

THE GUIDING ENVIRONMENT: the dynamics of residential living

American Edition

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By
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FOREWORD

We take pleasure in bringing to the American people the thoughts of Karl Grunewald, M.D., on the latest trends in living arrangements for mentally retarded individuals.

Doctor Grunewald, an internationally known scholar in the field of mental retardation, is Director of Mental Retardation Care Services, The Swedish Board of Health and Welfare, Sweden.

The paper, which is printed here, was presented at the First Regional Conference of the United Kingdom Committee of the World Federation for Mental Health in association with the National Society for Mentally Handicapped Children. The conference, which had as its theme "Action for the Retarded," was held in Dublin, Eire, on March 27th through April 1, 1971.

The enlightened application of the "normalization principle" to the retarded individual's daily living activities and the advances made in residential care in the Scandinavian countries have served as a pattern for mental retardation programs in the United States. Although we in America cannot adopt in their entirety the philosophy and patterns of programming suitable in a smaller country, there is much information in Doctor Grunewald's paper of import to our problems in residential care programming. It is a privilege, therefore, to publish this paper by one of the leaders in the "normalization" trend.

A handwritten signature in black ink, reading "Francis X. Lynch". The signature is written in a cursive, flowing style with a large initial 'F' and 'L'.

Francis X. Lynch, Director
DIVISION OF DEVELOPMENTAL DISABILITIES

THE GUIDING ENVIRONMENT: THE DYNAMICS OF RESIDENTIAL LIVING

Karl Gruenwald, M. D., Director
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Four Stages in the Development of Provisions and Services

All types of provisions for services to handicapped individuals can be said to pass through certain stages of development. The first stage – and in Scandinavia it started 100 years ago – features identification of the particular problems that a specific group of individuals have. The first stage might be called the diagnostic stage since it is then that diagnoses are made and plans are formulated to meet particular needs.

The second stage is one of specialization as particular needs are met by special solutions specific for those needs. This leads to centralization of the services; for example, a single institution might be decided upon for the whole country or for a certain part of the country. The second stage is dominated by specialists to whom the consumers of services must subordinate themselves and, thus, the other needs of the handicapped individuals become of secondary interest to the experts.

The third stage can be called the stage of differentiation. At this stage it is realized that a particular service cannot be standardized for all recipients. Factors affecting differentiation are, for instance, different age groups; need for interaction of medical,

educational, and social specialists; and the degree of retardation itself. The Scandinavian countries are presently in the stage of differentiation while other countries close to Scandinavia are mainly in the specialization stage.

Finally, provisions for services to individuals with the different handicaps reach the fourth, and what we think of today as the last, stage. It is a composite one characterized first by decentralization of services, then provision for integration of services to the handicapped with those similar services which non-handicapped individuals receive from the community. This is the stage we have only started to formulate and tackle. In order to effect decentralization and then integration in community services there must be enough trained personnel who can offer services in a given geographical area, a transportation system for the handicapped, and a general state of readiness and relative open-mindedness among the population.

Institutions and Development

It is easy to generalize, as I have done here, and declare our existing institutions bankrupt. It takes at least two generations to build a system of institutions in a country; it takes one generation to formulate what's wrong in the system, and another generation before one can make real what one has succeeded in formulating. It is not enough to tear down our institutions however, we must build up a new type of service based upon the knowledge we have today of the mentally retarded person's potential to develop.

Mental Retardation as a Function of Personal Relations

We all agree that the only thing that mentally retarded individuals have in common is a hampering of the development of intelligence. It is not those who labor with intelligence structures, but rather those psychologists who theorize that intelligence is the effect of a system of processes who have contributed the most to our understanding of methods for creating therapeutic environments.

Compared to one with normal development, a person with slow development of intelligence has a greater number of failures and consequently is more dependent upon his environment. If the environment is a poor one or the individuals within it are unwilling to understand the handicapped child, then the latter's readiness for failure is increased and positive aspects of his behavior are not reinforced.

Behavior is formed in a constant process of interaction between the individual and his environment. All mentally retarded individuals can develop and learn something, only it takes them longer and puts greater demands upon the environment than it does with non-retarded persons. We must focus upon these facts when forming suitable environments for the mentally retarded.

