

Chapter 17

Action Implications, U.S.A. Today

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The contributions to this volume have brought together the best thought available today in the realm of services in mental retardation. It is an impressive collection and one that adds substance to our hopes for a better future for the retarded. In this final chapter an attempt will be made to pull together the main trends of thought and relate them to issues which need to be faced in our country and our states, and by our Federal Government as much as by the citizenry at large.

This discussion has been structured around six broad areas of concern: philosophies and concepts; strategies of change (e.g., planning legislation, research, evaluation); human management programming; administration and financing; manpower and staffing considerations; and location and design of facilities. Obviously, there will be points which have relevance to more than one area; while there will be some cross-referencing, a point will generally be discussed in the area to which it appears to be most relevant.

#### Philosophies and Concepts

Without a doubt, as far as the future of residential (as well as many other) services is concerned, the concept of normalization presented in Nirje's chapter has emerged as the most important one in this book. Developed in Scandinavia where it had long been reflected in the broad network of human welfare services even before the particular term was adopted, this concept is elegant in its simplicity and parsimony. It can be readily understood by everyone, and it has most far-reaching implications in practice.

The author wishes to acknowledge his great indebtedness to Wolf Wolfensberger for considerable aid in the conceptualization and formalization of the material in this chapter.

There is need to clarify some terms that influence the way people think. One should think in terms of "residential services," as indicated in the title of this volume, rather than "institutions," a term which refers to congregate care practices of the past--but not of the future. "Residential services" is also more appropriate than "residential care," which implies a more narrow concept. Finally, the term "residential services" is appropriate in the plural, referring not merely to a relatively unitary concept such as embodied in the traditional institution, but to a range of diversified and specialized services as described by Tizard and Dunn.

The normalization principle draws together a number of other lines of thought on social role, role perception, deviancy, and stigma that had their origin in sociology and social psychology. It implies programming on three distinct levels.

1. On the first level, a deviant individual, in our case a mentally retarded person, should be enabled to behave in such a fashion that he will be perceived as non-deviant or at least less deviant. Nirje has outlined in considerable detail the course of action that is implied. Briefly, normalization entails helping a deviant person, within the limits of his capacities, to learn to speak, act, groom, eat, dress, etc., like typical persons of his age and sex. In other words, on this level, normalization parallels many of the practices of rehabilitation.

2. On the second level, the main task is to interpret the deviant person to others in such a fashion as to minimize his differences from and maximize his similarities with them. Here communication assumes great importance. It makes a big difference whether an adult person is presented in a normal tone of voice as "Mr. John Smith," or somewhat condescendingly as "John," or, in what ever spirit, as "a mongoloid." Interpretation can, of course, also be nonverbal. A person who is housed in a tile-decked hall with a drain in the floor and an open toilet in the corner and who is seen going about in diapers or an ill-fitting hospital coverall is, of necessity, perceived as a creature which bears little relation to a human being.

We must keep in mind that interpretation of this nature has a circular effect. It affects not only outside observers but also those who work with the interpreted person. Thus, an attendant who constantly sees retardates exist in zoo-like surroundings will cast them into the animal role and will, in turn, himself assume the keeper role. Similarly, an institutional worker who sees retardates in an environment which makes no developmental demands and which emphasizes the deficiencies rather than the strengths of residents will come to believe that they are not capable of growth and learning. In turn, a mentally retarded person will tend to go along with this "nonlearning" role that is thrust upon him.

3. On the third level of programming for normalization, emphasis is on molding attitudes of the public so as to make it more accepting of deviancy in general, including deviancy in intelligence,

-The term "typical" is chosen here because it refers more clearly to a statistical concept such as the median, or mode, in contrast to the term "normal," which evokes controversial theoretical notions regarding the nature of normality.

education, appearance, manners, dress, grooming, speech, etc. The deviancy of the retardate will be diminished to the degree that ordinary citizens gain a broader perception of normality and become accepting of a wider range of variation in the performance, appearance, and capability of fellow human beings.

Four highly interrelated concepts of residential service can be derived directly from the normalization principle. These are integration, dispersal, specialization, and continuity.

#### Integration

Integration refers to those measures and practices which maximize »; , a retarded person's community participation. Obviously, there are degrees of integration. Maximal integration is achieved by the retarded person who lives in an ordinary family setting in ordinary community housing, who moves and communicates in ways typical for his age, limited though they may be, and who utilizes, in typical ways, typical community resources such as schools, churches, hospitals and clinics, bowling alleys, swimming pools, and job placements. For others, this pattern of maximal integration is not feasible; they are in need of one or more specialized services, and must be restricted in certain ways or excluded from certain commonly enjoyed activities. The important and too frequently neglected point is that one restriction, exclusion, or limitation should not automatically invoke a host of others merely because this is in keeping with the perceived pattern of mental retardation.

Individualization is an essential feature of normalization and assures social approval while granting maximum integration into those normal life patterns of which a retarded person is capable at any given time. Individualization, in turn, requires recognition of basic human and individual patterns of growth and change, of the rise and wane of needs. Hence there must be provision for periodic review to make certain that services are not only instituted but also terminated in keeping with changes in needs.

We are finding increasingly that special grouping of retardates is not always necessary in order to meet special service needs. Thus, we are gradually moving away from the traditional concept of special education via segregation, and toward a concept of special education which utilizes to the maximum possible extent regular public school and other educational services, and which provides special instruction to meet special needs with a minimum of segregation.

#### Dispersal

Here, one of Nirje's principles is of the utmost importance: every effort should be made not to congregate deviants in numbers

larger than the surrounding community can absorb and integrate. Among other things, this principle implies that a large number of small facilities should be developed and dispersed, not only so that there are residences in the various population centers of a state but so that these residences are dispersed within these communities.

Obviously, neighborhoods will differ in regard to what they can absorb. In all likelihood, upper lower-class neighborhoods of medium density population and with a large array of resources (post office, library, churches, playgrounds, movies, stores, etc.) will be capable of absorbing mentally retarded persons at a high rate. Thinly populated upper-class suburban areas beyond easy walking distance from community resources would probably be least suited.

Dispersal is also likely to enhance rehabilitation. First, normalizing opportunities associated with dispersal are likely to increase social skills, in contrast to habilitation programs in institutions where each habilitative measure is likely to be counteracted by powerful abnormalizing and dehumanizing conditions. Second, dispersal permits placement of residences near industry and work opportunities, again in contrast to many institutions which either have more residents than surrounding business can absorb in unskilled and semiskilled jobs or are located far from employment opportunities in general.

#### Specialization

Dispersal is difficult, perhaps impossible, to achieve without specialization of residential functions. It is inconceivable that a small residence in a neighborhood could adequately and simultaneously serve all those functions that the traditional institution serves. In other words, a small residence could not serve both the newborn infant and the senescent, the mildly and the profoundly impaired, the well-socialized and the ill-socialized. Nor, as pointed out by Wolfensberger, Nirje, Tizard, and Dunn, is it desirable to perform omnibus functions in one residence even if one could.

Dispersal not only serves the principle of normalization but, as Dunn has so well analyzed, it also opens up new possibilities for manpower utilization and economy. Particularly in urban areas, it will be possible to draw from such a large number of retardates needing residential service that hostels with very strongly focused functions and very homogeneous resident groups can be constituted. Thus, many hostels can specialize on becoming inexpensive "sleeping homes." Others could house residents who stay only from Monday through Friday, and who return to their families on weekends. In addition, there can be hostels where resident children attend ordinary community schools during the day, or where resident adults go to regular or sheltered jobs in the daytime. But school attendance and ability to work in the community in open or sheltered employment are by no means necessary

prerequisites for hostel living. As Denmark has long proven, aged and infirm adults can also profit from this normalization, provided they do not have acute medical and nursing needs. In short, a considerable portion of the institutionalized population in the United States could fit into this scheme if the necessary community services (schooling, employment, leisure-time activities, day care) were developed concomitantly.

### Continuity

Continuity of personal functioning is important in achieving normalization. This requires a continuity of available services, and a continuity between those aspects of a person's life which are supported by special services and those which are not.

The concept of a continuum of available care goes back to one of the recommendations of the President's Panel on Mental Retardation, but the word "available" has been added to underline that while an inclusive array of services must be in existence, the retarded individual would not necessarily be in care on a continuous basis, and would not be moved automatically from one service to the next. There may be periods when his family or, later on, he himself can manage without aid--yet as soon as the need arises he should be able to move back into a service system that will aim at "minimizing his disability at every point in his life span" (President's Panel, 1963). Services may well be given under a variety of governmental and nongovernmental auspices--the term "system" should connote a coordinative cohesion which bridges administrative or functional fragmentation.

In regard to residential services, continuity implies an uninterrupted interplay between the family and the residential facility where the mentally retarded person is being served. Just as entrance to a residential facility should be gained easily and informally, so ongoing contacts--correspondence, telephone calls or inquiries, visits by the family and visits to the family home or relatives' homes--should be easily accommodated. A very important aspect of this continuity refers to the closest possible involvement of the appropriate family member(s) as far as crucial decisions in the service process are concerned.

### Concluding Considerations

It is obvious that integration, dispersal, specialization, and continuity are inseparable. Dispersal permits the development of small living units in neighborhoods in which integration becomes possible. Continuity, especially between home and residence, further facilitates integration because it supports those ties that most citizens have to their families.

The far-reaching implications of the normalization principle-- simple as it is--should now be apparent. Unfortunately, the simplicity of a term or concept is not necessarily an asset when one considers the desirability of making it the springboard for large-scale social action. There is a danger that people will brush aside a concept they consider simplistic and self-understood, without bothering to explore its concrete implications. It is therefore particularly fortunate that in 1966, David J. Vail, a well-known psychiatrist and administrator of the mental health and mental retardation facilities in the State of Minnesota, published a book entitled *Dehumanization and the Institutional Career*. In this brilliant work, Vail provides a detailed documentation of the many ways in which our institutions serving the mentally ill or the mentally retarded go about stripping from the residents their human dignity, their identity, their motivations, their privacy, their basic human rights. In short, not only does Vail's book provide the most cogent reason for adoption of the general concept of normalization, but item by item it would be possible to put into juxtaposition for every example of dehumanization given by Vail a corresponding situation characteristic of the process of normalization.

