RESIDENTIAL SERVICES NEWSLETTER

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the record

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INTERNATIONAL LEAGUE OF SOCIETIES FOR THE MENTALLY HANDICAPPED ISSUES REPORT OF FRANKFURT CONFERENCE

During September, 1969, the International League of Societies for the Mentally Handicapped held a symposium on residential care in Frankfurt, Germany. Although the 47 participants from 13 national member societies brought differing views to the discussions, areas of general agreement did emerge.

These conclusions are not presented as the final word regarding residential services, but rather as a condensation of current thinking in this rapidly evolving area. Too often today's progressive pronouncements become tomorrow's obstacles to innovation. Hopefully the conclusions of the Frankfurt Symposium will never be used as immutable principles or self-evident verities; they are hypotheses to be tested by time.

Basic Principles

All retarded children and adults are basically human beings, who must be treated with dignity and guaranteed fundamental human rights.

Efforts must be directed at 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.

Retarded individuals should be treated so as to promote emotional maturity. They should not be treated as children throughout their lifeime, lest childishness become fixed rather than replaced by adult patterns of behavior.

Most mental retardation programs have paid little attention to the goals of retarded persons 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.

Fostering happiness of retarded children and adults is a desirable goal, just as is fostering happiness of non-retarded individuals. Yet, as is true with the non-retarded, fostering happiness of the retarded should become secondary to the goal of developing their human qualities. Children of normal intelligence are not allowed to give free vent to their hedonistic demands, since they are expected to adopt culturally sanctioned behaviors; the same principle should apply to retarded children. Programs which are aimed simply at generating happiness in retarded individuals are failing to meet the more basic goal of maximizing their human qualities.

Retarded children and adults in general experience happiness just as their normal counterparts. Usually they are made happy by the same things and situations which generate pleasure in the non-retarded, so, they should be encouraged, whenever possible, to share such situations with the non-retarded.

The Principle of Normalization is a sound basis for programming, which, by paralleling the normal patterns of the culture and drawing the retarded into the mainstream of society, aims at maximizing his 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 "form of life" and the nature of the physical environment should approximate the normal cultural pattern as much as possible.

The most appropriate model for 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 potential 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 normal children and young adults. The adequacy of programs as well as of physical environments can be evaluated in terms of the degree to which they fulfill this goal.

In general, this goal is best reached by applying the Principle of Normalization and including the retarded 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 retardate's human qualities, such departures do not violate the Principle of Normalization, although they might lead to practices or physical settings which differ markedly from the cultural norm.

The goal of programming for adjustment to community living is desirable and appropriate for most

retarded individuals, yet it may be unrealistic and need to be modified for some seriously handicapped individuals, who may come closer to maximizing their human qualities by adapting to a specialized environment. 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 programs clearly reveals the inappropriateness of this goal.

Symposium Conclusions

1. Residential services should be viewed as one segment of a continuum of services available to the mentally retarded. These services should be administered and interrelated to insure easy transition from service to service, based on the unique needs of each resident at any given time. The concept of lifelong "institutionalization" is inappropriate for the great majority of retarded persons.

2. Program planning for the individual retardate should be based on analysis of his unique needs at any given time rather than on a static diagnosis. Since these needs change with time, it follows that periodic re-evaluations are essential.

3. The basic goal in programming for the retarded is to maximize their human qualities. The effectiveness of programs, including physical environments, should be evaluated on the basis of the degree to which they achieve this goal.

4. Congruence between the physical environment of the residential unit and residences in the community being served will tend to optimize the human qualities of the retarded residents. There may be instances, however, in which specialized environmental modifications will increase the retardate's ability to control his environment and to choose among alternative courses of action — to the extent that such modifications enhance the retardate's ability to control his environment and to choose among alternative courses of action. To the extent that such modifications enhance the retardate's human qualities, they are in harmony with the principle of normalization, even though they might result in physical environments that differ markedly from the cultural norm.