Thus, in practice we must always view mental retardation in relation to the person's environment. This means that the environment we create for the individual must always be evaluated according to the same principles and with the same accuracy we use in evaluating retardation itself. The more complicated the environment, the more retarded the

handicapped will function or — as in developing countries — the less complicated the environment, the fewer the individuals who will function as retardates.

The Principle of the Small Group

There is an old observation made by those who work in institutions that severely retarded individuals appreciate a "small environment" where the number of interactions with other people is few. Many workers have observed the positive effect on a severely retarded individual when he was moved from a large ward of 20-30 persons to a small group of 10 or less (5 - 8 would be preferable). Suddenly the retardate's reactions become predictable and one sees that he can recognize and grasp reality. Observations such as these have led psychologists to formulate the Principle of the Small Group.

From these observations we deduce that an influence for favorable development is to be found partly in the small number of interpersonal relations forced upon the retardate thus making them potentially stimulating rather than frustrating, and partly in the homelike atmosphere and equipment of the room and of the unit to which the room is connected.

The homeliness — or homelikeness — may need to be modified when one considers certain more or less permanent medical needs, and such technical arrangements as necessary to provide a suitable environment for individuals with certain additional handicaps.

What is important when planning for residential living is that the starting point be an environment normal, homelike, and small.

When reviewing our provision for care in historical perspective we are astonished to learn that it is the size of the group cared for that constitutes the greatest failure in our provision for care. First, large inhumane collective wards were established having extremely poor physical facilities. These collectives were by no sense necessary, but they fitted well into the value pattern of many generations -- that mentally retarded persons were regarded as subhuman persons with deprived sensory and esthetic experiences. Actually the retarded became more so in the unorganized, complex environment and thus could express neither feelings nor have experiences in a manner that would be called human.

To summarize, we might very well say that we do not have any mentally retarded people, but we do have retarded environments or surroundings. Of course, this is particularly true in regard to our institutions. Being inside such a collective ward, one is sometimes tempted to ask which is the most retarded, the person living there or his environment!

HETEROGENEOUS GROUPS

In a guided environment interpersonal relations among residents play an outstanding role, perhaps even more so than relations between residents and staff. The prerequisite for the favorable environment is that the composition of the small group -- those

who live together in a unit (ward) – is carefully planned. Within the limits of the children's or adult's grouping, the small group has to be as heterogeneous as possible. This philosophy is in opposition to that of segregating those with physical handicaps, the blind, the deaf, etc., into special units. A distribution of these "minorities" among all units limits the number of multi-handicapped persons in each unit and gives them an environment more active and rich in stimuli than otherwise. The prerequisites for this arrangement are that enough specialists and specialized services be available and that the ward be properly equipped to take care of the additional handicaps.

The one group with which one may have to break this fundamental principle is the group of deaf adults and school age children – but of this group we know too little as yet.

As to the degree of retardation within a group – the most hampered should always be in a minority within the group so that they may be "drawn upwards" by the other group members. And the span of retardation should not be larger than the group activities permit for maximal benefits to the individual group member.

We have started a very careful mixing of the sexes in the mildly and moderately retarded groups and some of them are allowed to live as married.

LEARNING AND APPLICATION

Psychologists have taught us the importance of a clearly-structured learning situation for the individual-. Research shows us how much we can achieve with the gravest retarded persons by individualizing and simplifying the influence techniques. Psychologists and educators are producing increasing amounts of carefully programmed and systemized learning sequences based upon exact pretraining analysis of the level each retardate has reached in his various capabilities. These clearly-structured sequences must be realized in both individual and group situations. Applications of these structured influences must be made in a small group and in an environment very rich in stimuli as e.g. in a surrounding that contains all that is found in a normal home and which makes possible normal self- and group activity. In these situations the child or the young persons should have the opportunity to experience what the psychologists call "transfer" to related situations.

The point is that the pupil does not have to change his conceptual structure in order to apply what he has learned, as these must be basically the same in one situation as another. There must be slight concrete changes, however, in order to be transferable to increasingly different situations. This transfer ability determines the potential for development of intelligence and eventually for the integration of different abilities at increasingly higher levels.

