular education. However, integration must be accomplished on an individual rather than group basis. As a guideline, the integration or segregation of retarded children from regular class students should be viewed on a continuum. Students of borderline intelligence and a portion of mildly retarded children can function in the mainstream of public education, some with and

POLICY:

¹Further information regarding NARC's position on classification and placement may be found in: **Classification and Placement in Special Education Classes, An NARC Position Statement**. Arlington, Texas: National Association for Retarded Children, 1970. (Reproduced in Appendix A)

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some without supportive services. Some mildly retarded and moderately retarded children should receive their basic instruction in special classes but can be integrated into the regular education program on an individual basis in specific areas for portions of the school day. Some severe and all profoundly retarded children should receive their basic instruction in self-contained units. Teacher aides, paraprofessionals, and volunteers may participate in certain aspects of the educational process, but only under the direct supervision of the classroom teacher. Under no circumstances should aides or volunteers be used to replace teachers.

PROBLEM: The borderline child

Many students falling within the category of "borderline mental retardation" are placed in special education classes for mentally retarded persons for want of other programs.

POLICY: The "borderline" child should not be labeled as mentally retarded, and should receive special assistance through itinerant teacher or other appropriate services. The itinerant teacher would provide special materials and methods to the regular classroom teacher so that the borderline child can be retained in the regular school setting.

PROBLEM: Lack of standard nomenclature

The field of special education appears to be burdened by a number of unfortunate misnomers which carry with them destructive implications regarding the learning abilities of retarded children. These labels connote group expectancies or generate self-fulfilling prophecies regarding ability limits which decrease the probability of optimal individual achievement.

POLICY: The terms "educable," "trainable," and "sub-trainable" should be replaced by the AAMD classification of **borderline, mild, moderate, severe** and **profound** mental retardation. In addition, there are serious inconsistencies in terminology from state to state, concerning the definition of mental retardation and categories therein, as well as discrepancies in standards of eligibility for services and legal descriptions of competence. The NARC recommends that the problem be viewed as national in scope. In order to provide comprehensive service, NARC supports comprehensive planning of terminology and nomenclature on topics such as severity and age-eligibility concepts.

PROBLEM: Student mobility within the educational program

Promotion or upward mobility from one school level to the next (e.g., primary to intermediate) has been typically based upon stu-

dent age and length of time at a given level rather than achievement criteria.

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Specific achievement outcomes must be spelled out for each level of retardation and for each component of the curriculum. A child should continue at his school level until these minimal outcomes or expectancies have been attained. If a child appears to be retained at a particular school level for an inordinate time period, the accuracy of his placement and/or the teacher's effectiveness and appropriateness of curriculum content must be re-evaluated.

POLICY:

Provisions for the early education of mentally retarded persons

Entrance into school programs has in many cases been significantly delayed for mentally retarded persons on the grounds that they need longer to attain the mental age levels prerequisite to success in school programs.

PROBLEM:

The public schools should provide services for children according to their educational needs, regardless of age. Research indicates that the best time to ameliorate a child's developmental disabilities is within the period from birth through the early childhood years. Retarded children can profit from formal public school experiences as early as age two, and a commitment should be made by the public schools to initiate home care training programs of infants with special needs in the first year of life.

POLICY:

Need for continuing educational services

Although the validity of continuing education for normal adults seems now generally accepted, the relative lack of such programs for retarded persons suggests a widespread belief that persons with below average intelligence somehow cease to learn beyond the age of approximately 20 years.

PROBLEM:

Education is a life-long experience. NARC believes that young retarded persons should have the opportunity to develop further during adulthood by means of programs of continuing education. The rapidly changing environment in which most retarded adults must live necessitates continuing education to insure competence in handling problems of daily living.

POLICY:

Appropriateness and scope of school curricula

There has been little or no attempt to develop school curricula for all levels of retarded students particularly the severely and pro-

PROBLEM:

APPENDIX I foundly retarded. Present-day curricula for mentally retarded persons frequently represent a simplified version of curricula originally intended for the "average" school student.