5. Small living units and grouping of retardates into small groups are considered essential to maximizing their human potentials.

6. The hospital model is inappropriate for residential services for most of the mentally retarded. Special training is in no way uniquely qualifying for administration of mental retardation services. The multidisciplinary team is the preferred approach to programming for the retarded.

7. Parents should play an important role in residential services for the retarded. They should be involved in general policy making as well as in close cooperation with staff regarding details of programming on the living unit.

8. Retarded residents should not be used as part of the residential facility's work-force, unless they are hired as regular members of the staff. This principle does not negate the value of assignment to work stations as part of specific vocational training programs. Likewise, performance of chores related to daily living, such as keeping one's bedroom cleaned or making one's bed, is a valid aspect of the normalization process.

9. Although the specific size of a residential center will differ with the characteristics of the cultural matrix within which the center is located, it must be recognized that increasing size tends to foster self-containment and separation from the remainder of the community. Large specialized facilities are likely to generate self-fulfilling prophesies.

10. Children should live in separate living units from adults. The needs of the two groups differ so that they require different physical environments and programs. Transfer from children to adult units facilitates modification in self-concept of the maturing retarded resident.

11. Research is needed to evaluate the relative merits of different models for long-term residential services, using maximization of the resident's human potentials as the basic criterion. At least two viable models currently embody most principles advocated by the Symposium: the decentralized institution physically scattered within a community, and the simplified community-like institution which maintains active interaction with the community.

12. The relationship between parent and child residing within a residential center should remain as congruent with the normal cultural pattern as possible.

13. Volunteers performing services in residential facilities should not replace staff or be used to alleviate manpower shortages. Volunteers can serve the extremely valuable function of catalyzing rapprochement between residential centers and the remainder of the community.

14. Parents can work most effectively with residential centers by uniting into organizations. Such associations can consider issues with greater objectivity than individual parents.

Sponsors for the international symposium were the Federal Ministry of Health, Youth, and Family, at Bonn; the Hessian Ministry of Labour, Social Affairs and Health, at Wiesbaden; Bundesvereinigung Lebenshilfe fur Ceistig Behinderte, at Marbur.

Tom Mutters served as chairman of the Symposium. Dr. Philip Roos, Mrs. Eleanor Elkin, and Mr. Gene Patterson represented NARC at the Symposium.

Copies of the final report will soon be available through NARCs publications department.

STATE RANKINGS FOR FIVE PARAMETERS OF RESIDENTIAL CARE IN STATE INSTITUTIONS FOR THE MENTALLY RETARDED, FISCAL 1969*

	Rank for maintenance expenditure[1]	Rank for number full-time personnel[2]	Rank for total number of admissions[2]	Rank for net releases alive from institutions[2]	Rank for least number of deaths[2]
Alabama	48 1	49	49	4	7
Alaska	43 18	2	6	8	35
Arizona	4	33	44	20	29
Arkansas		1 22	2	43	1
California			29	17	
				16	44
Colorado	7	21	26	7 5	
Connecticut		23	7	26	13 5
Delaware	9	13	40	38	47 2
Florida	2	11	5	9	
Georgia	0	15			
	19		9		
	10				
Hawaii	25	35	28 3	10	37
Idaho	30	36	33 36	2	49
Illinois	13	19	22	11	46
Indiana	14	17		33	21
Iowa	6	4		4	39
Kansas	3	3	15	12	31
Kentucky	28	16 10	8	3	32
Louisiana	15	14 28	14	22	33
Maine	16		24	6	19
Maryland	27		17	31	40
Massachusetts	29	41	37	35	41
Michigan	11	27	34	30	26
Minnesota	22	18	35	13	17
Mississippi	49	44	23	21	10
Missouri	31		1	1	28
Montana	35	20	12	14	25
Nebraska New	46	47	48	49	14
Hampshire New	41	43	47	19	43
Jersey New	32	30	45	44	15
Mexico		5	21	29	9
New York	23	31	42	34	34
North Carolina	33	26	11	25	16
North Dakota	47	34	38	39	48
Ohio	40	48	32	32	38
Oklahoma	24	9	10	8	4
Oregon	34	40	25	28	22
Pennsylvania	17	25	46	24	36
Rhode Island	5	24	31	41	6
South Carolina	45 42	42	4	36	11
South Dakota		45	19	18	18
Tennessee	26	12	16	45	24
Texas	39	37	30	42	20
Utah	37	39	43	47	30
Vermont	36	38	13	15	42
Virginia	44	46	27	40	45
Washington	12	32 6	39	37	12
West Virginia	21	7 29	20	23	3
Wisconsin	2		18	27	23
Wyoming	38		41	46	27

