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ABSTRACT

In an effort to indicate the needs and goals of residential care for the mentally handicapped, the booklet defines residential care and presents a statement of its purpose. Discussed are conditions under which residential care is appropriate, the legal rights of the individual, needed services, regional and community resources, and the living environment. Additional topics concern architectural design needs, programs and research, administrative and management services, advisory services, technology and new methodology for improvement, and parent and citizen volunteer workers. (JM)

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Residential Services For
The Mentally Retarded:
AN ACTION POLICY PROPOSAL



The President's Committee on Mental Retardation, Washington: 1970

EC005-823E

A major priority of the President's Committee on Mental Retardation since its establishment has been to promote improvement in standards of residential service for the retarded and to develop a national policy on improved living conditions for those mentally retarded citizens who live in public and private residential facilities.

This booklet offers for public and professional review a proposed policy statement on residential services for the mentally retarded. The statement was prepared with the assistance of the National Association of State Coordinators of Programs for the Mentally Retarded and in cooperation with the National Association for Retarded Children, the American Association on Mental Deficiency, and the International League of Societies for the Mentally Handicapped. The President's Committee on Mental Retardation has approved the statement as a baseline for planning.

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For
The Mentally Retarded
AN ACTION POLICY PROPOSAL

The President's Committee on Mental Retardation
Washington, D.C. 20201

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May 1970

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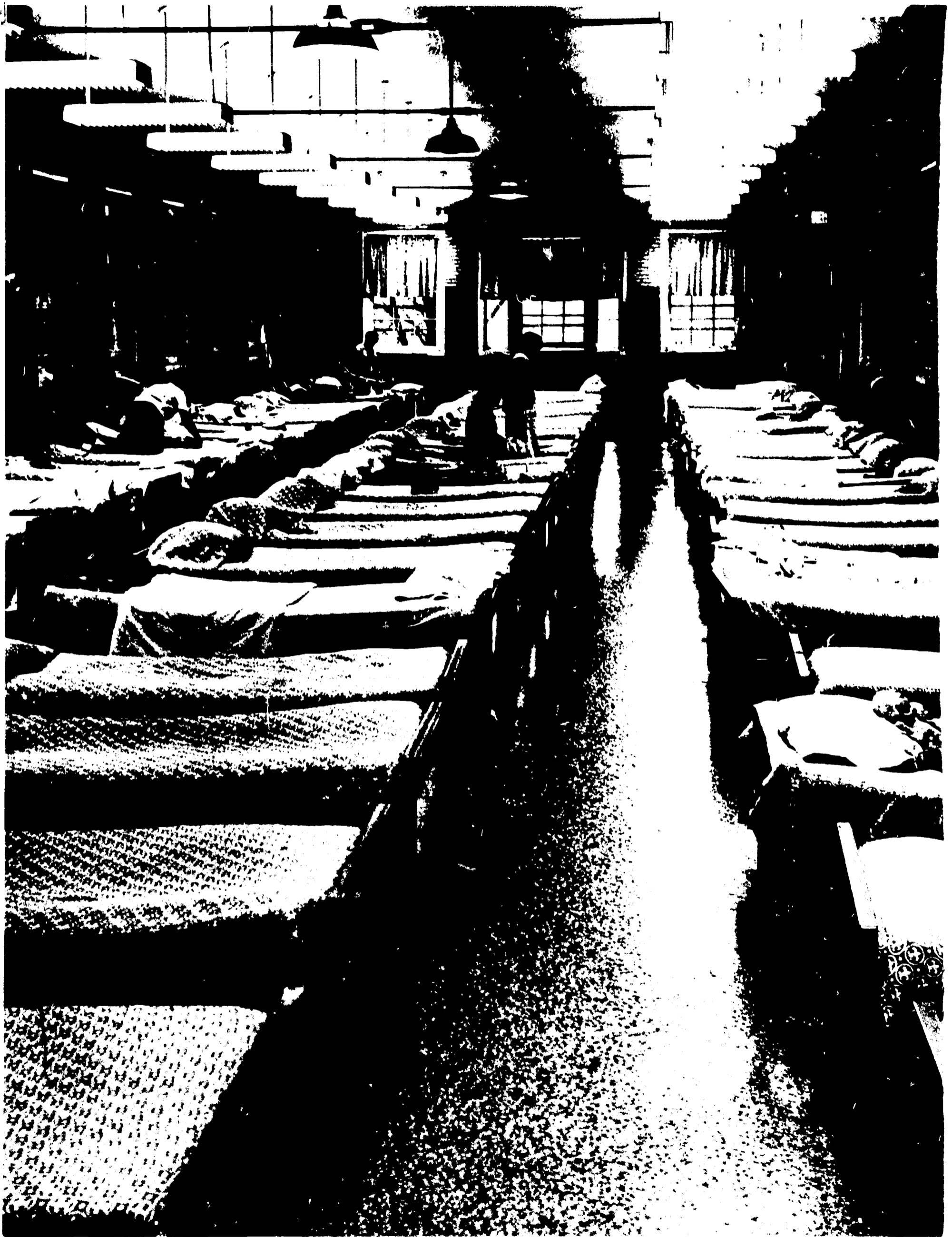