POLICY: Curricula for mentally retarded students should be designed with the intention of providing an individualized educational experience for all retarded persons. A test of curricular adequacy for any level of retardation is that the educational plan should allow students to: (1) increase the complexity of their behaviors; (2) increase personal control over their environment; and (3) attain behavioral characteristics which are culturally designated as "normal." Classroom activities and teaching materials should be relevant to the chronological or social age of the child. Curricula should be geared toward the practical aspects of daily living and effective integration into the community. Obviously, an early emphasis upon vocational skills is essential. Curricula should also stress the effective use of leisure time via generic community recreational and social outlets.

PROBLEM: **Extent of family involvement in the educational process**

It is not uncommon for educational plans to be formulated without the benefit of input or goal-setting by parents of the school children who are the consumers of the educational service.

POLICY: Provisions should be made for ongoing communication between educators and family members in order to insure that what is taught has relevance to the activities of daily living in the home setting. In addition to goal-setting, the family should be involved in the educational process by carry-through in the home (e.g., homework) which reinforces and facilitates transfer of school learning to community life.

PROBLEM: **Qualifications of special education teachers**

Current teacher education programs vary considerably across the nation, and frequently restrict teacher preparation to the educational needs of the "average" student only. Even course work for teachers of the exceptional child rarely covers training technologies appropriate for use with severely and profoundly retarded students.

POLICY: Teachers of retarded children should be highly qualified individuals who are especially trained to deal with the full range of educational needs of all retarded persons. Special education teachers should meet at least the same technical and personal qualifications as their counterparts working with non-retarded pupils. In this regard, there is a definite need to develop national standards for

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teachers of retarded persons, and teacher certification requirements in mental retardation should be standardized nationally, making teacher certificates valid on a reciprocal basis in any and all states. Cultural dissonance is often produced when teachers from middle class backgrounds are placed in special education classes comprised primarily of children from poverty sectors. It would thus seem that specialized training should be provided in colleges and universities to equip young teachers to function effectively in low-income areas.

Class size, composition, and teacher-pupil ratios

PROBLEM:

In many instances class size, composition, and teacher-pupil ratios are inadequate, and are determined administratively without regard to individual student needs.

POLICY:

School policy regarding class size, composition, and teacher-pupil ratios should allow considerable flexibility in order to design the appropriate classroom setting for every retarded child. In general, class size can be increased as the age of the students increases. A guideline for teacher-pupil ratio in classes composed of mildly and moderately retarded students below 13 years of age should be no more than 10 students to one teacher; and, above 13 years of age the ratio might increase to 15 students to one teacher. Also, a chronological age span of not more than three years, and an instructional span of not more than three grade or achievement levels is recommended. At the same time, severely and profoundly retarded students generally require ratios of one teacher to six or eight students at all age levels, with teachers' aides as necessary, depending on accompanying handicaps such as physical disabilities or epileptic seizures.

Supportive services

PROBLEM:

Programs of care, education and training are not self-sufficient, and they cannot be expected to function optimally without supportive services.

POLICY:

Diagnostic facilities are a vital service which, to be meaningful, must be closely coordinated with other education services. Evaluation should be seen as an ongoing responsibility of teaching and supportive personnel. Results of traditional psychometric tools (e.g., standardized intelligence tests) should be seen as cross-sections of current abilities, and considered as supplementary only to day-to-day evaluation of specific achievement outcomes.²

²**Classification and Placement in Special Education Classes, An NARC Position Statement.** Arlington, Texas: National Association for Retarded Children, 1970. (Reproduced in Appendix A)

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POLICY: The public school systems and/or appropriate state agencies should have the resources to identify the retarded persons in each community in order to initiate appropriate education services for these students. That is, educational authorities should adopt an active rather than a reactive posture with respect to the identification of mentally retarded children and the delineation of their educational needs.

POLICY: Whenever facilities are provided by public funds, free transportation must also be made available to all students, as needed.

POLICY: In order to insure effective communication and working relationships between teachers and supportive personnel (e.g., psychologists, nurses and caseworkers) inservice education programs should be so designed as to insure a clear understanding of staff roles, responsibilities and interrelationships.