Several of the contributions to this volume make it very clear that the principle of normalization applies to the parents as much as to the mentally retarded himself, and indeed to the role of the family as the generally accepted social setting for interaction between parents and their children. Since Cooke's free choice principle essentially aims at assuring for parents of mentally retarded children the kind of access to a multiplicity of services which usually is (or ought to be) available to individuals in our society who are faced with a problem, it appears to have a straight logical relationship to the process of normalization. This is underlined by the fact that even though Sweden is almost wholly committed to public services, Nirje in his chapter specifically speaks of the desirability that parents have available to them choices in making decisions on behalf of their retarded child.

But what is the relationship of Wolfensberger's cost-benefit scheme to the normalization and free choice principles? At first glance one may be tempted to see a basic contradiction between free choice and the bureaucratic decision-making apparatus through which Wolfensberger's principle would have to be carried out. What needs to be emphasized is that his proposal is predicated on a human management approach, an approach which is based on human factors such as the psychological needs of the child and the parents, and the best way to meet them. To imply that his proposal would allow a bureaucratic organization to force the parent to select whatever course of action is cheapest is to pervert grossly his proposition. To the contrary, he rightly points out that in many cases today, parents are pushed or led into wrong decision-making simply because they had no access to



information which would have spelled out for them the entire range of alternatives of care available to them in planning for their retarded child.

#### Strategies of Change.

Throughout the United States, one can observe isolated examples of excellent specialized programs for the mentally retarded which have been in existence for many years, but which have not been adopted or adapted by other states or communities. A large number of professional workers, representing many disciplines, have written reports on outstanding services for the mentally retarded in other countries, and have furnished elaborate documentation through the printed word and photographs. Numerous committees and commissions in many states have reported on needs and available services for the mentally retarded, and have made sweeping recommendations for improvement. Of particular significance, of course, was the nationwide effort towards comprehensive statewide mental retardation planning which was a very important piece of the legislative program of President Kennedy enacted by Congress in 1963. Yet, with all this, progress has been slow, and has been particularly unsatisfactory in the area of residential services. Therefore, it is of great importance to search out and identify those phenomena which appear to constitute obstacles to change, and those which might facilitate it.

#### Obstacles to Change

The Societal Role Perception of Retardates as Deviants. The still widespread perception of the retarded person as a menace or a subhuman organism provides a particularly prominent obstacle. Fear of the mentally retarded has led community groups to protest not only the location of a workshop or a hostel for retarded young adults in a given neighborhood but even the establishment of nursery classes in public school buildings.

Usually, various role perceptions underlie use of terms and language which can be change inhibiting. A typical example is the language of the medical model so well described by Wolfensberger; this language constitutes a major obstacle to the conceptualization of a nonmedically oriented residential developmental program for those retardates whose primary needs are not in the health area.

The Momentum of the Current Service Pattern. The sheer extent, size, and monetary value, and the economic utility to certain communities, of the current physical plants, facilities, and services for the mentally retarded tend to block or delay action toward change. On the one hand, the objecting vested interests are very strong, and on the

other, changes, in order to be effective, have to be of a radical, almost revolutionary rather than evolutionary, nature.

The major professional organization in the field, the American Association on Mental Deficiency (AAMD), which could exert a powerful influence on the course of events, unfortunately has traditionally, and to a large extent to this very day, been oriented towards the conventional, institutional model. Thus, AAMD has tended towards the endorsement and strengthening of the present system rather than to a searching appraisal of the degree of its continuing usefulness and to the identification of the service areas which need restructuring. The recently introduced AAMD program for nationwide evaluation of state institutions for the mentally retarded is symptomatic of this situation. This evaluation system is oriented toward quantitative improvements in current institutional models rather than towards qualitative change through innovation. Even at that, there are no provisions for censoring or incisive reprimand for even the most undesirable, most dehumanizing practices. Indeed, the procedure of having institution superintendents evaluate each others' institutions could have resulted in little else.

Another problem develops when a state, or planning area, becomes too rigidly locked in on a long-range plan. Even when a new approach is developed, those in the system may be so involved in implementing it and in giving or developing services that there is lack of time and opportunity for thought and re-evaluation which might identify needed change. This relates to an often-observed resistance of institutions to consultations on a system level. Consultation at this systemic level can address itself to policies, basic concepts, priorities, and organization, and changes in these areas can often lead to more effective utilization of existing limited manpower, and to great improvement in services on the clinical level. Instead, less effective assistance and consultation on the clinical level alone is much more frequently sought and more readily accepted. Yet services at this level can be extremely inefficient or even futile if the basic systemic structure and process of the agency need change.

Obstacles to change are by no means to be found only in projects started long ago. Planning of recent origin can and does contain such obstacles, and the risk is particularly great when the planning includes residential facilities. For instance, Connecticut has justly received considerable accolades for pioneering a community-oriented regional system of programming for the mentally retarded. The focal point of Connecticut's regional system is the regional center. As Klaber points out in his chapter: "...in theory, a regional center could function in rented space in an office building with its director and coordinators never giving direct assistance to *retarded persons*." In the early stages of developing this plan, the Connecticut authorities, however, decided to structure the regional center as a building complex including a "small" residential facility accomodating up to 250 beds. The

resultant problem--the tail wagging the dog--appears to bear out a theoretical formulation, developed by Sarason in this volume, which refers to situations where the overall purposes of a setting become secondary to the purposes of its component parts. Sociologists recognize a similar phenomenon in the conflict between latent and manifest (the real and the apparent) functions of organizations.

Administering a "little institution" housing 100, 150, or more individuals is a major responsibility which invariably brings with it tasks of an urgency which must take precedence over tasks related to situations where the responsibility for 24-hour care rests elsewhere, e.g., with the family. Once the regional system is thus tied to centers where administrators, planners, and staff are confronted with constant and immediate responsibility for a sizable group of handicapped residents, its potential to change and to develop other service alternatives is gravely jeopardized.

Looking at the problem of change from a broader nationwide perspective, it seems that one can characterize the present development of mental retardation services in the United States somewhat as follows: although there has been widespread advocacy for increased emphasis on nonresidential services, the need for residential services is perpetuated and reinforced by the placing of a low fiscal priority on nonresidential services and a high fiscal priority on maintenance and construction of residential facilities. This results in a shortage of nonresidential services, which, in turn, leads to an accentuation of the urgency for the creation of additional residential services which are storing up an ever larger number of individuals, since those ready to return to the community cannot be released because of the inadequacy of the supportive nonresidential services. A vicious circle, indeed.

Legalism as Change Inhibitor. A number of well-intended but rigid legalisms have interfered with change and progress. Originally designed as protective measures, they now produce an overprotection that is in striking contrast with rehabilitative needs. Typical of this are cumbersome procedures for commitment, admission, and various forms of release, and building codes such as those which make it virtually impossible to construct group homes which do not contain dehumanizing features.

Staff Concern With Job Status, Job Security, and Job Opportunities. In the past, institution attendants were generally among the lowest paid state employees, frequently had to work long hours, were excluded from civil service benefits, and lacked union organization. While pay, and in some jurisdictions hours, may still leave much to be desired, attendants are now more frequently protected by either union organization or civil service or by both. However, civil service regulations and union agreements have a tendency to become rigid and thus interfere with innovative and flexible programming.

On the professional side, a similar phenomenon can be observed. Certain medical and nursing groups have staked out jobs as their preserve and vigorously resist changes in programming that could lead to more dynamic and diversified services, since their group might then lose jobs, roles, and status of which they may now be the only holders.

Denial of Reality. The need for change can be effectively repressed by denying unpleasant realities which would underline the urgency for change. For instance, it is considered bad form for workers in the field to publicly label the gross inhumanities which are being committed upon residents of institutions. Those who expose the atrocities will find themselves much more sharply attacked than those who commit them. Blatt and Kaplan's (1967) *Christmas in Purgatory* is one example, and another from a related field is the excellent documentary film *Titticut Follies*, which depicts the process of dehumanization in an institution for deviant offenders. Even Senator Robert Kennedy had to experience that the people of the State of New York had very little interest in listening to an account of the horrible conditions existing at a large state institution located within the boundaries of New York City,, and they were even less inclined to do something about them. The reference in Sarason's chapter to "eyes that do not see, ears that do not hear, minds that deny the evidence before them" is very much in place here.

One paradoxical but successful maneuver has been administrative protests against invasion of the privacy of institution residents, hereby blocking exposure of institutional practices which result in routine denial of privacy, rights, and dignity of residents.

A kind of patriotism, state chauvinism, or even parochialism also plays a definite role: the great state of . . ., proudly proclaiming its preeminence in industry, finance, culture, and education, cannot afford to let it be known that with all its riches, its glittering state office buildings, its highways and freeways, it treats in its institutions human beings, children among them, day by day in inhuman ways.

Chauvinism was even apparent in reactions to early drafts of this volume, because it has drawn heavily on contributions of foreign thinkers in the field. This offended the sensibilities of a number of people. One objection raised was that cultural differences are such that experiences and practices in foreign countries have little or no relevance to us. Such reasoning can be seen only as defensiveness.

It should be obvious to any reader that while many program specifics may be culture-bound, many other program specifics, and above all, program principles, are very generalizable and probably even universal. Thus, the normalization principle first developed in Scandinavia appears to have universal validity. Comprehensive services,

under a single administrative umbrella, for clearly defined, relatively small, geopolitical units such as cities or counties, as exemplified by Copenhagen, and by Malmohus and Essex Counties, are clearly applicable to the United States, as is apparent by the Connecticut program.

Progress as an Obstacle to Change. While technical progress usually is change producing, it can sometimes serve to strengthen the status quo. An all-too-typical example here has been the routine dispensing of tranquilizers and similar drugs to large numbers of residents in institutions for the mentally retarded. On the face of it, this seems preferable to the traditional method in poorly managed institutions of having large numbers of residents in handcuffs or straightjackets. However, the "modern" drug method permits human managers to take advantage of easily accessible and easily imposed external control, dispensed as needed medication, rather than to develop programs which place reliance on human interactions and which teach the residents internal controls.