•Prepared by Edward Eagle, Ph.D., Illinois Association for the Mentally Retarded, from basic data in Residents in Public Institutions for the Mentally Retarded, Current Facility Reports, fiscal 1969, published by Division of Mental Retardation, Rehabilitation Services Administration, U. S. Dept. of Health, Education and Welfare, 1970.

[1] Per average daily resident

[2] Per 1000 average daily residents

EDITORIAL COMMENT

For a theoretical model to be reliable in its application, it must hold in its explanatory power, to a wide variety of behaviors (individually and collectively). If, therefore, the developmental model is truly applicable in its use, it should apply to the strategies we employ as an organizational effort to educate the public as well as it applies to programming for the retarded. The developmental model can indeed stand this test of use. The strategies we use, therefore, should be carefully assessed against the same criteria we would utilize to assess programming in the educational sense: (1) Increasing the complexity of skills; (2) Increasing control over the environment; (3) increasing culturally appropriate behaviors.

NARC is currently involved in a wide variety of public education activities through its Public Information department and the parent training project.

The strategies most applicable to this stage of our efforts would appear to involve altering the negative expectations society holds for retarded individuals. If we expect nothing, that is what we get—nothing. It appears that we have begun to outgrow the expectancies upon which our current service models are based. This evidence of social evolution is logical since even the current models are based on expectancies which are much higher than those at the turn of the century when so many of the state institutions were constructed.

We seek, not destruction of a system, but the internal reformation of that system to bring it more in keeping with the culturally approved attitudes of equality and individual autonomy. This, we feel, is a highly constructive approach for an organization such as NARC.

The uniqueness of NARC as an association, is the underlying concept that its members represent an informed public. The responsibility of its members and staff, is to be informed in order that its organizational function will influence the direction of services to retarded and handicapped individuals. In spite of our devotion to the fairly restricted field of mental retardation, one cannot overlook the fact that until all deviant and handicapped children are provided equal opportunities to develop, we will not be able to achieve our goals for the retarded population. The developmental model would appear to demand that we increase our organizational efforts toward increasing culturally appropriate behaviors within society in order that all people regard retarded and handicapped children as "normal but not average." Within this context of social concern, we will be able to provide programming which meets the developmental needs of people as opposed to programs which support and maintain an attitude of deviancy.

E. Gene Patterson
Consultant in Program Services

NATIONAL STUDY SHOWS MORE INSTITUTIONS —FEWER RESIDENTS

While there has been an increase in the number of public institutions for the mentally retarded in the nation, a recent Facility Report from the Department of Health, Education, and Welfare discloses a slight decline in resident population over the past two years.

For the fiscal year ending June 30, 1969, the department lists a total of 189,394 residents against 193,188 in 1967. Admissions remained almost constant over the past five years, averaging almost 15,000 per year, but releases have increased steadily from almost 8,000 in 1965 to 14,701 in 1969. This shows the expanding movement of specific types of handicapped individuals to other living situations.

At the close of the statistical period, more than 107,000 full-time personnel cared for residents in these institutions as against 69,000 in 1963. The most marked change in the table's accountings is found in maintenance expenditures. In 1960, the national average was $4.25 per day spent to care for retarded residents in public institutions, while in 1969, that cost had risen to $10.95 per resident day for a total of $764,605,791.