POLICY: A vital supportive activity of the school is the provision of parent (family) counseling services. Many professionals, including teachers, have traditionally viewed parents of the mentally retarded as emotionally disturbed persons primarily in need of psychotherapeutic services. This stereotype should be replaced by the concept of the typical parent of a retarded child as an intelligent and concerned individual capable of full involvement in planning and decision-making with respect to his child's current and future needs.

Classification and Placement in Special Education Classes

APPENDIX A: AN NARC POSITION STATEMENT

As indicated in the PCMR report, **The Six-Hour Retarded Child**, a significant number of disadvantaged children, especially in urban areas, have been misclassified as mildly retarded and inappropriately placed in "educable" classes. Growing recognition of this problem has caused concerned parents and professionals to bring increasing pressure to bear upon the educational system and to demand that corrective measures be instituted. Inherent in this movement, however, is the danger of over-generalization to the point of assuming that **all** persons heretofore classified for placement in special classes for the educable retarded can, with proper stimulation and remedial opportunities, function adequately in a regular classroom setting.

The situation is further complicated by the renewed controversy surrounding the "nature-nurture" issue as related to cognitive development and the increased popularity in some quarters of the pure environmentalist position. The therapy that cognitive development is subject to genetically-based differences in rate and upper limit is considered entirely inapplicable by adherents of this school. In the extreme case it is thus posited that, in the absence of demonstrable organic deficit, children who appear to be func-

tionally retarded can be brought up to a normal level of functional "enrichment" through the application of appropriate technologies.* This represents an extreme swing of the pendulum away from the equally untenable position that all "subnormal" functioning is based on genetic factors and poor inheritance. In view of the above trends, NARC has developed a series of action guidelines which address themselves to the problem of mislabeling, while at the same time reemphasizing the need to develop and maintain meaningful special education programs for those persons who are truly mildly retarded, regardless of cause.

These suggested action guidelines are being forwarded to State and Local Member Units because of our very real concern that if corrective measures for the screening, evaluation and placement of children into special classes for the mentally retarded are not significantly modified as suggested below, and the attacks which are developing are allowed to go unanswered, we run the risk of having all special classes for the mildly retarded abolished in every state of the union.

NARC agrees with the President's Committee on Mental Retardation that there are a number of children who are misdiagnosed and who should not be in special classes for the retarded. We would hasten to point out, however, that there are a large number of children who have been properly evaluated and are correctly placed in special classes for the mentally retarded. The answer to poor evaluation procedures is not the elimination of special classes for the mildly retarded, but rather the constructive modification of screening, evaluative, and placement procedures to see to it that only truly mentally retarded children are placed into special classes. We feel that the implementation of the guidelines that follow will be a significant step in that direction.

ACTION GUIDELINES FOR STATE AND LOCAL ASSOCIATIONS

A) Case-finding, screening and evaluation procedures for school children suspected of being mentally retarded:

- 1) No child should be classified as mentally retarded until he or she has been evaluated by an evaluation **team** composed of qualified diagnosticians who bring to bear skills needed to assess medical, psychological, social, educational and vocational factors, as applicable. The team should assume responsibility for proposing and interpreting an individual educational plan for the child in the school setting, with provisions for ongoing evaluation of the child's progress and/or needs. The team should also develop suggestions for assisting the child and his family to maximize his growth potentials within his out-of-school hours;
- 2) The classification of retardation should not be applied until the child's adaptive behavior has been assessed in relation

*It should be noted that the results of studies dealing with the effect of environmental factors on cognitive development are equivocal, while definitions of what constitutes a stimulating vs. a deprived environment are at best imprecise.

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to the community and family situation, taking into account the cultural norms of his natural milieu. Where adaptive behavior in any life situation is found to be significantly discrepant from intellectual expectations, the label retardation should not be used, at least until further observation has justified it;

3) The classification of retardation should be applied only to those children who continue to function at a significantly sub-normal level even after various remediation attempts. Special attention should also be given to the identification and treatment of debilitating physical conditions such as auditory and visual impairments, malnutrition, epileptic seizures, or other sensory-motor impairment;

4) Psychological evaluation for the purpose of classification should always include the use of individual test procedures which measure a range of skills and which are appropriate to a child's cultural and linguistic background. Testing should assess specific learning disorders, if any, and the extent to which inferior performance is due to reversible environmental factors such as repeated failure, cultural dissonance, inappropriate expectations by teachers, situational anxieties, personality disorders, or inadequate motivation;