Bureaucratic Subversion of Public Policy. Public policy is usually identified by programmatic statements emanating from top public officials or governmental commissions and by preamble statements of statutory enactments. A more realistic appraisal of "true" public policy can be achieved, however, through a comparative review of budget requests and legislative appropriations. Pursuit of the second approach will show that despite about ten years of constant emphasis on the development of nonresidential facilities in the community on the part of public officials, commissions, professional and civic groups, efforts to enlarge such programs are usually met with the greatest resistance, whereas hundreds of millions of dollars are made available for new construction (and inevitably increased maintenance costs) of residential facilities. Legislative discussion, if any, centers on how many institutions or how large an institution can be afforded, and hardly ever on a searching realistic exploration of alternatives to residential care. The phenomenon we observe here is known to sociologists as "system maintenance": bureaucratic structures develop a powerful drive for self-perpetuation and repulsion of outside influences which might be change producing. Expressed public policy raises the citizen's hopes, but then frustration sets in as the bureaucracy substitutes emasculatory changes in place of the "true" public policy.

The fact that proper attitudes are so essential to the change process may explain why a number of small states have made great progress,

Institutions in the United States are under a barrage from drug firms whose "detail men," aided by various enticements, push for a steady increase in the use of a large variety of drugs. The situation is such as to suggest the need for a nationwide survey of the use of drugs in institutions for the retarded, and the relationship of drug usage to the promotional practices of the drug firms.

while some of the worst institution conditions are found in some of our largest and richest states. In a small state, a mere handful of persons in key positions need to possess good attitudes; in a large state, a hierarchy of hundreds of individuals may stand between a new idea and its implementation.

### Facilitators of Change

From the foregoing review of obstacles to change, we now proceed to define means and ways of facilitating the change process.

Change Orientation. First and foremost, it is important that those associated with institutions, no less than those associated with any organization or agency, attempt to make a conscientious and sincere commitment to the process of change. Change must not merely be allowed to happen, nor does it suffice to develop a vaguely favorable attitude toward it. What is needed is the adoption of conscious strategies of change, especially strategies that appear to be consistent with sociological knowledge and established experience.

Likert and Lippitt (1953) identified certain conditions that must exist before people are ready to utilize the methods and findings of science. One of these ingredients is problem sensitivity, i.e., there must be awareness of shortcomings and problems in prevailing practices. Another ingredient is a belief that there are better ways of doing things. These two conditions are probably complementary; if one truly wants to improve things, one should first perceive and admit the existence in one's field or agency of inadequacies, archaisms and anachronisms, lack of validity of theories and procedures, and inefficient, perhaps invalid and even harmful, practices.

Strengthening the Empirical Orientation of Services. As Wolfensberger has pointed out in his discussion of cost-benefit rationales, the introduction of a service system built on these rationales would make it necessary to consider research as an integral part of service operations. One of the many advantages of a service system incorporating cost-benefit principles is that by the very nature of cost-benefit operations, the system will be tied to research designed to evaluate the comparative validity, benefits, and costs of alternative service practices and options. Inherent in such research is quality control and the ascertainment of the degree to which day-to-day procedures of management are consistent with the stated policies of the agency.

However, large-scale operational research in institutions for the mentally retarded has been comparatively rare to date. Granted that research can not be straightjacketed in a rigid operations schedule, and that we must put a premium on the creativity of the research worker and therefore grant him sufficient freedom and independence

in his pursuit, what could be more uneconomical than the hundreds and thousands of small ad hoc research studies undertaken disjointly and haphazardly in the hundred-plus institutions for the mentally retarded in the United States.

If we wish to underpin consideration of needed changes in mental retardation programming in general and in residential services specifically with solid research findings, there is first of all the need of posing the right questions to the research workers. Since studies aimed toward change must of necessity include an assessment and analysis of that which is to be changed, we are back at a point repeatedly treated in this chapter and book, namely, the reality of the present inadequacies in institutional care. To assess these fully, the research staff must be given free and unhindered access to the totality of the institutional situation without exception. Important as these research efforts are, their value will be limited by the fact that, of necessity, they must be largely retrospective. All the more it is necessary to provide generous federal financing for evaluative research to be built into new designs for human management practices and facilities.

The term "built-in research" should be applied rather literally to the construction of new facilities. Questions as to the desirable size of units, the number of people in different age groupings to be accommodated in one bedroom, the size and shape of rooms, the type of furnishings, the influence of acoustics or the type of floor covering, dining procedures, the proper arrangement for sanitary facilities, etc., will eventually be answered with greater certainty if the administrator, the architect, and the research worker, supported by the appropriate behavioral experts, will work out a scheme whereby different "settings" will be created so that these can be compared in terms of their effect on residents, staff, and cost. With availability of federal financing it should be possible to conduct collaborative and/or parallel research projects simultaneously in several states.

In sum, federal funds should be made available to test out on an experimental basis in one or two states (preferably of relatively small size) Wolfensberger's decision-center model operating under a cost-benefit rationale. The cost-benefit rationale should also be applied to an appraisal of federally supported research efforts in the field of mental retardation generally. It is always somewhat dangerous to guess in advance the result of a research assessment, but there have been some very definite indications that the millions (one could probably say scores of millions) of dollars spent in recent years on research, quasi-research, and evaluation projects have provided us with very limited returns. Partially, these limited returns are probably a result of the cautious, conservative, and unimaginative research grant proposals which have been elicited, reviewed, and approved. The question which suggests itself is whether we would not be further ahead in

practical knowledge if money had been made available from federal sources for some carefully evaluated projects of daring experimentation with innovative services.

Federal funds should be appropriated for such research, and special procedures should be instituted to elicit and review bold, imaginative, innovative, and well-designed research and evaluation proposals in the service area. One possible mechanism would be to convene one or more conferences of innovative thinkers in the field in order to discuss and define ideas and proposals. Some of these proposals could then be selected for implementation, and workers in the field could be encouraged to submit, specific proposals that could be reviewed competitively in regard to quality of design, cost, and likelihood of the applying investigators and agency to be able to carry out the study.

Encouragement of Healthy Controversy. Vigorous exchanges of viewpoints, and the airing of far-out concepts, new and old, appear to be an important medium of change. Thus, disagreement over practices and policies should be encouraged rather than inhibited. Such controversy should be encouraged even if it may be at times painful, unpleasant, or embarrassing; the field has been much too apt to be concerned with the feelings of **the** administrators of institutions rather than with the feelings of the inhabitants. The American Association on Mental Deficiency in particular owes it to its professed objectives to enter actively into the many controversies which have been raised in recent years and to use the pages of its journals to reflect these issues. When institutional mismanagement, brutality, and indolence occur newspaper exposes perform an essential public service; however, of necessity they are "shot from the hip," and therefore all the more the profession should discuss in its journals the vital issues concerning practices in administration, rehabilitation, and therapy which are put into question through these "explosive" situations,

By the same token, institutions should actively seek the establishment of study and review committees, rather than having investigations and reforms thrust upon them. Such committees can be established to concern themselves both with the institution as a whole as well as with specific departments or activities, as suggested by Blatt.

Governmental Study. A mechanism of which the present book is a manifestation is government study, both on the national and the state level. Such study on a long-term basis is likely to have very salutary effects on the field. Already the federal government has made a vital contribution with its sponsorship of the President's Panel on Mental Retardation and the President's Committee on Mental Retardation, and its support of a nationwide effort for statewide comprehensive mental retardation studies. However, the very



comprehensiveness of these studies on the one hand, and on the other, their coverage of only one state at a time, constituted a severe limitation. What is needed are studies jointly sponsored by the federal government and a number of states which will analyze, on a comparative basis, certain acknowledged problem areas in the field of residential services for the mentally retarded, leading to meaningful recommendations which relate to the reality encountered in the studies.

On a national level, relatively narrow but important areas within the broader scope of the subject matter might be singled out for study. For example, the President's Committee could sponsor the development of a handbook on normalization, spelling out in as much detail as possible, normalizing features of services and buildings.

Change in Governmental Granting Practices. The government can do much more than appoint study groups. It can give new directions by exercising greater discrimination in its granting practices. Federal legislation is needed which not merely encourages new service patterns but discourages continuation of the old ones. If the federal government will undertake the kinds of study suggested above, there would be increased likelihood that Congress would make it possible for government agencies to award grants more selectively. Thus, grants could be awarded to institutions that have shown evidence of their willingness to change, rather than to make awards in the hope that these will lead to change. Those states could be given priority which are actively supporting dispersal and integration of residential services, rather than states which continue to enlarge existing large institutions, or which place new residential facilities in remote locations.

Parents of Retarded Children as Change Agents. Aside from brief references in the chapters by Bank-Mikkelsen, Grunewald, and Klaber, relatively little has been said in this volume on the role and functioning of parents of retarded children in the field in general and in residential services in particular. Yet the official record will show that in Denmark, in Sweden, and also in Connecticut the associations of the parents of the mentally retarded not only played a most significant supportive role in the development of the service models described in this book but entered into the preceding conceptualization and social engineering in a very decisive way.

There are many other examples from the international scene showing parent associations as effective change agents. In the United States, the National Association for Retarded Children (NARC), with its research fund and distinguished research advisory board, contributed substantially to a change in scientists' view of this field as a legitimate and worthwhile area for scientific inquiry. From Canada, the Ontario Association for Retarded Children mobilized international interests in the special physical training needs of mentally retarded

children and adolescents. In Western Australia, it was the parent associations which introduced a specialized clinic for the study of the mentally retarded in a setting since taken over by the state. In England, the National Society for the Mentally Handicapped contributed substantially to a change in service concepts for the severely retarded by the establishment of a national training center and hostel at Slough and of vacation and short-stay homes. Finally, in a symposium held in Stockholm in 1967, the International League of Societies for the Mentally Handicapped developed new formulations of the individual rights of the mentally retarded which have been recognized widely as the forerunner of a whole new conceptualization in the field of mental retardation, underpinning the broader concept of normalization.