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INTRODUCTION

History tells us that the separation point in philosophy regarding the weak, the crippled, and the infirm is well depicted by the divergent practices of the Spartans and the Athenians. While the ancient Spartans purportedly left the malformed to languish and die, the Athenians chose the road of care, haven, and nurture for the ill.

On the surface, it would appear that we in the United States have chosen the Athenian way. But realistic evaluation of our practices in housing and caring for the mentally retarded in residential facilities should give us reason to pause. Indeed, we must pause and reflect openly and honestly among ourselves. For administrative systems in public facilities for the retarded are rife with make-do arrangements that have grown up to compensate for bone-bare budgets and general indifference to the facilities' needs.

Many residential services and programs as they exist within the 50 states comprise a tragic paradox for the wealthiest nation in the world. On the one hand, our knowledge of environmental design and care for the retarded has never been greater and increases daily. On the other hand, the gap between what we know how to do and what we actually are doing seems to increase at an even more rapid rate.

Among the major causes of failure to provide proper housing and program 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 retardation, the inherited philosophy is too often one of isolation, coupled with disease-oriented treatment. The result is mass housing, built and administered on an outmoded model,

usually removed from community life and society. Almost all public institutions for the retarded are overcrowded, many seriously. Yet, nearly every state has long waiting lists of individuals waiting for admittance to a residential facility for the retarded.

There are few physical cures for mental retardation; therefore an attitude of hopelessness often exists toward these residents despite the good intentions of the staff. A reorientation in thinking will require considerable effort as public officials, administrators, professional workers, and the lay public all come to understand that the retarded can be helped by training, education, and habilitation.

Today, concerned professionals, government agencies, and parents of the retarded are demanding a complete departure from dehumanizing custodial care. Some administrators have already adopted a new approach; others are seeking to make such changes. This new philosophy calls for a variety of decentralized residential services, and a recognition of the human and civil rights of the retarded, among them programing according to the nature and degree of the individual's handicap. In short, the trend is toward normalization, a principle emerging as an entire new approach to management and programing for the retarded. This principle refers to allowing the retarded to obtain an existence as close to the normal way of life as possible in a residential setting.

The following policy statement is intended to be a major step toward realizing the goal of normalization for the retarded, especially for those in residential facilities. The goals in programing and housing cited here will not all be achieved overnight. The volume of activity to improve residential serv-

ices must be sufficiently increased. We no longer can be satisfied with the often deceiving evaluation of the progress of the past or the vague promise of improvement in the future.

Today, more than 200,000 citizens of the United States who are mentally retarded are living in public residential facilities. The cost of operation of these facilities each day is in excess of \$2.3 million, which is more than \$1 billion a year for direct services alone. Far too many of these facilities consist of an impoverished living environment that is not distinctly different from the environment experienced by prisoners of war during the past three decades. The general public becomes highly incensed and concerned—and rightly so—when learning of abuses to prisoners of war. Unfortunately, the same public expresses little or no concern about inhumane living conditions that exist in their own communities.