5) A child who is suspected of being mentally handicapped should be observed in his regular class setting. However, classroom behavior alone should never be used as the criteria for labeling a child mentally retarded. Regular classroom teachers should be assisted to ascertain the wide variety of reasons other than retardation which may contribute to inappropriate responses to the school academic environment and to under-achievement. They should be assisted to implement behavior modification procedures, when appropriate, both to enhance learning and to help the child develop behavior which is more acceptable to his peers; and

6) No assessment of a child should be considered complete unless the parents have been actively involved in the evaluation process as significant observers of the child and his performance. In addition, assistance to parents in the home management problems related to optimal child development should be offered through a trained home visitor, where appropriate.

B) Special class placement of a child who appears to be mentally retarded may be appropriate when:

1) There is a documented history of retarded overall functioning which is substantiated through evaluation by a team of qualified diagnosticians;

2) There is consistent impairment of adaptive behavior in the child's home and community as well as in the school culture and environment;

3) There is no significant alleviation in the child's inferior performance and achievement after the modifications in school and home environments;

4) There is a significant continuing residual disability which

cannot be expected to respond to environmental manipulation alone;

5) There is the considered opinion of an evaluation team that the curriculum of the regular class composed of age mates will not maximize the child's potential for learning and achievement as effectively as a modified curriculum individualized and directed by a teacher especially trained to teach children with impairment of learning potentials; and

6) There remain daily opportunities for the special class child to interact with regular class students in non-academic situations.

C) Compensatory and Remedial Education

Children who are functioning at a retarded level academically but who do not meet the criteria for placement in special classes should be provided with a school experience designed to develop latent potentials and to enhance all kinds of learning. Such programs may help to prevent prolonged experiential deprivation and thus reduce the risk of the child falling into the mentally retarded group at a later age.

APPENDIX II

Accreditation Standards for Facilities for the Mentally Retarded

Voluntary Accreditation: What and Why?

Accreditation is a means of identifying for the public institutions, facilities, or agencies that meet predetermined requirements for providing a high quality of care or service. It not only protects the consumer by identifying for him high quality facilities, but it also contributes to his well-being by helping those facilities maintain high levels of service.

A voluntary accreditation program provides for the continuing and objective outside evaluation of services rendered, through a mechanism that minimizes domination or interference and provides freedom to experiment and innovate on the part of the facility, as well as freedom to refine and improve the mechanism and raise the standards of measurement on the part of the accrediting body.

The voluntary accreditation programs of the Joint Commission on Accreditation of Hospitals are based on the development of nationally accepted, professionally valid standards, and of procedures for measuring compliance with those standards, by which the quality of a facility's program or services can be assessed.

Uniquely American, voluntary accreditation differs from, yet complements, government regulation — whether that regulation be licensure or certification. Since accreditation is not mandatory but is a process of self-regulation, the accrediting body does not have the dual responsibility of evaluation and enforcement. It may, if it chooses, provide evaluation only, or it may, as does the Joint Commission, provide education or consultation services. For the facility, loss or lack of accreditation brings with it professional or consumer, rather than legal, sanctions. Regulation, on the other hand, grows out of public law and the regulating agency is responsible to the public not only for determining whether the law has been adhered to, but also for initiating action when it has not been. The agency must be both evaluator and enforcer, and the loss of a license, for example, is the loss of the right to do business.

From the point of view of the facility, the why of accreditation lies not only with its importance as the identification of quality for the consumer of services. It is also important as it relates to the accountability of that facility to individuals and organizations that provide its financial support. Through the fact that the facility is accredited, its supporters will know that their funds are properly used and that the facility's goals are in keeping with the current philosophy of service. For some facilities, the seeking or achievement of accreditation may make possible additional funds through government or private grants; for some facilities, it may also lend support to its efforts in the area of legislation. Accreditation may also facilitate the development of cooperative training and research programs with universities.