Yet there has been and still remains in some quarters considerable uneasiness about an involvement of parents of the mentally retarded in the development and administration of services and in planning for change. Administrators are far more ready to extend to them their sympathy, guidance, and concrete assistance than to acknowledge them as active participants in the process of social programming. On occasions when representation of citizen interest on civic bodies, committees, and study commissions is involved, the opinion is likely to be voiced that representation from the parent association is not desirable, since they are too close to the problem. Yet when it comes to discussion of agricultural problems, farmers are not content with having leading citizens represent them, and physicians will not even recognize committees dealing with health matters on which they are not prominently represented. One often hears the stereotyped objection that parents and parent groups are interested only in immediate solutions and lack or are unwilling to apply long-range viewpoints. Yet the same can be said of administrators of public programs, and in recent years parent associations have repeatedly objected to the expediency of make-shift relief measures and insisted on adequately thought-out, long-range programming.

Unfortunately NARC has lost much of its original forcefulness, and particularly in the area of residential care it has not been aggressive enough in informing the general public, legislative bodies, and key professional organizations of the disgraceful situations in our state institutions, involving gross violation of state law and state standards, gross lack of the most essential pieces of clothing

An example of this occurred in Illinois, where the parent association successfully objected, in spite of long waiting lists, to the construction of an additional residence building on the grounds of an already over-large institution, even though they were informed that their objection might delay availability of additional bed space.

and bedding, gross violation of residents' civil rights, and instances of cruel and inhuman punishment, unjustified use of restraints, and prolonged detention. Of all these matters no one has a more penetrating knowledge than NARC's membership, but not enough has been done to use this knowledge strategically for the ultimate benefit of the institutionalized mentally retarded children and adults, who are so desperately in need of a forceful advocate.

Volunteer and Citizen Contribution. A vital factor on the American social scene is the volunteer, and in this particular context, the volunteer who as an interested citizen activist gives freely of his time to participate vigorously in organizing, guiding, and critically reviewing and appraising human welfare services in his community, his state, and his country. As an independent citizen without vested interests in the subject matter, he is often an ideal person to call to public attention disturbing developments which require change, such as the existence of dehumanizing, unworthy, or inadequate services to other human beings. To the degree that it requires controversy to accomplish this, he can and should create such controversy. To the degree that sustained publicity is required to elicit public concurrence, he is in a position to develop it. In the role of ombudsman, adopted from the Scandinavian model, he can introduce a new pattern of safeguarding the rights of the mentally retarded, of their parents, and also of those who work with the retarded. Citizen volunteers can perform an invaluable service by gaining the support of individuals or groups in the community who for various reasons are opposed to the initiation and maintenance of services and facilities on behalf of the mentally retarded. Without the help of volunteers, change may be long delayed; with their active participation, change may be considerably accelerated.

It is of vital importance that there be always consumer groups and citizen activists who retain their freedom to criticize the established agencies and policies. Thus, such consumers and activists should be careful not to be maneuvered into situations of financial or other dependency upon the agencies they should survey. However, agencies such as institutions, state departments concerned with institutions, and other service systems could increase their orientation to change by employing some intelligent, alert consumers as well as attorneys as staff members in order to actively seek out ways of safeguarding the rights and welfare of the clients, investigate complaints, and communicate with citizen and consumer groups.

If, in this fashion, citizen volunteers, consumer groups, professional organizations, and government collaborate as equal partners on the local, state, and national level, they will constitute a powerful force for change and for accomplishing a vital social task.

Needed Crash Programs. In a consideration of the entire problem of change, and of the most feasible and appropriate ways of bringing change about, there is one painful aspect that has to be faced. This is that conditions in some institutions are so bad that sudden revolutionary, rather than slow evolutionary changes are needed. When a natural disaster occurs, citizens and government will respond with a crash program. Some of our institutions are disaster areas, and require emergency measures for change.

However, mere money cannot bring about the needed changes. Among the greatest obstacles are the attitudes in the minds of those who administer institutional programs, not merely those on the institution level but also those on the state level. It may be necessary to remove from office those individuals who see retarded persons as subhuman, or as human but primarily as menaces, as diseased organisms, or as incapable of growth and adaptation. In their place, it is essential to have individuals who see the retarded as human beings, as citizens, and as developing, adaptive persons.

Here, it is worthy of note that among present program administrators, Vail's (1966) book on dehumanization and Blatt and Kaplan's (1966) pictorial demonstration of the subject have not produced much apparent effect. Can the field trust those who are so comfortable with the status quo? Can it rely on them for leadership toward the needed changes? How is one to utilize persons who do not perceive the evidence before their eyes and ears?

Needed Documentation. Early in this chapter we have discussed the sad consequences of the unwillingness to face the realities of cruel, harmful, and inhuman treatment in institutional settings. Through recent years the opposite has also been noted by competent observers in this country: an unwillingness to acknowledge the validity and indeed the existence both in our country and abroad of new and vitally different service measures and facilities, and of their success. Obviously, what is needed is careful, comprehensive and convincing documentation, documentation that can not only be utilized to persuade responsible administrators, legislators, and citizens leaders, but that can also be utilized to train staff to assist in the change to new approaches, procedures, and techniques. The motion picture or video camera in the hands of a skilled and sensitive photographer who is, in turn, guided by a small team of experts can bring back results which will be well worth the expenditures, particularly as these results can not only be made available so readily on a nationwide basis to residential facilities and the responsible state departments but can also form invaluable teaching tools in various institutions of higher learning.

## Human Management Programming

Human management seems to be a most appropriate vehicle to introduce the concept of normalization into the service delivery systems on behalf of the mentally retarded. In this section, an attempt will be made to reinforce points stated elsewhere in this chapter regarding the change and reorientation that must be effected in our pursuit of these new objectives.

Obviously, normalization for the mentally retarded individual can best be maintained and safeguarded if this principle is brought into play at the very beginning of his lifespan. And this, of course, implies that normalization must govern and apply equally to the parents of the mentally retarded child. A great deal has been written on what needs to be done to improve counseling and informational services to parents, particularly at the time they are informed of the fact that their child is or is suspected to be mentally retarded (for an exhaustive survey of this, see Wolfensberger, 1967; Wolfensberger & Kurtz, 1969). But very little has been done and is presently available to assist the parents in their child management, particularly in cases of severely and profoundly retarded children, who often manifest even in the very earliest developmental stages special needs, and who create special problems which are most disconcerting and puzzling to the family.

The beginnings of the process of dehumanization become quickly evident when institutional placement is recommended for a severely impaired infant who at that particular time does not offer special management problems, as is common with the child with mongolism. Not only is a low level of expectation urged upon the parent at a time when there is little clinical basis for such prediction but services are withheld or put into question which would be extended to other children as a matter of course. The key slogan, so well known to many parents, is the phrase "Why bother?" Why bother with remediation of minor physical defects, why bother with intensive health supervision, why bother with feeding problems, etc.? And all too often in the background there is the question, Why keep him alive? Usually, this is unspoken, but in 1968 a professor of theology wrote in one of America's most sober magazines: "In dealing with Down's cases, it is obvious that the end everybody wants is death," and he made quite clear that he meant death by the physician's hand, at or immediately after birth (Bard & Fletcher, 1968).

Of course, the cautious member of the medical association is not likely to make such a drastic pronouncement in a specific case, and is even less likely to act on it. Instead, he may accommodate himself with the recommendation that the child be immediately placed in an institution, often coupled with the suggestion that the mother not see the child. Official policy notwithstanding, this is still an

all-too-frequent occurrence in the United States. It is not the point of this discussion to judge or belabor the difference between the physician who practices euthanasia at birth, the physician who recommends lifetime banishment to an institution, and the physician who waits for the first serious illness as the appropriate opportunity to terminate life by withholding available therapy. The emphasis here is on the broader implication of this viewpoint, which, in a less acute form, simply conveys: my practice (or our clinic) is too valuable to be concerned with "this type of case." And in the process, the parent is segregated and de-normalized along with his child.

Thus, human management service in mental retardation must be predicated on the availability to the parent of the same array of diagnostic and informational, therapeutic and supportive services that a forward-looking community must make available to all its infants and young children. The fact that the mentally retarded child may need more of these services and need them in greater intensity than the average child should not mean that parent and child are segregated into a special service from the time of the child's birth.

For the mentally retarded child, next in importance to maintenance of life is maintenance of his place within the family, even when clinical, educational, social, or rehabilitative factors may require his physical absence from the home on a short-term or a long-term basis. An important implication of this for human management is that the parent should participate to the greatest possible extent in significant decision-making in all stages of programming. And it needs to be emphasized that this should extend even to significant decisions made in and by an institution where the child may be a long-term resident.

Participation of parents in the decision-making process relative to human management services on behalf of their child should be paralleled by a continuing effort to maintain and strengthen the ties between the child and the family during periods when removal from the home is necessary. Even though it may appear trite and redundant to state once again that services away from home should, with very rare exceptions, supplement rather than supplant the role of the family, there is a real need to emphasize that the parent should have access at all times to his child, and every effort must be made (including subsidy where this is necessary) to have the child visit back in the home during periods of residential care. Frequent, sometimes prolonged, visits have proven their value in preventing undue prolongation of residential care.

At present, there is widespread belief that the current ratio of about 1.0 residential place per 1,000 persons in the population is inadequate, and the length of institutional waiting lists are

frequently cited as evidence. Also, it is widely believed that the need for residential places is related to the desire of many parents to sever themselves permanently and completely from their severely and profoundly retarded children. However, there is good reason to believe that to a significant degree the present demand for placement is increased by four extraneous factors:

1. The inadequate or even misleading counseling given to parents at the time they first become aware that they have a severely handicapped child.

2. Prevailing negative community attitudes toward severe disablement.

3. The severe degree of frustration within the family engendered by a lack of community service, including appropriate medical services, which would diminish the family's burden.

4. The deplorable conditions of institutions, and especially the offensive and literally sickening state of the wards for severely disabled young children, which produce in the family on the one hand revulsion and, on the other, feelings of guilt; both reactions quite naturally contribute toward increasing separation from or abandonment of the child.