Thus one can say that good adaptation requires transfer training; that transfer requires a small environment rich in stimuli; and that individualized, well-structured, and meaningful influence techniques are required in order for the handicapped individual to achieve the greatest benefit from the stimuli of a small environment.

I want to stress that the application milieu must be a socially real and concrete environment. It is not possible to build up substitute situations within institutions. The retarded individual needs training in a situation identical to that in which he is going to function, however at his own pace. This means that we must offer our severely retarded persons social environments and situations where they may apply freely and in a natural way that which they have learned in the specific instructional situation. This application concept is an important consideration when determining where in our community a hostel or residential home for retarded individuals is to be located.

CONSEQUENCES FOR RESIDENTIAL PLANNING

Attempts to construct socially-real applicational environments have already been made in Sweden. We have built a residential home for severely retarded children that is situated in a normal private residential area in a town. Streets, sidewalks, and traffic are part of the regular pattern in the community. The children can watch traffic from the windows or be taken outside onto the sidewalks to experience natural light and sounds, to

play in the yard or exchange greetings with neighbors and passersby. They have the opportunity to visit shops along with the staff members as the latter go to buy magazines, etc. Thus the children have some of the opportunities a normal child experiences in a close community.

Another home, partly for severely retarded children less than 7 years of age, consists of three houses in an ordinary block of row houses.

These examples of placing smaller residential units in the centers of our communities are only hints of how to give the most severely retarded children and adults a concrete and close educational environment.

THE PLANNING OF COMPREHENSIVE SERVICES

How are we to build up our services if we accept these fundamental principles of learning mentioned before? First, we cannot run systematic programs of guidance without considering the emotional ties of the child or young person. Therefore it is quite evident that services of the future will support parents to a much greater extent than presently. Those children who cannot stay at home continuously will at first be taken into residential units for short-time care and for observation or relief care. Educators will teach those children who cannot come to a group, in their homes, and the parents will be offered courses individually or in groups.

We must plan our services by starting from the normal community. The flow and development of increasingly comprehensive services should be from without the institution to within and not from within and out towards society. This means that specialists who organize services and supervise staff must not be tied to, institutions. All services for retarded persons must be regarded as of equal importance and the priority for serving residents in a residential home on a 24-hour-a-day basis must be broken. The development of care at home and other kinds of day care will benefit. This concept of serving the retardate in the community also means that we should put greater demands on all kinds of • specialists whose skills we can use in our provision of services and buy such services as far as possible instead of building up a specialists' service of our own. Personally, I think the time has passed when there are reasons for a particular speciality categorizing doctors who worked with retardates, some kind of oligophrenia doctors. We need exactly the same specialists for retarded persons as for other children or adults. What retarded individuals have in common – retardation in development of intelligence – is not in itself of medical interest.

The emphasis on provisions for services should be transferred to the community. The retarded individual should be regarded only as one among all others who needs some form of support or service,

It is not enough to normalize the retarded person but we must also normalize our services and the entire organization of services. In reality, the retarded persons are part of the total community and can help us in a process of de-intellectualization that I think is necessary for the good of all.

When planning and forming future services for mentally retarded individuals two important factors must be considered: one is that we apparently will have less severe retardates in the future.

According to certain Swedish statistics we have a concentration of the most severely retarded in the age group 15 to 25 years old. In older groups there appears to have been a very high death rate.

With the age groups below 15, we have been more active in habilitation and have given better prophylactic care. Possible contributory causes to the concentration of severely retarded in the 15-25 year age group are that these individuals did not benefit from recent improvements in premature care, which now save the lives of many children, and the widespread use of penicillin and other antibiotics. In the future I think we will have a decreasing number of additional severely retarded individuals each year. At the same time we can expect an improvement in the functioning level of the severely retarded individuals for whom we now provide.

The other factor is that we must be consistent when we build up services for retarded individuals in separating residential living, occupation, and leisure time. This applies also as much as possible to 24-hour institutions for the retarded. We want a geographical

distance, for instance, between the school and the residential home as well as between all other types of living and the daily occupation. It also means that as far as possible we want to use the community's leisure-time and recreational facilities. Our goal is to have leisure time spent out in the community, preferably individually but otherwise in groups.