We must begin, continue, and intensify in the nation and each of our 50 states a movement to improve our residential facilities for the mentally retarded. We must make residential facilities and their programs cost effective in terms of human lives salvaged from the limbo of neglect and given, to the fullest individual degree possible, the dignity of place and value in daily life and work.

The policy proposed in this booklet is offered both as a goal and a guideline. Its implementation, we believe, will be a *saving* act—in human resources, in program effectiveness, and in financial cost per individual served through human service programs.

The welfare of the mentally retarded should be the concern of all Americans. Their hope for the future is in our hands.



“The proper use of behavioral management should involve appropriate motivation and training reinforcement, reflecting an understanding of human development. There is no place for excessive use of physical restraints, abusive use of drugs and prolonged periods of isolation for the sole purpose of controlling behavior . . .”

Proposed Action Policy on Residential Services for the Mentally Retarded

Definition

A residential facility for the mentally retarded is any housing facility other than the individual's natural home, which provides supervised living with appropriate services related to the individual's needs.¹

Statement of Purpose

1 The prime purpose of residential services for the mentally
2 retarded is to protect and nurture the mental, physical,
3 emotional and social development of each individual requir-
4 ing fulltime responsible services. Inherent in this commitment
5 is the responsibility to provide those experiences which will
6 enable the individual (1) to develop his physical, intellectual,
7 and social capabilities to the fullest extent possible; (2) to
8 develop emotional maturity commensurate with social and
9 intellectual growth; (3) whenever possible, to develop
10 skills, habits; and attitudes essential for return to con-
11 temporary society; and (4) to live a personally satisfying
12 life within the residential environment.

¹ The definition here stated and the ensuing policy statement may be considered in the context of private residential facilities if they are comparable to public residential facilities in terms of residential population.



“Individuals who function at the level of staff in certain occupational or training activities have the right to enjoy the same privileges as staff and, when used in other than training situations, should be paid at the legally required wage level.”

Considerations Under Which Residential Care Is Appropriate

1 Mental retardation in itself is rarely sufficient cause for
2 the removal of an individual from his natural home. None-
3 theless, more than 200,000 retarded persons in the United
4 States currently live in publicly operated residential pro-
5 grams. These residential facilities should offer services to
6 retarded individuals, specifically to those severely and
7 profoundly retarded, and those with multiple handicapping
8 conditions, who require highly specialized programs.

9 Less severely retarded persons may profit by short-term
10 residential services for the amelioration or modification of
11 specific problems such as emotional instability, asocial
12 behavior, physical disabilities, or for specialized educational
13 and training programs.

Legal Rights of the Individual

15 A basic obligation of residential services is to assure the
16 rights of the individual. Each retarded person, regardless of
17 the degree of retardation or additional disability, should be
18 treated with respect and given every opportunity to exercise
19 his own judgment in conducting his affairs and should be
20 given the right to own and control property.

21 The responsible person concerned with and involved
22 in program planning for the retarded should make an impar-



“The interrelationship of design and architecture to residential programming is vital . . .”

1 tial case review as often as deemed necessary but no less
2 than annually.

3 The mentally retarded shall have the same constitutional
4 rights and guarantees as every other American citizen.

5 The use of residential facilities for punitive purposes or
6 for long periods of incarceration violates not only the rights
7 of the individual but also the principles of residential care.
8 The residential facility should be used for programming, not
9 punishment.

10 Voluntary and involuntary admissions should be based
11 on sound professional considerations. The reason for place-
12 ment must depend on the individual's need for residential
13 services, not on what is expedient or convenient at the time.