THE PROGRAM OF THE ACCREDITATION COUNCIL FOR FACILITIES FOR THE MENTALLY RETARDED

The Accreditation Council for Facilities for the Mentally Retarded (AC/FMR) was organized in July, 1969, to establish a national, voluntary program of accreditation to improve the level of services provided all mentally retarded persons. The Council is composed of two persons appointed by each of its five Member

Organizations: The American Association on Mental Deficiency (AAMD), American Psychiatric Association (APA), Council for Exceptional Children (CEC), National Association for Retarded Children (NARC), and United Cerebral Palsy Associations (UCPA). As a Categorical Council of the Joint Commission on Accreditation of Hospitals, the Council's Program Office was activated in January, 1970, and projects designed to develop standards and survey and accreditation procedures for both residential and comprehensive community services for the mentally retarded.

Historical Background

Although the Council's Standards are the first to be issued for use in a formal accreditation program for facilities for the retarded, the development of standards in this area began in 1964, when AAMD published **Standards for State Residential Institutions for the Mentally Retarded**. AAMD's Standards were presented as minimal, as generally attainable within five to ten years, and as a basis for future evaluation and accreditation activities. Subsequently, AAMD's three-year "Institutional Evaluation Project" applied these Standards to one hundred and thirty-four state institutions. Other organizations, such as APA and NARC, were also interested in the development of standards for facilities for the retarded, and these groups, with AAMD, recognized the desirability of centering standard-setting and survey operations in an agency that would represent organizations

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in the mental retardation field, rather than fragmenting such operations among the individual organizations themselves. Accordingly, AAMD instigated, in 1966, the formation of the National Planning Committee on Accreditation of Residential Centers for the Retarded, composed of representatives of AAMD, APA, CEC, NARC, UCPA, and the American Medical Association (a Member Organization of the Joint Commission). In 1969 the Member Organizations of the National Planning Committee agreed with the Joint Commission to establish the Accreditation Council.

The Philosophy of the Council's Program

The basic philosophy of the accreditation program is that services can and must be provided to meet the developmental needs of the retarded person and to maximize his human qualities, so that he may live as normal a life as possible. While the Council's standards do not describe a prototype nor mandate a model, they do call for maximum flexibility and creativity in meeting the unique developmental needs of each individual served. Facilities seeking accreditation, therefore, must show evidence of the implementation of the stated philosophy in the services which they render. Such evidence will be as persuasive a factor in the determination of a facility's accreditation status as will compliance with any specific standard.

Standards and Procedures

The development of Accreditation Council standards involved participation by representatives of professional organizations, of government, and of the consumers and their representatives, as well as by researchers and practitioners in the field. The standards

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will be reviewed at regular intervals in order to keep them contemporary, clear, comprehensive, and challenging. To do this, a percentage of survey fees will be set aside for use in reviewing and upgrading standards and in encouraging their use in education and consultation activities.

The procedures for measuring compliance with the standards includes a self-survey, done by the facility's own staff, to be followed by a site visit by surveyors of the Accreditation Council. Accreditation decision will be made by the Council, but it is important to emphasize that due process will be observed.

Eligibility

Facilities will be eligible to apply for accreditation if they are licensed or recognized by the appropriate governmental agency, have been operating under the same ownership for at least 12 months, and are primarily engaged in providing services to the mentally retarded, or have an identifiable unit providing such services. In the latter case, AC/FMR accreditation will be limited to the unit for the mentally retarded, but other units within the same facility will be required to seek accreditation from the appropriate programs offered by the Joint Commission. To be eligible, the agency must also be willing to participate voluntarily in the process of self-evaluation and in the site survey. Such participation will include providing appropriate information as requested by the Accreditation Council.

Standards for Residential Facilities

The Council adopted in May and published in September, 1971, **Standards for Residential Facilities for the Mentally Retarded** developed with the participation of over two hundred individuals, including representatives of forty-seven national organizations concerned with retardation. The twenty-three committees that contributed to this work represented all the disciplines necessarily involved in providing adequate services to the retarded, the administrators of state programs and public and private facilities, and the consumers of residential services. The Standards emphasize the delivery to each resident of those services that will enable him to attain maximum physical, intellectual, emotional, and social development, and they are designed to be applicable to all facilities — public and private, large and small — that provide 24-hour programming services. The published document reflects the spirit of the Declaration of General and Special Rights of the Mentally Retarded and the Policy Statements on Residential Services of NARC and the President's Committee on Mental Retardation. It includes standards for the professional and special services and programs that may be needed by residents, in addition to domiciliary services, whether or not such programs are provided by the facility's own staff.