A SURVEY OF THE IMPLEMENTATION OF THE PCMR'S POLICIES FOR RESIDENTIAL SERVICES

Although there have been numerous publications concerning desired standards for residential schools for the mentally retarded (for example, AAMD, NARC and PCMR standards), there have been very few attempts to determine the extent to which such policies have made an impact on residential schools and the manner in which such policies are being implemented. For purposes of future planning, feedback of this nature could be of considerable value and hopefully will yield information about the amount and quality of change which is occurring at a national level. Although the U.S. Department of Health, Education and Welfare's publication on "Residence in Public Institutions for the Mentally Retarded" gives much information concerning provisional resident movement and administrative data, there is very little empirical data available to document the types of programs or factors which are involved in the development of trends such as the increment in net releases or placements.

The purpose of the present study is to determine the methods currently being utilized to implement the President's Committee on Mental Retardation's policies for residential services. A survey will be developed and sent to all private and public residential facilities for the mentally retarded in the United States. The data collected hopefully will describe conditions, services, programs, etc., which exist in the public and private residential schools. Items to be included in the questionnaire will be directly related to the PCMR's action policy proposal for residential services.

Items in the survey may include the following:

1. Admission policy,
2. the availability of specialized programs,
3. provisions for individual's storage of possessions,
4. the extent to which residents' rights are guarded — for example, how many are registered voters, how many have driver's licenses, policies concern- marriage, etc.,
5. the types of placement resources utilized,
6. the utilization and role of parent organizations,
7. the extent to which residents go on regular home visits or receive mail,
8. policies regarding the use of physical restraints and the extent to which they are used,
9. reliance on short-term and long-term programs for the mentally retarded,
10. the availability of community resources and the development of them.

The above are examples of areas which might be included in the survey and are only intended to represent areas of possible consideration. The estimated cost for the development of the survey, its distribution and analysis and presentation at the AAMD convention is $1,000.

Survey being conducted by:

David Rosen, Chairman,
National Association for Superintendents
of Public Residential Facilities
and
Marvin Bruno, Ph.D. Coordinator of
Psychological Services Lakeland Village

ACCREDITATION COUNCIL FOR FACILITIES FOR THE MENTALLY RETARDED

Fact Sheet

Purpose: To establish a national, voluntary program of accreditation which will improve the level of services provided all mentally retarded persons.

Organized: July, 1969; Program office opened January, 1970.

Member Organizations:

American Association on Mental Deficiency (AAMD)
American Psychiatric Association (APA)
Council for Exceptional Children (CEC)
National Association for Retarded Children (NARC)
United Cerebral Palsy Associations (UCPA)
The Council is composed of two persons appointed by each Member Organization.

Historical Background:

1964 — AAMD published "Standards for State Residential Institutions for the Mentally Retarded," presenting minimal standards thought to be generally attainable within five to ten years and to be useable as a basis for future evaluation and accreditation.

1966 — AAMD's "Institutional Evaluation Project" applied the standards to 134 state institutions.

1966—National planning Committee on Accreditation of Residential Centers for the Retarded organized by AAMD, APA, CEC, NARC, UCPA, and the American Medical Association (a Member Organization of the Joint Commission on Accreditation of Hospitals).

1969 — Member Organizations of the National Planning Committee agreed with the Joint Commission to establish the Accreditation Council.

Standards for Residential Facilities:

- Developed by twenty-two committees, representing all disciplines necessarily involved in providing adequate services to the retarded, including some 200 individuals and official representatives of 42 national professional organizations concerned with retardation.
- Intended to be applicable to all facilities — private and public, large and small — which provide 24-hour programming services.
- Designed to be relevant to both institutional and non-institutional models for the delivery of residential services.
- Focused upon the delivery to each resident of those services which will enable him to attain maximum physical, intellectual, emotional, and social development.
- Incorporating 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.
- Expected to be adopted and published in 1971, and to be followed by the development of survey and accreditation procedures.
- To be continuously reviewed and revised to maintain currency with the best thinking in the field.