Thus, despite the overwhelming evidence that has been publicized over the past 10 or more years, it is still unfortunately necessary to emphasize that the stated need for residential services for the mentally retarded must be related to the absence of basic human management services in infancy and early childhood. While some people may feel inclined to dispute this statement, its justification is easily demonstrated by a realistic and objective yardstick: money appropriated for this purpose from local, state, or federal public funds. The facts in this regard have been stated over and over in this report: money is available to the tune of hundreds of millions of dollars for construction or renovation of institutions, but is most scarce and in many areas of the country totally nonexistent for the development of such supportive services for the family as home consultation and guidance from public health nurses, nutritionists, physical therapists, and child development workers; homemaker services, babysitters, day care or occasional night care; and short-term residential care where there is need for crisis intervention or planned relief for the family.

A plan which was recently approved in principle and supported with an appropriation by the Douglas County (Omaha, Nebraska) County Commissioners specifically proposes the establishment of a Crisis Assistance Unit (CAU), with 12 beds for short-term residential care during family crises. The CAU would also provide less than full-day

residential care both for crisis and stress relief, and thus give parents the reassuring knowledge that there was a "back-stop" service to aid them as need would arise (Greater Omaha Association for Retarded Children, 1968a, 1968b).

Another innovative service worthy of experimental government support is vacation homes. Under NARC or other sponsorship, a series of camps and homes could be set up at strategic locations. These facilities would specialize on providing vacation resources. One would think that even if the full cost of such a service had to be borne by the parents, there would be enough of them to support several such facilities if they only existed or were well known. The utility and success of such vacation homes has been amply demonstrated in other countries such as England, Germany, and Scandinavia.

Tizard (1968) and Klaber in this volume have found that it is the social organization of our present residential institutions for the retarded which is the main factor responsible for the poor quality of care which many of them provide. This highlights the need to direct our attention to the extent which the traditional hierarchical staff organization at institutions for the mentally retarded has brought on a situation deleterious not only for the resident but also for the basic care staff. Adequate human management requires that priority be assigned to the upgrading of this basic staff with whom rests the greatest share of day-to-day contact with the residents. Upgrading must occur in terms of salaries, qualifications, and last but by no means least in terms of status both in relation to the rest of the staff and in relation to parents and to persons outside the immediate realm of the residential facility.

As an example of needed change, reference can be made here to the regulation, still in existence in many institutions, that the basic care staff is not to discuss the residents' functioning, that this may be done only by the physician or another designated member of the administrative staff. It is encouraging that from within the ranks of the basic care personnel has come recognition of the anomaly of their situation (Carter, 1968).

The normalization principle also provides helpful orientation as to which type of staff should render human management services in residential centers. Obviously, mentally retarded residents with acute medical and nursing problems should be cared for by a highly qualified nursing staff. Similarly, special psychiatric services must be available to children and adults with severe behavior disturbances. However, as has been brought out innumerable times in recent years, a very considerable percentage of children in these institutions do not have such problems, and therefore the obvious answer for them is to have staff acquainted with good common child care as long practiced in good children's homes. Tizard (1968) and his



colleagues in England have likewise stressed a need for a child care orientation in institutions serving mentally retarded children, and have put into question the suitability of a nursing background.

Unfortunately, discussion of this very crucial subject matter in terms of planned change meets two critical obstacles. One that will be dealt with in a later section of this chapter pertains to job security and union rights. The other is a more subtle point: a hesitancy on the part of administrators to put into question a nurse's qualifications to care for children on the one hand, and, on the other hand, to face the nurses' displeasure for having questioned their suitability for the task when their devotion to sick children has been so amply demonstrated.

The point, of course, lies in the very word normalization: mentally retarded children need a normal environment and not the formal environment of nursing which has been developed in our hospitals. A good example of this formalism was encountered in the planning for a new residential facility in an eastern state. The plans centered on small units serving eight individuals with two of such self-contained units within each building. Even though these buildings were designed for an ambulatory group, the supervisory nursing staff insisted not only that in each of the self-contained units of eight there be a nursing station, but in addition that in each building there be a separate nursing office, even though in each of the units of eight there was provided a staff sitting room with adjoining toilet. The formal trappings and prerogatives of the nursing profession had to be preserved at all costs.

Normalization in human management services runs counter to an expedient employed with increasing frequency, namely, the all-purpose center designed to meet in one building-complex and often under one roof all the needs of the mentally retarded. Normalization implies the kind of separation of functions usually encountered in normal living. Children leave home to walk to school. Adults leave home to go to work. As Norris points out, this separation of function also implies that the child should not encounter the houseparent in the classroom in the role of a teacher. Implications of the principle of normalization in terms of the child's physical surroundings in residential care are discussed in a separate section devoted to architectural considerations.

## Administration and Financing

### Administration

"Please note that under the mental hygiene law a person defined as mentally defective is one mentally ill and since mentally ill under the Mental Hygiene Law has equal significance with the term mental disease, it follows that an institution that cares for mentally defective is an institution for mental diseases. . . ."

This quotation from an August 8, 1967, letter from the New York State Department of Social Welfare and pertaining to a private residential facility serving retarded young adults engaged in agricultural and industrial work projects illustrates a major source of the administrative problems that have been and are encountered in the development of mental retardation services. Administratively and fiscally, the mentally retarded person is claimed by the psychiatric profession as belonging in the realm of mental illness, but literature, service statistics, and psychiatric training abound with evidence that scientifically and clinically, psychiatry has been indifferent to mental retardation and largely still continues to be so.

In all the larger states of the Union one can observe a long-standing tradition that the problem of mental retardation belongs into the power structure directed by the psychiatric profession, i.e., into a department or division of mental health. As a logical consequence, the claim is made that institutions serving the mentally retarded are psychiatric institutions and must be developed under the medical model, i.e., by staffing key administrative positions on the state as well as institutional level with medical personnel and by viewing, interpreting, and structuring institutions like hospitals. Against this administrative construct stands the reality of the institution-made-to-look-like-a-hospital: the day-to-day routines encountered by the residents are not merely overwhelmingly devoid of the procedures of what the literature considers good psychiatric management, but are in many ways grossest violations of accepted psychiatric principles. Furthermore, the majority of the persons in institutions (excepting a few specialized facilities) are rarely in need of acute medical care, nor do they have acute psychiatric disturbances except for those that have resulted from the deleterious climate of the institution itself. The personnel problems which arise from this paradox of medical power structure in an essentially nonclinical setting will be reiterated in a later section on manpower. What needs to be added here is that typically the strongest force next to the superintendent is that of the business manager or steward who is geared to efficient management.

Efficient management is without doubt a useful concept but only if there is clarity as to the objective of such management. The irrationality which characterizes the management of residential facilities for the mentally retarded in this country is that it is related to the narrow mechanical objective of maintaining an institution rather than to the only tenable broad human objective, namely, the rehabilitation, education, and ameliorative treatment of the residents. The first objective considers the institution as an independent, self-fulfilling entity and is strictly internally oriented. The second objective looks upon the institution as one of many interdependent facilities and services, and judges its efficiency primarily in terms of the adequacy of residents' responses to its education, treatment, and rehabilitation programs.

While human management effectiveness is, of course, a universal consideration, it is of the most crucial significance in the field of mental retardation, where, speaking from a purely fiscal point of view, 3 or 4 years of intensive, high quality, multifaceted training and rehabilitation at \$7,000 a year must be contrasted to the alternative of a routine program of institutional "care" over 25 or more years at \$3,000+ a year.

Interdisciplinary Administration. Human management for the mentally retarded involves a multiplicity of disciplines (education, medicine, psychology, nursing, rehabilitation, social work, and others). Yet, true interdisciplinary collaboration is rarely encountered as a pattern of the administrative process. All the more significant is the concept of the directorate sketched by Bank-Mikkelsen in his description of the Danish mental retardation service. From the psychiatric side, Maxwell Jones (1968), the well-known British psychiatrist, recently pointed out: ". . . multiple leadership is probably the most important aspect of leadership, and it is here that there is the greatest need for change. The hierarchical structure of institutions, whether medical, industrial, or political, invest the leadership role with enormous power . . . . Multiple leadership means the distribution of authority and power to many people, and even more important to people who communicate freely in groups . . . . The principles of multiple or group leadership are difficult to apply to hospitals and infinitely more difficult to apply to the community".

While the principles of dispersal and specialization recommended throughout this book would lessen the problem of multidisciplinary leadership, the process of regionalization will definitely bring this problem increasingly to the forefront, because the regions will encompass a wide array of services under different professional auspices. Already we have witnessed that in spite of an initial recognition at top level of the separate needs of mental retardation and mental health (mental illness), the procedure adopted in several states has been to make the regional mental retardation director subject to the supervision

and direction of the regional mental health director, even though the latter in most instances has little or no working knowledge of or interest in the field of mental retardation.

Regionalization and the Traditional Institution. A considerable problem in effecting a reorientation from the large central institutions to small, dispersed, specialized residential centers derives from the fact that the large institution exists and occupies a position of strength, while the new structures, i.e., the regional and community centers, in most cases must be newly developed and are too small and too informal to counterbalance the large institution. Eventually, of course, the network of community services will constitute a major force, but in the meantime there is danger that the reality and convenience of the existing large institution will suggest unsound modifications of the plans for regionalization, dispersal, and specialization. For instance, it may appear expedient to develop smaller community residences as "satellites" of the large institution, or, similarly, to use the accommodations of the institution as bases for the development of regional services. Obviously it will be difficult to effect the necessary changes toward regionalization and dispersal in a state where the large state institution has for many years been the focal point for services to the mentally retarded.

The absence of effective or appropriate state regulations, standards, and controls of and for state residential services for the mentally retarded has been a serious problem throughout the country. It certainly would be foolish to assume that the greater visibility of the smaller facilities recommended throughout this work and by many previous commissions and reports would obviate the need for regulatory supervision. While regionalization, dispersal, and specialization will assure greater benefits to the mentally retarded, they will create serious problems of management and coordination as compared with the large centralized institution. The mere fact that there will be a large number of residences of differing sizes serving a distinct variety of clients will make it essential to develop standards which will assure programs capable of meeting the needs of the individual residents, proper management, and the needed cooperation with governmental and voluntary agencies within the framework of the continuum of "available care." Therefore, the standards must address themselves not just to the facilities (as is now the case in many states in similar situations) , but must include the program and the resident.