14 The integrity of the individual's family must be pre-
15 served and a close relationship between the family, the
16 retarded individual and the staff should be encouraged. The
17 admission of a mentally retarded person to a residential
18 program should in no way be construed either by parents or
19 staff as a termination of parental responsibilities to said
20 individual unless legal action has occurred to sever these
21 ties. It should be the philosophy of the residential program
22 that parental involvement and participation in all aspects of
23 services to a given mentally retarded person is normal,
24 desirable, and expected, and that a cooperative, communica-

“ . . . a close relationship between the family, the retarded individual and the staff of the residential service facility should be encouraged . . . ”



1 tive relationship between the facility and the parent will
2 result in decisions and services which place the retarded
3 persons' interests and welfare as a mutual responsibility and
4 concern.

5 Family members or their official representatives should
6 be allowed to visit and be free to communicate with their
7 relatives by correspondence or telephone at any reasonable
8 time.

9 Legal guardians should be appointed, whenever neces-
10 sary, for both minor and adult retarded persons to insure
11 full protection under the law.² The responsibility of the
12 guardian is primarily to insure the retarded person civil and
13 human rights (including termination of residential services) ;
14 the protection of his property; and to assure determination
15 and representation under criminal and civil law.

16 **Residential Services**

17 The best residential services meet individual needs. They
18 combine the attributes of a positive home life with modern
19 management techniques and skills available from the
20 behavioral and medical sciences.

21 A residential service should be conducted in an atmos-
22 phere of warmth and affection, dignity and respect, with
23 programs designed for each person's individual needs.

² It is advisable for each state to study and develop its own set of laws governing guardianship of the person and his estate.

1 The proper use of behavioral management should
2 involve appropriate motivation and training reinforcement,
3 reflecting an understanding of human development. There
4 is no place for excessive use of physical restraints, abusive
5 use of drugs and prolonged periods of isolation for the sole
6 purpose of controlling behavior or for punitive reasons. An
7 active and effective program will serve in many cases to
8 improve behavior.

9 Good residential programs provide both long-term and
10 short-term services and are governed by the goal of helping
11 each mentally retarded person develop and make the best
12 use of his capabilities.

13 Long-term services usually are required by the more
14 severely and profoundly retarded whose needs—medical,
15 physical, social, educational and psychological—frequently
16 require continual attention. Programs need to be planned for
17 maximum adjustment, since each individual has potential
18 for some progress, no matter how severely impaired.

19 Ideally, short-term programs should be made available
20 to the retarded with emotional, social, and/or medical
21 problems who require intensive treatment or training within
22 a sheltered environment. Further, model short-term programs
23 should include temporary, reserved space and respite care
24 to relieve critical family situations.

1 It is the obligation of the residential facility to develop
2 each individual's economic potential as well. The work
3 and training settings should train him to perform meaningful
4 remunerative work outside of the residential facility.

5 Individuals who function at the level of staff in certain
6 occupational or training activities have the right to enjoy the
7 same privileges as staff, and when used in other than train-
8 ing situations, should be paid at the legally required wage
9 level.

10 In addition to providing services to the retarded, resi-
11 dential facilities should offer a variety of programs to the
12 family. Every effort should be made to maintain family
13 integrity through intensive counseling and supportive serv-
14 ices for the individual and his family before, during, and
15 following residential placement. Alternatives to residential
16 placement should be explored thoroughly with parents and
17 community agencies.

18 **Regional and Community Resources**

19 It is essential that a residential facility cooperate and
20 coordinate its programs with other regional and community
21 mental retardation services, in order for the development
22 of a full range of comprehensive services.

23 Residential services will vary considerably depending
24 on the residents' needs and the availability of alternative

"It is the obligation of the residential facility to develop each individual's economic potential . . . The work and training settings should train him to perform meaningful remunerative work outside of the residential facility."



1 resources. Residential services should be but one identifiable
2 service coordinated with the general and specific regional
3 and community programs available to all citizens. A high
4 percentage of the retarded are capable of being integrated
5 into community living situations, when supportive generic
6 services are available.

7 The comprehensive residential facility can take an active
8 role in serving a region or community by providing, when
9 appropriate, diagnostic and counseling services, outpatient
10 services, special treatment centers, and in general, participat-
11 ing in all phases of comprehensive planning. Administrators
12 and program staff need to become actively involved in
13 regional and community health, education, rehabilitation
14 and welfare planning.