As the Standards emphasize the services to be provided residents, in accordance with their needs, the survey procedures concentrate upon confirming the delivery of such services through a "program audit" of a representative sample of residents. The Standards themselves will, as indicated, be subject to continuous review and revision to maintain currency with the best thinking and practice in

the field.

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Copies of the standards and accreditation procedures are available in a loose-leaf format from the Accreditation Council.

For further information concerning both general and specific questions about the Accreditation Council's program, you may contact the Program Director:

Accreditation Council for Facilities for the Mentally Retarded
Joint Commission on Accreditation of Hospitals
645 North Michigan Avenue
Chicago, Illinois 60611

APPENDIX III

Project Countdown System

The Project Countdown System is designed to assist the committee chairman or committee member in increasing his effectiveness through improved project planning and followup. The system is aimed at minimizing the roles of guesswork and memory in project planning and implementation.

The system provides an orderly framework for analyzing a project in terms of its component steps or phases, estimating the time required to complete each phase, and establishing a target date for its completion. A master time table or "countdown" is developed for the project, thus ensuring that vital steps are not overlooked completely or discovered beyond the critical period for their completion. The development of a comprehensive timetable also provides a means of determining whether it is in fact feasible to complete a given project within the time limits imposed, as well as enabling the person to anticipate potential problems and devise solutions to them prior to initiating the activity.

The implementation of the Project Countdown System involves the following steps:

1. The chairman or member assigned responsibility for the project prepares a tentative master timetable by completing the form PCS-1, filling in the information indicated at the top of the sheet and listing the project phases, persons responsible for their implementation, and the proposed completion dates.
2. The proposed plan is reviewed with the chairman, the committee, or those involved in its implementation to ensure that all necessary steps have been included and that the projected completion dates are agreeable.
3. The PCS-1 form is completed, with copies given to those individuals responsible for the project. The chairman should, of course, retain a copy.
4. The critical dates for various steps in the project should be noted on a calendar for frequent reference to assure that certain delayed phases of the project are not forgotten in the rush of other activities.
5. Upon completion of each step or phase of the project, the date should be entered on the form PCS-1 and brief notes regarding the activity should be entered on form PCS-2.
The advantages of this brief diary of activities become obvious when it is time to prepare a report of activities. The summary on PCS-2 provides an automatic record of the project's progress and prevents the accidental deletion of important points when writing the final report.

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Committee Report Forms

APPENDIX IV

NATIONAL ASSOCIATION FOR RETARDED CHILDREN

Project Countdown System

[illegible]

FORM PCS-1

NATIONAL ASSOCIATION FOR RETARDED CHILDREN

Project Countdown System

[illegible]

APPENDIX IV

REPORT OF LOCAL RESIDENTIAL SERVICES COMMITTEE

ARC Unit _____ # _____

Address: _____
(street or P.O. box) (city) (state) (zip)

Date of Report: _____

Chairman: _____

Committee Members:

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Dates and Location of Committee Meetings:

Objectives for the Year of this Report:

Activities:

Major Accomplishments for the Year:

Plans for Next Year:

APPENDIX IV

REPORT OF STATE RESIDENTIAL SERVICES COMMITTEE

ARC Unit _____ # _____

Date of Report: _____

Chairman: _____

Address: _____
(street or box) (city) (state) (zip)

Dates and Location of Committee Meetings:

Objectives for the Year of this Report:

Activities:

APPENDIX IV

Major Accomplishments for Year:

Plans for Next Year:

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1. Number of local residential services committees in state: _____
2. Are there state regional committees? yes: _____, no: _____ If yes, how are they appointed and conducted?
3. Number of public residential facilities in state: _____ (attach available information on size, programs, etc.)
4. Number of residents in public residential facilities: _____
5. Number of individuals on waiting lists for admission: _____
6. Number of private residential facilities in state: _____
7. Number of residents in private facilities: _____
8. Major problems identified regarding residential services in state:
9. Are all residential facilities accredited? yes: _____, no: _____ If "no", indicate status and plans for accreditation:

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10. What type of information or assistance would be most helpful to the work of the state residential services committee?
(be specific)

11. What national level projects would the state committee recommend to the NARC Residential Services and Facilities Committee?