Notwithstanding the development of a large variety of smaller residential centers, states with large population concentrations will most likely continue to have for the foreseeable future large institution complexes. This last term is used to indicate the desirability that there be established functional units which could operate with a considerable degree of independence. However, in order to develop toward the necessary balance between the major types of services,

state governments (and in terms of its granting programs, the federal government as well) should recognize and adhere to the principle that no money be appropriated for any type of residential facility without concurrent consideration of and appropriation for essential related nonresidential services in the community. Owing to the striking differences in structure, organization, function, and extent of mental retardation services and related other services in the various states, it is quite impossible to think of any set formula for the proportion of expenditures for residential to nonresidential services; however, there can be no question that this is one of the most crucial issues faced at this time.

#### Finances

The various proposals which have been made in this volume and before that by innumerable committees and commissions in regard to improvement of mental retardation programming suggest any number of fiscal proposals and solutions.

However, of immediate and paramount importance must be an all-out effort throughout the country to recognize the indisputable need for immediate adjustment of appropriations to make sure that in the future, institutions for the mentally retarded can buy enough clothing so that no resident needs to be naked, no child need be kept from playing out of doors for want of a pair of shoes or a sweater, no resident need freeze at night for lack of a blanket, and that essentials such as soap and toilet paper are available. Each of the examples just cited refer to actual situations in the recent past in the two richest states in this country, and in each case, the official explanation was lack of funds.

Of equal urgency and unrelated to any one specific plan or proposal is the need to raise to an acceptable minimum level the salaries of those to whom we entrust the major share of the rehabilitation, training, and care of the mentally retarded. The disgraceful conditions in our institutions for the mentally retarded, so forcefully pointed up by the President's Committee on Mental Retardation (1967), are related to the disgraceful salary level for basic care personnel. In one state, it was lower than that paid to exterminators of vermin; in another, lower than that of a disemboweler of chickens; and in a third, lower than that of an attendant of a public toilet. There is no escape from the fact that in some states the necessary appropriations to correct these inequities which are such a blot on our nation's record will constitute a definite burden on the public treasury. That is the price of decades of neglect.'

In order to establish a rationale for public expenditures in the field of mental retardation, not only to the average citizen but

to many public officials and legislators, our financial accounting should be linked to social accounting. The cost-benefit scheme proposed in the chapter by Wolfensberger should provide the necessary frame of references. Admittedly our tools for such social accounting of fiscal expenditures in the field of human welfare are quite inadequate as yet, but nothing else is as likely to speed improvement in many states.

New Avenues of Financing. One important feature of several of the new programs suggested by the various contributors to this volume is that they open up new avenues for the financing of services for the mentally retarded. For example, regionalization and dispersal make it possible to combine local and state funds to provide the matching money required under federal law for certain federal monies, some of which may not have been directed specifically to the mental retardation field.

In states where the county has to pay for part of the costs of care for its residents in a state institution, this money could be applied to various kinds of community services, residential as well as nonresidential, with or without state subsidy. Indeed, the shifting from residential care in a state institution to community-based care in the retarded person's own home or in a small community facility opens the way for a variety of federal financing, primarily under various provisions of social security and public assistance programs. Admittedly, there is at the moment a great deal of confusion as to which circumstances may be applied to which provisions (the quotation from the letter of the New York State Department of Social Welfare appearing elsewhere in this chapter illustrated such an instance of confusion), and, admittedly, some of the federal and state agencies involved are not very eager to extend these provisions to the mentally retarded. However, pressure from the local, state, and national associations for the mentally retarded and from interested citizen groups will, in time, enlist cooperation from state governments and local governmental units once these recognize the fiscal advantages, and this should lead to early clarification.

Desirable as it is to gain a greatly broadened financial base for mental retardation programming, it is necessary to caution against what has already happened in several states where unscrupulous administrators have exploited or misapplied provisions of new amendments to the Social Security Act. Thus, there have been moves to shift the residential burden of the state to the federal government by wholesale transfer of mentally retarded individuals into facilities inadequately regulated and unsuitable for them, since they were designed and maintained for persons with a different problem constellation. Here is a good instance where social accounting should negate the fiscal reasoning. Joseph T. Weingold (1968) , executive director of the New York

State Association for Retarded Children, characterizes such a procedure aptly as "using the mentally retarded in the state school as the anvil on which to hammer medicaid funds from the federal government."

Certainly states should make every effort, and indeed have an obligation towards their citizens, to use all available funding sources in appropriate fashion, and censure is due to states negligent in that regard. But considerable significance must be attached to the phrase "in appropriate fashion," and certainly appropriateness must relate itself to the interests and welfare of the mentally retarded person and his family.

Finally the conflict between principle and realism brought forth by the application of the principle of normalization to the area of financing must be recognized. On the one hand, it is desirable that to the maximum feasible extent payments for services for the mentally retarded come from the same source as those for corresponding services for the population at large, while on the other hand, long experience has shown that in any general non-earmarked distribution of funds the retarded are likely to be left out or at least disadvantaged. Temporary earmarking until the service is clearly integrated into the activity pattern of the agency may be one solution.

An Insurance Scheme for Residential Services. Of very considerable importance for future programming in the field of mental retardation would, of course, be Cooke's proposal outlined in an earlier chapter in this book for the extension of our social security system to cover residential and other service costs of the seriously mentally handicapped dependent of a participant in the social security system. As Miller (1968) recently stated in another context: "... the market approach has wide implications because it is supported on the basis of efficiency as well as on desirability of consumers' choice. To what extent does one try to make it possible for those individuals who are involved to make decisions which affect them?"

However, there are some problems which must be considered. First, such a measure might make it too easy to use residential rather than non-residential services, and would thus contribute further towards the unsound imbalance between the two. Second, parents might place their children into residences hundreds of miles away or out of state, even though equally adequate local residences may be available. This would mean that public funds were used to support probably unsuitable and even harmful practices. Third, unless such systems were subordinated to very strict control on either the state or the local level, planning of services would become virtually impossible. The need of and/or for various types of services might become so unpredictable that no economical or longrange plan could be maintained, and nursing home entrepreneurs might choose to locate their services in haphazard

or inappropriate patterns. Finally, such entrepreneurs might have very little incentive for habilitation programs or the utilization of sheltered work settings. Indeed, the scheme might actually inhibit the development of habilitational programming in residential settings, since habilitation would be likely to threaten the entrepreneur's livelihood.

In any case, Cooke has injected new and challenging thoughts into the problem of service delivery in the field of mental retardation. His proposal undoubtedly should be given extensive further study before it is implemented, and such study should encompass a controlled research demonstration in one or a few states, provided that rigid safeguards can be furnished in the form of administration and regulation.

One of the inscrutable incongruences in the provision of care at public expense, not just in the field of mental retardation but in many other fields as well, is that while funds for expensive residential care are readily available, it is most difficult and in some circumstances indeed quite impossible to get public funding when opportune circumstances make it possible to provide for the same individual not only equal but superior care in a private home on a boarding or foster care basis. As Wolfensberger said: "It is indeed ironic that many children have ended up in the high-cost and low-love setting of an institution because the medium love of relatively low cost foster parents was judged as being insufficient by an agency."

A somewhat similar situation exists in regard to adoption of mentally retarded children. Admittedly this is not an easy task, and the utmost care must be exercised to protect both the interests of the retarded child as well as those of prospective adoptive parents. Still, there are people who are able, willing, and indeed desirous to undertake the task of raising a handicapped child, and with the real and expected expansion of supportive services in the community the feasibility of such an undertaking has been very considerably increased. Yet, institutions still admit many infants with mongolism for long-term (and all too often life-time) care involving an expenditure conservatively estimated at something like \$100,000 to \$150,000. A mere fraction of this cost, such as \$30,000, would support a small adoption service staffed by two senior social workers and a secretary for 1 year. If this staff would be able to find in a year's time just one adoptive home for a child otherwise placed in the institution, the total investment in the agency would already have been justified. Therefore, it is highly desirable that states, perhaps with some federal assistance, initiate more aggressive action in this area.



Where Does the Money Come From, and Where Does It Go? Lack of money has been a major stumbling block in the past, but equally serious has been poor utilization of funds that have been available. Indeed, there is no question that the all-too-ready availability of hundreds of millions of dollars for construction purposes without preventive and follow-up services in the community has been most detrimental, as has been premature allocation of money for large-scale programming, construction, etc., when appropriation of a much smaller sum for well-controlled and evaluated community services would have been far more desirable.

As touched upon by Wolfensberger, there exists an "American illusion" that money is the answer to most problems. In other words, if one spends enough money on a defined problem, it will eventually be conquered. This illusion is sadly evident in the attitudes of many defenders of our institutional system. In essence, they cannot conceive of an alternative concept or model--be it residential or even nonresidential. Thus, we hear calls for more institutions, as well as more money for existing institutions, and unfortunately many states are taking this route, often without clear priorities assigned to different categories and alternatives of service.

In early 1967, we were spending at a rate of \$600 million a year for about 200,000 institution residents. However, merely to maintain the standards and rate of current institution services will require a rapid rise in institutional costs. By 1975, we could be spending \$2 billion a year on our institutions, and they could still be most inadequate. That this is a strong possibility is underlined by the fact that some public institutions with the highest per diem expenditures in this country are grossly dehumanizing.

The point is that money alone is not the answer, not to the problem of institutions or to many other problems. What is ultimately more important than money is philosophies, ideologies, and concepts, and a system of priorities based on these.

#### Manpower and Staffing Considerations

Several sections of this chapter have referred to personnel problems in the development of an adequate service system for the mentally retarded, and in particular have emphasized the effects to be expected from programs oriented toward specialization and dispersal of residential services. The following observations and propositions will highlight additional aspects of the manpower situation.

While state government invariably has set unreasonably high standards for the construction of residences, it has shown the greatest resistance toward making adequate allowance for even minimal standards

when it comes to the staffing of these residences.