15 In addition to developing a needed program within the
16 residential facility, the administrator should plan for resi-
17 dents to participate in educational, social, and recreational
18 activities in the community. Residential personnel should be
19 encouraged to stimulate the development of regional and
20 community programs when they are not otherwise available.

21 **Residential Living Environment**

22 The model residential environment should provide a
23 warm, stimulating social setting, devoid of any form of
24 dehumanizing conditions. The retarded should be helped

“Large dormitories should be remodeled to give privacy and individuality to the residents . . .”

“The model residential environment should provide a warm, stimulating social setting, devoid of any form of dehumanizing conditions . . .”



1 to live as normal a life as possible in safety. While those of
2 similar behavior and chronological age may be grouped
3 together, the practice of rote separation based on sex, clinical
4 classification, or handicapping conditions is seldom justified.
5 Small groupings designed to promote maximum social and
6 emotional growth appropriate to the retarded person should
7 be effected.

8 The staff must reflect attitudes and behaviors consistent
9 with the concept that they are family surrogates, i.e., that
10 they are providing services on a daily basis in lieu of the
11 retardate's actual family. However, the continuing pre-
12 rogatives and responsibilities of the child's true parents
13 should also be recognized and respected, even though they
14 may exercise these only on a periodic basis.

15 It is desirable for direct-care personnel to possess at
16 least a high school education (or its equivalent) and to have
17 access to an extensive inservice training program. A "career
18 ladder" should be instituted, enabling qualified staff to take
19 relevant college or university courses when specialized
20 training needs arise.

21 The residential facility and college or university should
22 be interrelated in such a way that the institution of higher
23 learning contributes directly to inservice training of resi-
24 dential personnel, and residential staff and resources should



“The staff must reflect attitudes and behaviors consistent with the concept that they are family surrogates, i.e., that they are providing services on a daily basis in lieu of the retardate’s actual family . . .”



1 be used in professional training and recruitment. Joint
2 appointments should be considered.

3 **Architectural Considerations**

4 Facilities preferably should be designed to serve and
5 maintain programs for a specific population. In planning the
6 facility, attempts should be made, through flexible design, to
7 accommodate advancements and changes in program tech-
8 niques and methods. The interrelationship of design
9 and architecture to residential programming is vital. Con-
10 sequently, the use of facilities constructed for other purposes,
11 e.g., tuberculosis sanatoria, military installations and obsolete
12 nursing homes should be studied carefully before a decision
13 is made to adopt them for the mentally retarded.

14 Design and construction of new facilities should adhere
15 to a number of basic principles:

16 1. The location should be within the community served
17 and provide for normal contacts with the life of the
18 community.

19 2. The size and type of units should be based upon the
20 residents' needs in a comprehensive program.

21 3. The living quarters should provide maximum oppor-
22 tunity for privacy, with closets, lockers, etc., for personal
23 possessions. Living quarters should be consistent with
24 cultural norms, with due regard to health, safety and con-
25 formity to accepted community standards.



“The best residential services meet individual needs. They combine the attributes of a positive home life with modern management techniques and skills available from the behavioral and medical sciences.”



1 4. In new design and construction, consideration should
2 be given to flexibility of programming and, at the same time,
3 to the concept that the structure should be in harmony with
4 the program.

5 Existing facilities should be studied carefully so that
6 antiquated buildings can be scheduled for demolition and
7 remaining buildings converted to specific programmatic units.
8 Facilities can be divided into small program-administrative
9 units which are relatively autonomous and self-contained.
10 Large dormitories should be remodeled to give privacy and
11 individuality to the residents.

12 The yearly budget should include a realistic mainte-
13 nance factor, plus an emergency or contingency fund.

14 In summary, existing facilities as well as proposed
15 facilities should attempt to establish a total environment—
16 physical, psychological, and social—that will provide effective
17 programming for small groups of individuals in a highly
18 personalized atmosphere.