THE DYNAMICS OF LIVING

The dynamics of residential living are initiated and developed by our creation of small heterogeneous environments so rich in stimuli that the retarded individual assimilates the benefits of the environment and can advance to a new and even more normal setting. In the future we will need many relatively small units located in the middle of society, which are more or less specialized for the functional level and actual needs of the retardate. This means that the retarded individual, as he progresses, will have to move more often than he has had reason to so far. Movement is regarded as a disadvantage by many people who think it is good and a matter of security for the retarded person to live and stay in one place for his entire life. We ourselves, however, often experience economic or personal development and renewal when we change places of work and residence. So the experience should not be specifically restricted to the non-handicapped.

1. With Children

In the future children will not have to live in special residential homes but will live at home to a greater extent, or as an alternative

Today we have had good experience with group homes housing 4 to 6 children in each unit, located in ordinary flats in apartment buildings and private houses. In each service district at least one central unit is needed with 7-day homes relatively near a training school.

In this respect some of our educators have given guiding examples. They have proven that all children aged 7 to 17 can be instructed. This means that every child should receive some form of educational stimulus with the contents adapted to the needs of the child and the time limits set for what the child can manage. From this information I conclude that our architects must design future group homes so that even the most severely retarded children can live in them. There is no longer any reason to separate these children from the less-retarded. The special medical services they need can be given in one house as well as in another. Of course a certain age differentiation will be needed, but in principle one should strive towards heterogeneous family-like groups. That children should not live in the same area as adult retardates, I see as self-evident.

Apart from these group homes, places, (units) in hospitals are needed for those retarded children who also are ill. These hospital units should be used for short-time care for children who otherwise would live in group homes or in their own homes, and also for longer term

one in each of our 25 counties) average 200 beds each. When the plan is fulfilled in 5 years about 35% of the adults will live in this type of residential home.

The next step in the normalization process is to live in a local hostel organized as an annex to a central residential home. There are a little over 100 of these in Sweden. Their number will increase in the next few years and they will house on the average 48 people each. In order to be economically stable these hostels cannot have less than approximately 25 residents each, which still means that they are relatively small homes, and -- being community centered -- will have a fairly good potential for promoting social relations. Thirty-eight percent (38%) of all adults -- the greater part of all of our adult retardates -- will live in these local residences.

Our greatest achievement in collective living at present is with the group-type home. In only a few years the number of such homes has increased from a handful to some 90 homes. The average number of beds per home is approximately 8. Around 6% of the adult retarded individuals live in these homes today, but in four years this percentage will increase to 14%. This means that we then will have 2200 adult retardates living in such small group homes, most of which consist of regular flats in apartment buildings, rented by the county administration on the same conditions as for private tenants. Renting, by the way, contributes to quick availability of this type of home.

In the future there will be different types of group homes from those housing 3 to 4 persons and practically no staff to those with 7 or 8 retarded persons in each home. A larger number is not desirable. Small apartments should be concentrated in one residential area. Together they constitute a Group Home with a supervisor who assigns staff as needed. We want to avoid "night personnel" in group homes for adults, and we make a clear distinction between group homes for adults and hostels.

Decentralization and integration of residential living into the community result in a more flexible relation to other provisions for services, particularly different types of day care. In a community one could build up a Service Center with a specialist staff who could provide comprehensive services for every retardate in that community. This would yield greater possibilities for adapting services to the individual needs and conditions. Such flexibility would provide more option and make it easier to rid oneself of a home or a form of service that no longer meets actual demands.

The creation of different normalized environments makes possible dynamic living where the retarded person is stimulated by being a member of a small group. Here the adult retardate will be able to develop simply by living.

In this manner, one may formulate new norms and organizational forms that tear down what earlier generations have built with much toil

and economic hardship. With humanity, however, it is one of the rules of the game that rigid and sterile order is broken by creative unrest • just as upheaval follows upon rest -- and that the establishment of a new order requires new means. Indeed, in our society, this is living itself.

Footnote 1/

Sweden has 8 million inhabitants of which 0.37% as retardates receive some form of services. 0.20% live in 200 24-hour-homes and hospitals (group homes excluded).