Throughout this book, references have been made to administrative arrangements and conditions, now prevailing in institutions, which create very unfavorable working conditions. It should be reiterated in this context that particularly in residential settings, careful thought needs to be given to the dignity and comfort of care personnel as well as residents. |

Application of the principle of normalization to the personnel field requires that personnel on any level, working with the mentally retarded, should meet at least the same personal and technical standards as equivalent workers in other settings dealing with nondeviant groups.

#### Training and Recruitment

The relative newness of mental retardation as a field of professional study and the unusually rapid development of new knowledge and approaches in the field make it imperative that residential and other service agencies place strong emphasis on the development of their professional staff. Means would include adequate and accessible professional libraries; regularly scheduled staff development seminars which include persons from related disciplines, services, and agencies; and attendance at state, regional, and national professional meetings. Necessary arrangements must be made with civil service or other relevant authorities for a period of induction training of professional personnel lacking prior training and experience in the field of mental retardation.

By means of incentive grants, universities should be encouraged to develop training programs for leadership at the predoctoral level, e.g., a 2-year master's degree in retardation administration and program development. Graduates of such programs should be able to step into a wide range of leadership positions, including state planning, program administration, workshop direction, executive positions in the parent movement, etc.

To attract young people to mental retardation careers early in their academic-professional development, the SWEAT program should be strengthened and expanded. However, SWEAT awards should be made very discriminatively and only to those agencies which are ready to invest a high degree of interest and guidance in the students.

Kugel's introductory chapter for an explanation of SWEAT.

A promising innovation aimed at development of intermediate level personnel has been initiated in several states through collaboration between state agencies and junior colleges in training persons in retardation. Encouragement of such programs through financial participation of state and federal government appears desirable.

Service systems should make major efforts to utilize part-time workers, especially those who have some skill and experience in retardation but who cannot or will not work full time. This is increasingly being done in the fields of education and nursing. Administrative flexibility in scheduling would enable more housewives and students to work in the field, and would be likely to attract more students to retardation-related careers. Part-time work should be particularly easy to arrange in special-purpose hostels where residents are out working or studying during the day, so that peak coverage is required for weekends and for relatively short periods in the mornings and evenings. Finally, some hostels could permit part-time working students to live in, offering them free room and board in return for some work, and again attracting them to eventual careers in the field. The establishment of small, specialized, and dispersed hostels makes such practices much more feasible than in the past.

To help meet the need for attendants, houseparents, and houseparents assistants, states as well as governmental units below the state level should establish long-term training programs for adolescents who do not have an interest in academic careers. Properly oriented, such programs could provide a human service challenge to many young people groping for a meaningful career commitment. Some such training programs might be developed in cooperation with the public schools along the lines of the work-study models that have seen such great growth in recent years. This would permit youngsters to enroll as early as age 16. If it is advisable that the first few programs of this nature be federally supported, this might be achieved with modifications in existing manpower-oriented legislation.

#### Unionization as a Factor in Residential Services

Increased unionization of care worker personnel in residential facilities appears inevitable. Every effort must be made to assure the employees and their spokesman, the union, a dynamic and constructive share in long-range and day-to-day programming. At the present, unions are too often maneuvered into a posture of opposition, and then insist on rigid adherence to seniority and similar rights in ways which are detrimental to program objectives. Obviously, imagination and skillful interaction between management and union is needed to present to the union desirable alternatives to such practices. In most states, this must be done in collaboration with civil service or personnel boards, which, on their own part, need to show greater

flexibility in making appropriate allowances for special needs in a residential care setting without sacrificing the essential elements of employee protection.

By the same token the promotion of care personnel in situations where union practices are no obstacle need to be examined. Promotion to middle-grade supervisory positions in many institutions is frequently not based on understanding of program objectives, skill in day-to-day work with residents, or favorable response to inservice training, but rather often results from favoritism, political influence within the institutional power-structure, or from just having put in years of service. This has brought about all too often situations where "old line" middle-grade supervisory staff stand in the way of effective program change and can neutralize the dynamic orientation and inservice training programs for new staff even if directed by carefully selected training officers.

#### Manpower Consequences of the Medical Model

One additional major problem in the present manpower situation in residential services arises from the pursuit of the medical model. This creates manpower problems on two accounts. First, the medical model is an illusion in the sense that most institutions have neither the resources nor the clientele for implementing a high-quality and appropriate medical hospital model. In consequence, good physicians in general avoid an institutional career, leaving the field to poorly trained or poorly adjusted colleagues and to foreign-trained physicians whose backgrounds are serious handicaps in this situation. But equally serious is a second problem. The essence of a traditional medical model is the position of preeminence reserved to the physician and through him to the nursing hierarchy. Under the best of circumstances this greatly complicates the work by competent members of other professions such as, for example, psychologists, but when the physician "in charge" is patently lacking in competence in his own field, let alone in related areas, then the institution encounters great difficulty in recruiting and keeping good nonmedical professional staff. The specialization of residences proposed by Tizard and Dunn, and discussed elsewhere in this chapter, should overcome this problem in that a service continuum would contain medically oriented and directed residences for those retarded whose major need is hospitaltype care, as well as residences for other retardates built on educational, rehabilitational, correctional, and other models directed by the appropriate disciplines.

## Location and Design of Facilities

At the time of this writing, blueprints for the construction of residential facilities for the mentally retarded involving the expenditure of several hundred million dollars are on the drawing boards of state agencies throughout the nation. Most of these facilities are designed for the longevity usually expected from public buildings. That is to say, most of these buildings are expected to serve mentally retarded individuals considerably beyond the year 2000. It is all the more disconcerting that in many cases the design of these buildings reflects and incorporates concepts long considered outdated. It is hard to think of any other area of governmental activity where so many millions of dollars are expended in perpetuation of practices which have long been condemned as unsuitable and damaging in the professional literature, in the reports of governmental commissions and departments, and by concerned citizen groups.

Wolfensberger's chapter on the origin and nature of our institutional models has provided us with a careful documentation of a historical development which has led to this sorry state of affairs. To find the answers as to the reasons for its continuance despite all the protestations of recent years, one would have to look to the social scientist and his helpful interpretation of the nature of bureaucratic processes and of system maintenance. The question as to how to bring about change has been dealt with in a preceding section of this chapter; in this section, the emphasis will be on what needs to be changed in regard to certain aspects of the location and design of residential facilities.

### Human Management Versus System Management

To put it briefly, the traditional and unfortunately still prevailing method of designing and constructing residential facilities for the mentally retarded was predicated on and guided by system management. The new program to which this book is dedicated is based on human management. The traditional institution reflected a mass approach; the residential center of the future must be based on the needs of individual human beings.

The thought behind the traditional design was the need to create accommodations for diagnostic categories in quantity; in the new residences, services will begin with a human being, and rather than to create an environment to accommodate and maintain the level of functioning of his "category," we will need to provide an environment allowing for and indeed stimulating growth and development. Knowledge how such growth and change takes place thus becomes the key point of departure not only for the architectural design of rooms, buildings, and complexes of buildings but also for the crucial matter

of site location and the perennial problem of the size of a facility. Once the architect has accepted the overriding principle of normalization and the associated concepts of integration, dispersal, specialization, and continuity as they relate to a residential human management service, he will have a tangible frame of reference within which he can design and properly locate living space that will enhance rather than hinder growth and change on the part of mentally retarded individuals (Dybwad, 1968).

#### Site Selection

Much has been written in criticism of the location of institutions for the mentally retarded. What needs to be kept in mind is that these selections were preordained to failure because of the way the task was defined: to find a very large tract of land on which to place a large institution (usually with the thought of further expansion) at a reasonable land cost. Frequently, this prescription led to the acquisition of land nobody else wanted, thus affording the real estate speculator with political connections a handsome profit, or a town badly in need of a supporting "industry" would find it a good investment to provide such land free of charge. As far as the residents were concerned, they appeared only as a quantity, as a figure of 1,000, 1,500, or 2,500; there was no thought, indeed there was no possibility of thinking of them as individuals belonging to a family, or any thought of that family's geographic relationship to the institution harboring their son or daughter.

Normalization impinges on site selection in several significant ways reflecting the concepts of integration, and also of specialization and dispersal. Integration implies maintaining and indeed developing not just the sense of belonging but the closest possible physical proximity between the mentally retarded and the family. This implies visits from the family to the center, and visits of the mentally retarded individual to his home. But there is another dimension to integration; the principle of normalization not only refers to the life the mentally retarded leads in the institution and his contacts with the family but also bears upon his contacts with society, usually in the context of a community. This implies that the residential center not only should be within reasonable distance of the home of the mentally retarded but should have a definite ongoing relationship with the community, a relationship that has meaning not just to the center as a social institution, not just to a staff, but also to the residents themselves.

The concept of dispersal adds to the process of site selection another dimension in the literal sense of this term. It seeks to limit the center to a sensible size in terms of human interaction, interaction of the resident with his fellow resident, interaction of the resident with the staff, interaction of the director of the center with both the staff and the resident, and finally also interaction of the center as a

whole with the surrounding community. From the factors here enumerated, it will be obvious that there can be no set figure indicative of satisfactory dispersal. Much will depend on the kind of resident the center is serving, and much will depend on the interactional capacity of the surrounding community.

The concept of specialization also will play a role in site selection, at least in regard to certain facilities, for instance, centers serving individuals with acute medical and health problems call for location in desirable proximity to a medical center; a center serving children of school age should be so located that the children have an opportunity to attend special classes in a public school; a behavior-shaping oriented center should be near a college, a university, or a similar source of psychological manpower.

#### Some Principles for Building Design

The traditional mental retardation institution was and to a considerable extent still is being built in a fashion that might be characterized as "from the outside in," determined by such factors as the size and shape of the land available,, the number of people to be accommodated in the most economical size of buildings, and the most efficient distribution of buildings on the available land, taking into consideration length of steam tunnels, required electric cables, factors pertaining to food preparation and distribution, etc. After due consideration of all these factors, plans are designed for the most economical use of the building, and eventually one arrives at the space allocated to individuals and groups. And although the prescribed minimum square or cubic footage has been provided, the result (as has been amply described in this volume) is inadequate.