Standards for Comprehensive Community Services:

- Being developed in cooperation with AAMD and a Technical Advisory Committee representing programs, organizations, and disciplines serving the retarded.
- Will include the concept of community accreditation, with measures of program effectiveness and follow-through as priority items.
- Emphasizing the necessity of a comprehensive network of interrelated services which meet all the needs of all retarded persons at all points in the life span, utilizing generic services whenever possible, specialized services where necessary.

• To include programmatic standards which require the delivery system to focus on the plan to maximize the human qualities of each individual.

• Intended to be applicable to all specialized services, generic agencies with identifiable programs, and plan ning and coordinating agencies.

• Expected to be adopted and published in 1972, with the development of survey and accreditation proce dures to follow.

• To be continuously reviewed and revised to main tain currency with the best thinking in the field.

Sources of Support:

• Federal grants for the development of standards for residential and non-residential services.

• Contributions from each Member Organization.

• Contributions for the Joint Commission.

• Survey fees when the accreditation programs be come operational in 1972-73.

For Further Information, write:

Dr. Kenneth C. Crosby, Program Director
Accreditation Council for Facilities for the Mentally Retarded
Joint Commission on Accreditation of Hospitals
645 North Michigan Avenue Chicago, Illinois
60611 Telephone: 312/642-6061

PARENT TRAINING PROJECT

The National Association for Retarded Children has received funds from H. E. W., Division of Social Rehabilitation Services, to implement an eighteen month *Parent Training and Residential Programming Project.* The project was initiated in January, 1971.

The major purpose of the project is to help the parents of institutionalized mentally retarded persons become more knowledgeable and discriminating consumers of residential facilities.

It has been a long recognized fact that most parents of residents in public and private residential facilities have little or no information concerning the types of programs that should be available or how to evaluate existing programs.

Another purpose is to directly benefit the more than 200,000 residents in public and private facilities by supporting the standards for residential services which have been developed by the Accreditation Council for Facilities for the Mentally Retarded, (J.C.A.H.). Such standards describe minimum service standards, and participating residential facilities may request the accreditation survey beginning around the end of 1971. The Council is now in the process of formally adopting recommended standards and developing procedures for implementation.

Project Objectives

The objectives of the project are to provide information and materials to parents in an effort to help them become discriminating consumer representatives of residential services for retarded persons, thus ultimately helping parents to become knowledgeable participants in the evaluation of residential services. The objectives of the project would be accomplished by:

A. Developing a set of training materials and curricu lum designed to provide parents and other interested individuals with:

1. a factual orientation to mental retardation and its implications for a person's future,
2. knowledge of residential programming in ac cordance with the best technical information available to date for optimizing a child's devel opmental level regardless of his functional po tential, and
3. an orientation to the process and/or develop mental type of program evaluation being de signed currently by the Accreditation Council in order that parents will have an evaluation framework similar to professional workers in the field of mental retardation.

B. Implementation of the training program through NARCs Regional Representatives and nationwide net work of State and Local Associations by:

1. training the staff of NARCs six Regional Offices who will in turn conduct training sessions at annual Regional Conferences to be held during the Spring of 1972, and
2. assisting State ARC Representatives trained at the Regional Conferences to conduct work shops at each of the State ARC Conventions during the Spring and Fall of 1972, and
3. ultimately, through such established mecha nisms as Local ARC Residential Services or Parent Counseling Committees to conduct pub lic workshops at the local level for parents and other interested individuals, particularly where the local ARC is in close proximity to a residential facility.