19 **Residential Programs and Research**

20 It is important that research and data collection be a
21 part of the total residential program. To date, outside agencies
22 do much of the research conducted within residential facili-
23 ties. The use of residential populations by various research
24 agencies is not to be discouraged. However, each residential

1 facility should examine its own research potential and, when
2 realistic, establish its own mechanisms for conducting such
3 research programs. It is important that the principles
4 promulgated in "Use of Human Subjects for Research,"
5 published by the American Association on Mental Defi-
6 ciency," be followed. In essence, this statement declares:
7 "Research in mental retardation must conform to the scien-
8 tific, legal and moral principles which justify all research and
9 should emerge out of sound theoretical basis or follow
10 previously accepted research design." The protection of
11 human dignity, integrity and life must be recognized as the
12 first consideration in research planning.

13 Administrators of residential facilities need to be con-
14 cerned with studies aimed at improving programming and
15 treatment. Every effort should be made to use new knowledge
16 and techniques in programming for all levels of retardation,
17 with emphasis on preventive research in all areas of mental
18 retardation—biomedical and environmental.

19 The results of all research conducted within residential
20 facilities which are pertinent to continued programming
21 should be discussed with residential staff so that the findings
22 can be applied. Such research not only will increase

^a"Use of Human Subjects for Research." Policy Statement of American Association on Mental Deficiency, Compiled by Planning Board, AAMD May 13, 1969.

1 knowledge of the condition of mental retardation and the
2 role of residential services, but will also provide understand-
3 ing of many phases of human development.

4 **Administration and Management Services**

5 It is the responsibility of the appropriate and designated
6 agency of state government to develop a philosophy and
7 purpose of residential services for the mentally retarded. The
8 philosophy should be consistent with the current status of
9 knowledge and information available on residential services.
10 The agency responsible for residential services should have a
11 director or coordinator of programs for the mentally
12 retarded. He should be authorized to provide executive
13 direction and administration for all levels of residential
14 services.

15 The administrator of the facility should implement
16 program and staff policy, and direct and coordinate all phases
17 of residential services. Staff should be able to identify ineffec-
18 tive programming and suggest improvements.

19 The administrator and professional staff should have
20 training and experience in administration and human welfare
21 services. Administrators should not be required to have
22 academic training in any one special discipline, but must
23 have administrative abilities, the quality of leadership and
24 an understanding of the condition of mental retardation.

“Administrative policies should recognize the importance of the interrelationship of parents, volunteers, staff, and residents . . .”

“Each retarded person, regardless of the degree of retardation or additional disability, should be treated with respect and given every opportunity to exercise his own judgment in conducting his affairs . . .”



“The use of residential facilities for punitive purposes or for long periods of incarceration violates not only the rights of the individual but also the principles of residential care. The residential facility should be used for programming, not punishment.”



1 systems to modernize laundries, food service and general
2 services. Data processing may be used in record systems
3 and inventories. Program budgeting should make allowances
4 for innovative planning.

5 **Parent and Citizen Volunteers**

6 The aid given by parents and citizen volunteers is very
7 supportive to the mentally retarded and the staff of a resi-
8 dential facility. Administrative policies should recognize the
9 importance of the interrelationship of parents, volunteers,
10 staff and residents. Parent associations should be encouraged
11 to meet at the facility and review with staff the program and
12 budget needs for providing services to the mentally retarded.
13 Volunteer services should always be regarded as additional
14 service and not as replacement of paid professional staff.

15 A staff coordinator of volunteer services is necessary for
16 the recruitment, training, and placement of volunteers in
17 positions that will be most helpful to personnel and meaning-
18 ful to the volunteer.

19 Youth and senior citizen volunteer groups should be
20 encouraged to organize and participate in the over-all pro-
21 gram for the retarded.

22 # # # #

23 This statement is intended as a guideline for policy-
24 makers, not as a final policy statement on residential services.

“The prime purpose of residential services for the mentally retarded is to protect and nurture the mental, physical, emotional, and social development of each individual requiring full-time responsible services . . .”



- 1 The intent is to provide direction so that administrators, staff
- 2 and personnel, as well as parents and the retarded residents
- 3 themselves, can adapt its philosophy to particular situations.

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