APPENDIX V

National Organizations Involved with the Mentally Retarded

AMERICAN LEGION

The American Legion and American Legion Auxiliary pledged their support to develop an understanding of the mentally retarded and their needs several years ago. They can be particularly helpful in legislation. State and local associations should be in contact with the American Legion, Child Welfare Division.

B'NAI B'RITH WOMEN

This organization has agreed in the past to assist in the effort to improve the quality of services to the mentally retarded citizen. They have over 135,000 members and over 900 chapters in the United States.

CIVITAN INTERNATIONAL

For several years, the Civitan International Awards have been presented to outstanding local ARC units. In addition to this awards program, many Civitan chapters have been active in local communities in assisting the mentally retarded. Local associations are encouraged to work with local Civitan organizations.

CLIPPED WINGS (United Airlines)

This Stewardess Alumnae organization adopted Research as a national charity project several years ago and have donated regularly to the NARC research fund as well as contributing their time and efforts in various state and local programs.

GAMMA SIGMA SIGMA SORORITY

This is one of the largest women's service sororities, with over 3,500 members on more than 50 college campuses. They have, adopted mental retardation as a national project in the past.

JUNIOR CLUBWOMEN, GENERAL FEDERATION OF WOMEN'S CLUBS

This national organization consists of over 80,000 members located in over 2,300 communities. They have consistently adopted mental retardation as one of their national projects since 1968. They have been particularly supportive of projects concerned with residential services and support the publication of the national NARC newsletter, **The Record**. In addition, they have also underwritten the cost of this handbook for committee chairmen.

JUNIOR LEAGUE OF AMERICA

Although the Association of Junior Leagues does not adopt special projects they have agreed to encourage local chapters to aid the mentally retarded when possible. Many chapters have been involved at the local level in assisting special projects designed to aid the mentally retarded citizen.

APPENDIX V

Kiwanis chapters in many communities have sponsored special projects for the mentally retarded and are generally quite helpful when asked to assist with local programs.

KIWANIS INTERNATIONAL

This National Federation is a social, educational and charitable organization. There are over 18,000 grandmothers as members in some 770 nationwide member clubs. They have, in the past, adopted mental retardation as a national project and may be willing to assist with local and state projects.

NATIONAL FEDERATION OF GRANDMOTHER CLUBS OF AMERICA

Nu Tau Sigma Sorority is a national sorority of young ladies matriculating at exclusive private business schools across the country. There are over 150 chapters which raise funds or give time to aid others.

NU TAU SIGMA SORORITY

This organization is the second largest auxiliary in the United States, second only to the American Legion Auxiliary and has, in the past, adopted mental retardation as a national project. Associations are encouraged to contact Auxiliary Chapters in their community for assistance.

RURAL LETTER CARRIERS (Ladies Auxiliary)

ZTA is an international sorority consisting of 300 alumnae and 122 collegiate groups with some 60,000 members. They have adopted mental retardation as a national project. They have requested that local and state associations feel free to contact their chapters in instances where they can be of service.

ZETA TAU ALPHA

This national organization operates and sponsors many programs for cerebral palsied children and adults and maintains an active concern for the problems of mental retardation. Local and state chapters can be very helpful in collaborating in special projects and should be regularly included in planning for community residential services.

UNITED CEREBRAL PALSY ASSOCIATIONS

In 1959 the Supreme Council of UCT adopted mental retardation as a national project and established a special scholarship fund to assist teachers of retarded children. Many local councils of UCT have supported programs for the mentally retarded.

UNITED COMMERCIAL TRAVELERS OF AMERICA

It is estimated that over 70% of Jaycee chapters, with 6,500 chapters and over 250,000 members are involved in assisting the mentally retarded, either on manpower or fund raising projects. The United States Jaycees Mental Health and Mental Retardation program was adopted in 1963. The first national seminar was held in 1964. In 1965 the program was adopted by Junior Chamber International at Sydney, Australia and now has world-wide activity. Representatives of the Jaycees should be regularly included in the committee's planning.