C. Continuous evaluation of training effectiveness and monitoring of the dissemination and training from the national to the local level by:

1. routinely testing training session participants regarding their grasp of training materials content,
2. maintaining accurate and detailed records of the number of participants, their demographic characteristics, and the nature or extent of their involvement in residential services; and
3. systematically sampling the opinions of parents and institutional administrators via mailed ques tionnaires related to perceived needs and ap propriateness of residential programming in different areas of the country receiving varying degrees of exposure to the training project.

The initial dispersion of training from national to regional, state, and local levels of NARC should involve a minimum of 2,000 parents and other interested persons. Subsequent dispersion of training materials will affect thousands of additional persons and hopefully will positively affect all retarded persons residing in institutions in this country.

Method of Implementation

The project will progress through two major phases. The initial twelve months of the project will be utilized for the development of training materials and curriculum and the preparation of the six NARC Regional Representatives who will conduct workshops at the NARC Regional Conferences.

In the second phase of the project, workshops will be presented by Regional Representatives during the NARC Regional Conferences occurring between February and June of 1972. Workshops will also be presented at state ARC conventions which begin early in April and progress through June.

In order to insure maximum participation across the nation, state ARC Executive Directors not able to attend Regional Conferences will be directly assisted in conducting training workshops at state conventions by the Regional Representatives for their area.

The local ARC representatives participating in the state convention workshops will be supplied with a sufficient quantity of training materials to enable them to conduct workshops at the local level.

CITIZENS ADVOCATE PROGRAM MEASURED

The Capitol Association for Retarded Children can now measure the results of its pilot project, the Citizen Advocate Program. Thirty retarded people are rapidly becoming first-class citizens in their community. This includes all ages from children to the aged.

Who are the volunteer advocates? We have 42 people who represent housewives, businessmen, professionals, nurses, church people, parents, Jaycees, youth, retired citizens, and others.

What are the qualifications of the advocates? They are people who are stable in the community, have a commitment to the advocacy concept, are of good character, and are competent in their chosen advocacy areas.

What are the various advocacy areas? These include the citizen friend, adoptive or foster parents, guardian, conservator, or the parent-like figure but not the parent-like arrangements.

What are the responses to the stimulation of an advocate? Men from the ages of 22 to 45 coming from the Beatrice State Home this spring are attending a community church; going fishing and camping; riding horses; being a part of a family; learning to shop; visiting their State Capitol; taking trips to farms, ranches, and other cities; as well as many other activities. As a result, these men are moving rapidly toward independent living and competitive employment.

Young ladies are learning how to dress and behave on the job and in their social lives. They are learning how to select, purchase, and use personal items and are a part of a family unit.

Residents of nursing homes are now eagerly awaiting their advocates' arrivals to go riding and sightseeing in their home town, speak in sentences, and, yes, one has gone to the movies and to the zoo.

Little children in foster homes are experiencing a family life with brothers and sisters and at an early age are learning how to behave socially, to swim, and to participate in many activities.

Focus on Mental Retardation
Nebraska Association for
Retarded Children

Spokane Wins Suit

The question of community acceptance of the retarded was met headon by the Spokane County ARC in a recent incident over the establishment of a Boarding House of mildly retarded adults now in one of Spokane's multiple family residential zones.

A building permit, originally issued, was revoked by the city of Spokane because it conflicted with existing ordinances prohibiting facilities for "Imbeciles" in a residential zone. Not being able to reach any satisfactory agreements with city officials the only alternative was to initiate Superior Court proceedings to resolve the issue. After two days of deliberations, the court voted in favor of the proposed Boarding house and ordered the city of Spokane to reinstate the Building permit.

The decision was based on two reasons: 1) a Boarding house by nature does not constitute an institutional facility, and 2) the men who will live there are self-sufficient, reasonably adjusted socially and cannot be considered "Imbeciles," even though they have been residents of Lakeland Village, a state training school for the retarded.

According to Roger Blue, Spokane ARC executive director, misunderstanding on the part of neighborhood residents was very apparent as evidenced by a petition against the boarding house which contained over 300 signatures.

The Executive
Conference of Executives of
Associations for Retarded
Children

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