If we are to move to an architectural application of human management principles, then, of course, it will become necessary to reverse the process, and to plan the building "from the inside out" (Dybwad, 1967). First consideration will be given to the space that is to be set aside as the personal territory of the resident: his bed; his bedside table; the place for his clothes and other belongings; room for the table, and for a chair if he is to have one in his room; and, of course, determination of whether he is to share his room with others. From this most personal territory, consideration would then move to the living space he would share in common with others, such as space for leisure, dining, hobbies, sanitary facilities, cloak rooms, and storage space, keeping in mind the total group that is to live in this unit, whether six, eight, or ten, but hopefully not more. Having thus outlined the resident's intimate personal sphere as well as his immediate group sphere, the next determination would be, with

due consideration of such factors as age, degree of handicap, etc., whether, in what fashion, and with how many other units this first unit may be joined.

The next consideration would then be how this larger constellation will be related to the surrounding community. There is no need to go into architectural details here. ||-

#### Group Homes in the Community

A very important part in the residential human management service will be played by small group residences in the community such as hostels for young men and women in vocational training, in sheltered workshops, or in open employment; group homes for children who cannot live at home but for whom foster home placement is not, or at least not yet, indicated; aged retarded men and women who are not in need of a nursing home; and a variety of temporary or transitional group homes. Some local authorities in some countries, particularly in New Zealand and Australia, have rushed into construction of hostels and other group homes with rather disappointing results; in order to make construction "worthwhile," the homes were usually built for too large a number of residents, and the design carried all the earmarks of institutional construction. Furthermore, in order to obtain land, the location was often disadvantageous, but once the land was secured, there was the temptation to erect other structures on it, and thus the workshop was just a stone's throw from the group home which adjoined the day care center.

Experience has shown that it is far more preferable to rent, lease, or buy existing residential structures which can be adapted to group home living, and Sweden has successfully pioneered in demonstrating the feasibility of using one or two apartments in an apartment house as a hosteltype group residence for mentally retarded adults.

#### The Old Institution: Renovate or Discard?

One of the many obstacles to the development of dispersed, specialized residential services has been the existence of the large traditional multipurpose institutions. A common argument is that these institutions cannot be "abandoned," and that in our efforts to improve the services to the retarded in the community by means of either residential or nonresidential services we cannot neglect the welfare of those retardates already in our institutions. Consistent with this are those who advocate massive financial investment in the existing institutions in order to bring the physical facilities and programs to what are considered acceptable standards.



Examination of some hard facts, however, reveals rather unequivocally that such a course of action is at best ill advised, and at worst unfeasible, and a poor service to the residents now housed in such institutions.

1. The majority of residents in our present institutions are housed in buildings which would fail to meet architectural-engineering standards. In a number of states, extensive architectural-engineer-surveys have shown that renovation of most of the older and sometimes even newer buildings costs as much or more than expenses involved in building, or utilizing existing buildings, in the community. In estimating the cost per place in these existing institutions, one must also take into consideration the costs involved in renovating supportive buildings such as kitchens, schools, activity buildings and areas, auditoriums, chapels, bowling alleys, swimming pools, and, above all, the fact that any adequate renovation will decrease the capacity of the traditional institutional building on the average by 50 percent. When the total cost of such architectural rehabilitation is averaged out, it may come to as much as \$11,000 per residential place.

The remarkable point here is that after expenditures of such magnitude, one would still end up with vast and essentially segregated facilities, located in areas where today one would not place residential facilities in the first place if one applied modern concepts such as normalization.

2. It is furthermore of interest to examine the cost factors in the operation of the traditional-omnibus versus modern-specialized residences. A number of considerations are pertinent here.

The more residents a building is designed to accommodate, the stricter become the building codes that must be observed. While small residences can be built at relatively modest costs, the cost per place increases drastically when buildings are designed to house more than approximately 8-20 residents. Furthermore, buildings erected at high initial cost are much more durable and therefore impose limits upon the exercise of options as time goes by. Some buildings with relatively short-life expectancy can conceivably be abandoned after approximately 20 years so as to enable the service system to engage in continuous planning, to incorporate new concepts and ideas into buildings, and to permit flexible relocation of services. Larger and therefore more durable buildings, on the other hand, may have to be utilized for several generations. Here, we have much to learn from Scandinavia, where residential facilities are increasingly designed and constructed along lines of ordinary community housing, which has, of course, a relatively limited life expectancy.

Application of the normalization principle will guide the architect in the design of rooms and buildings which will be as close to normal living situations as is possible. Keeping in mind the principle of growth and change, he will design rooms and houses with a maximum of flexibility so that furnishings may be added as the resident learns to cope with them, large bedrooms subdivided into smaller rooms, and confining spaces opened up to provide freedom of movement. While in the earlier stages each unit should be completely self-contained and separate from other units (if located in the same building they could be arranged as separate apartments), at a later date the flexibility of design might be utilized to create certain common social rooms to be used by two or more groups together while still providing separate living space in each of the basic units for those not ready to join the larger social grouping.

#### Some Special Problems

A large-scale application of the normalization principle and the associated concept of dispersal would bring over the next 10 to 20 years a steadily growing number of mentally retarded persons into our cities and suburbs as residents of various group residences. That mentally retarded individuals can live in small group residences in our cities and suburbs has been well demonstrated by now as far as the social aspects of this arrangement are concerned. Together with similar developments in the area of other handicaps, this will constitute a real challenge to urban planning and should, on the federal level, gain the sympathetic attention of the United States Department of Housing and Urban Development. At the present time, the multiplicity of zoning ordinances discriminate in one way or the other against handicapped citizens. Some of them are so biased in favor of property owners and against considerations of public interest that legislative relief seems to be called for.

Another series of obstacles in the development of better residential services for the mentally retarded is created through local and state building codes, the national safety code, and a long list of local, state, and federal regulations.

The United States Advisory Committee on Intergovernmental Relations had the following to say in a 1966 publication entitled Building Codes: A Program for Intergovernmental Reform: "Obsolete code requirements, unnecessary diversity of such requirements among local jurisdictions, and inadequate administration and enforcement, taken together tend to place unjustified burdens on the technology and economics of buildings. Too many building codes contain unnecessarily high standards, prevent the use of economical methods and materials in building, and include provisions extraneous to the basic purposes and objectives of building controls." Most architects who have been involved in the

design and construction of facilities for the mentally retarded would feel that this is a very mild statement indeed compared with the unreasonable and often irrational obstacles that they are encountering when trying to use informal and less expensive construction, particularly in buildings housing totally ambulant, generally able-bodied, mentally retarded children or adults. . . .

The origin of much of this difficulty is quite clear: once again it was the medical model and its application to residential facilities for the mentally retarded that established in the eyes of all the code authorities seemingly once and for all the mentally retarded as a sick and helpless person requiring the stifling protection of the most stringent code provisions.

This is a matter of extreme urgency and truly a nationwide problem. Not only are construction costs for mental retardation residential services unnecessarily increased, often by vast amounts, because of code requirements; beyond doubt more serious is the fact that many of these code requirements geared to the needs of hospital construction give the resulting buildings some distinct dehumanizing features.

There is no attempt here to play down the necessity for uniform building codes strictly enforced. What must be put into question are building code provisions which make rigid judgments about people or groups of people which are clearly unwarranted and prejudicial. What is to be put into question are building codes which are "rigged" to favor certain industries or certain construction methods and make practically impossible or in any case uneconomical the introduction of modern, equally appropriate materials and methods which are both cheaper and more serviceable. Nor is there any attempt here to denigrate the importance of fire protection. Anyone who has worked in a responsible position in the field of the aging or in children's institutions or around hospitals appreciates the importance of good regulatory fire protection and careful fire inspections. Not infrequently it is the fire marshal who by insistence on the definitive closing of buildings long condemned as fire traps will make decisions faint-hearted administrators lack the courage to make. The objections raised here pertain to rigid classificatory judgments written into the fire codes which, in their large-scale application, are discriminatory against certain individuals or groups of individuals and deprive them without cause of basic personal rights, such as the right to live in normal rather than dehumanized surroundings.

While the subject has been introduced previously, it is dealt with here in such length because it has been largely ignored by professional and citizen groups alike, mostly because of its complicated

technical aspects. This is an unfortunate misunderstanding because the question is not what kind of walls built from what kind of materials will give what length of fire protection; the question is whether young adults who leave their group residence to travel by public transportation to an all-day workshop, or a group of adult males in an institution who leave their building every morning to be used throughout the day by the state as cheap labor (driving vehicles, operating machinery, working in storehouses), can be considered by any rhyme or reason as requiring the same kind of fire protection in their living quarters as that prescribed for buildings which house 80 or more semi-ambulant, sickly, physically incapacitated, severely retarded young children.

Harking back to material presented earlier in this chapter, it is of course necessary to point out in fairness that the housing and fire code officials have merely reacted to traditional popular notions about the mentally retarded, and have been influenced by the picture of dehumanization they witnessed in public institutions. The need for change is obvious, and the burden rests on those working in the field of mental retardation to present well-founded and well-documented information which can be used to bring about a more rational approach to this whole matter.

Obviously research and carefully controlled experimentation is called for to convey a new and more adequate picture of the range of functioning levels and performance potentials of retardates, and to demonstrate the appropriateness of various types of construction in terms of such information. Considering that in the judgment of the President's Committee on Mental Retardation and of state commissions throughout the country, a vast number of outdated and long-condemned institutional buildings across the country must be demolished and replaced within the next 10 years, and sooner rather than later, with totally different types of buildings; and considering further that the greatly accelerated pace in accumulation of new knowledge and skills puts into serious question the past practice of erecting institutions to last for generations, one aspect needs particular attention. This is the possibility of introducing prefabrication methods when it comes to the construction of smaller and more informal residence buildings. Denmark, France, Czechoslovakia, and the U.S.S.R. are far ahead of our country in the use of prefabrication, and the Danish Mental Retardation Service in particular has successfully employed it to meet certain new and large-scale demands. A most important factor is that prefabricated methods will greatly speed construction, and no one could doubt that speed is of the essence in replacing our disgraceful human storage houses with new facilities that will permit humane management to become a reality.

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