UNITED STATES JAYCEES

APPENDIX V

VARIETY CLUB INTERNATIONAL

This is the largest fund raising organization for children. Since 1928, over \$10,000,000 has been raised for various charities. There are 36 Tents (organizations) in the United States and a number of these Tents have given support to retarded children.

OTHER ORGANIZATIONS

Other organizations such as **Lions, Sertoma, Eagles, Elks, etc.**, have supported retarded children in some local communities. Do not overlook the possibility of encouraging a service organization to assist or support the programs of your committee.

APPENDIX VI

Suggestions for Further Reading

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Suggestions for Further Reading

RESIDENTIAL SERVICES

Appropriateness of the Continued Institutionalization of the State School Population in New York State. Albany, N.Y.: State of New York Department of Mental Hygiene, 1969.

Baumeister, A. A., & Butterfield, E. C. (Eds.) **Residential Services for the Mentally Retarded.** Chicago: Aldine Press, 1970.

Bensberg, G. J. **Teaching the Mentally Retarded: A Handbook for Ward Personnel.** Atlanta, Georgia: Southern Regional Education Board, 1965 (available from NARC).

Human Rights for the Mentally Retarded. Dallas, Texas: The School of Allied Health Professions at the University of Texas Southwestern Medical School, 1971.

Klaber, M. M. **Conference on Residential Care.** West Hartford, Connecticut: The University of Hartford, 1968.

Kugel, R. B., & Wolfensberger, W. (Eds.) **Changing Patterns in Residential Services for the Mentally Retarded.** 1969, Washington, D. C.: President's Committee on Mental Retardation (available from the U. S. Government Printing Office).

Legislative Aspects of Mental Retardation: Conclusions of the Stockholm Symposium. International League of Societies for the Mentally Handicapped, 1967 (available from NARC).

Residential Care for the Mentally Handicapped: Conclusions of the Frankfurt Symposium. International League of Societies for the Mentally Handicapped, 1969 (available from NARC).

Residential Services for the Mentally Retarded: An Action Policy Proposal. Washington, D. C.: President's Committee on Mental Retardation, 1970 (available from the U. S. Government Printing Office).

Respite Care for the Retarded: An Interval of Relief for Families. Washington, D. C.: U. S. Department of Health, Education, and Welfare (U. S. Government Printing Office).

APPENDIX VII

Leadership Training

The fallacy of the notion that "leaders are born — not made" has been amply demonstrated through large-scale management and leadership training programs in business, industry, government, and voluntary agencies. Through the application of accepted behavioral science principles, it has been shown that the basics of organizational leadership **can** be taught — and **can** be put into practice for the betterment of the organization. This philosophy is basic to NARC's approach to training.

The NARC training program is conducted at national, state and local levels under the auspices of the Organization Development Committee (formerly the Leadership Development Committee) and the inservice education arm of the Conference of Executives of Associations for Retarded Children (CEARC) with funds allocated by the National Board of Directors. The program was initiated in 1962 when NARC received the International Award of the Joseph P. Kennedy Jr. Foundation for outstanding leadership in the field of mental retardation.

In order to cultivate the leadership potential of its members, NARC has evolved several training programs which are readily available to state and local units. The Leadership Development Seminar is a seven-hour program aimed at developing the problem-solving and communication skills of Association members. The Organization Development Workshop is a second major NARC training program. This nine-hour workshop focuses upon the Association itself rather than its individual members — stress is placed upon developing meaningful long-range goals and objectives and a systematic approach to change which will enable the unit — local, state or national — to better meet the challenges of the 1970's.

Detailed written materials for seminar leaders and participants are available from NARC for both these important training programs. Any state or local ARC can thus make leadership and organization development training available to its membership — **without** the use of expensive outside professional "trainers" and "consultants".

The publication and initial free distribution of this handbook to ARC units and Residential Services Committee Chairmen was made possible by funds contributed to NARC by the Junior Clubwomen of the General Federation of Women's Clubs.

Additional copies may be purchased from:

The National Association for Retarded Children
2709 Avenue " E " East / Arlington, Texas 76011