

Part V: Toward New Service Models

Chapter 8

Residential Services Within the Service Continuum

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RESIDENTIAL SERVICES WITHIN THE SERVICE CONTINUUM

The President's Panel on Mental Retardation (1962) stated with admirable lucidity the problems of providing both residential and non-residential services for the retarded. These problems face not only the United States, but all advanced countries of the world. As far as residential care is concerned, there is an overall shortage of places. Despite increases in the number of beds in recent years, the waiting lists remain long. More seriously handicapped retardates, especially children, are surviving and are being admitted to residential care at an early age; the expectation of life of these severely handicapped persons has increased markedly.

This chapter has to do with residential services. But, as the President's Panel noted, residential services cannot be considered in isolation from general community services. Before considering alternatives to current models of residential care, something will therefore be said about services in general, and the factors that influence needs for residential provision.

The Epidemiological Basis for Planning of Services

In planning for the needs of the mentally retarded, it is necessary to have an idea of the population whose needs would be met by the service. A conveniently sized population to plan for is one of 100,000. Many local authorities are of about this size, and estimates worked out on a base of 100,000 can be readily adjusted to meet the needs of larger or smaller communities.

As a working rule for planning day services for people living in their own homes, I suggest that the maximum size of the area which provides a service should be one in which any member of the population is within an hour's traveling time, door to door, of any center which he should be required to attend regularly. It follows that schools, treatment centers, hospitals, clinics, workshops, and recreational facilities serving a population usually will be best placed in the center of the area in which the population lives, rather than on the outskirts. In highly urbanized areas with a good transport system giving quick and easy traveling, a population larger than 100,000 might be served by one service system, but in rural areas it may be necessary to plan for the needs of smaller populations.

In order to plan services for the mentally retarded, it is necessary to know the number of persons who will require them. Ordinary administrative statistics are an unsatisfactory guide because they merely tell us the number of cases being dealt with, but do not indicate the extent of unmet needs. Increase the amount of provision, and the

numbers of "ascertained" cases increase; decrease it, and they fall. The number of beds for mentally retarded persons in the whole of India is only a few hundred. This gives no indication whatsoever as to the number of retardates who need them in that country.

Fortunately, a number of surveys of the prevalence of mental retardation have been undertaken in different Western countries in recent years (Gruenberg, 1966; Tizard, 1966). By and large, these surveys have yielded results which are highly similar as far as the rates of severe and profound mental retardation are concerned, though they differ in the rates arrived at in respect to mild mental retardation ($IQ > 50$). Enough is known, however, about these and the factors that influence them in order to serve as a basis for action.

A finding which has emerged from all surveys of the prevalence of mental retardation is that the numbers of cases discovered differ in the various age groups of the population. Rates are low in infancy, and then rise steadily until a "peak" prevalence rate is reached during the early teens. Thereafter, there is a decline in age-specific rates with age.

There are several reasons for the increase in numbers and rates throughout childhood. First, the diagnosis of mental retardation in infancy is not an easy one to make--indeed the diagnosis of mild mental retardation in the preschool years is often so conjectural that pediatricians, on the whole, prefer to "wait and see." Secondly, there are very few communities which have anything approaching an adequate and comprehensive network of health and welfare services for preschool children. Consequently, many retarded children are not brought forward for medical and psychological assessment until they start school. Thirdly, mental retardation in its milder forms is, more commonly than not, exhibited as a failure on the part of the child to master the rudiments of formal education; it is only when schoolwork becomes intellectually taxing that "slow-learning" children are seen to be falling markedly behind the standards achieved by other children of the same age. Fourthly, in advanced countries, there are more factors operant that increase rather than decrease the incidence of retardation during childhood.

The reasons why surveys carried out at a single point in time always show a decline in numbers with each decade of adult life are, first, inadequate case finding (compulsory schooling provides the one really satisfactory guarantee that few cases will be missed); secondly, the fact that the majority of mildly retarded children, when they leave school, are able to settle as ordinary, if usually somewhat limited, citizens in the ordinary community--that is, they are no longer "mentally retarded"; thirdly, the high death rate among the severely retarded reduces the numbers of gravely handicapped children who survive to adult life.

We know from several surveys that the "peak" prevalence rate for severe mental retardation is found in children and young persons between the ages of 10 and 20 years. In North American and European populations, this peak prevalence is approximately 3.6 or 3.7 per thousand population. There is good reason to believe that this rate approaches the true prevalence rate. Hence, among every ten thousand babies born, there are likely to be between 35 and 40 who will be severely retarded and who will survive at least until their teens.

This finding can be regarded as one of the best documented in psychiatric epidemiology. The administrative consequence is that inasmuch as the numbers of severely retarded children known to the authorities fall short of the predicted rate of 3.6 per thousand, they indicate, in a Western community, the extent of unrecognized needs. Of course, if there is malnutrition, if antenatal and obstetric services are poor, if child care practices and health and welfare services are unsatisfactory, the rates of severe mental retardation are likely to be higher. However, for severe mental retardation (IQ under 50) in childhood, a rate of 3.6 per thousand must be considered a minimal estimate of the true prevalence.

One cannot speak with such confidence about the true prevalence of milder retardation (i.e. the numbers of "educable" retarded children with IQs of about 50-70) because the term is an administrative one which lacks any clear social and biological definition. The term "mild mental retardation" resembles terms such as "poverty" or "social deprivation." There is no doubt that many people are "poor": but poverty in the United States or in the United Kingdom has a different meaning from poverty in, for example, India. It may be mentioned, however, that many educational systems have found that, in practice, between 1 and 2 percent of school-children are too backward to be educated in ordinary classes, and for these children some kind of special schooling is needed. To the extent that special provision within the education system is not made for the numbers of children who are officially recognized to need it, there are again unmet needs.

Are the Numbers Increasing?

The question is often asked whether the numbers of retardates are increasing. We know that because of better medical and welfare services, many handicapped children survive today who would formerly have died. Fears are sometimes felt (though perhaps less often expressed) that because of this, the very size of the problem of mental retardation may become such as to impose an intolerable burden of care upon the rest of society. Fortunately, fears that this may happen are groundless. In a community of 100,000 persons having a crude birth rate of about 18 per 1,000, only 6 to 8 children will be added to the severely handicapped group each year. Even if all of these were to survive until middle age, the total number requiring care would be well within the resources of any modern industrial society, particularly since we know that the

majority of even the severely handicapped require very little in the way of basic nursing when they grow up. Moreover, recent evidence has also suggested that the number of congenitally handicapped children born each year is decreasing rather than increasing. It looks as though the factors which have led to a dramatic fall in infant mortality have also greatly reduced the infant morbidity rate: many children who would formerly have grown up mentally or physically handicapped, today grow up as normal, healthy youngsters (Lizard, 1964). However, it seems certain that the numbers of handicapped adults are increasing, simply because handicapped children live longer now than they used to. The implication for services is that we shall have to provide more residential places for handicapped adults in the future, though the numbers of children who require services are not likely to increase proportionately.

A planning authority requires some estimate as to numbers, and sooner or later most planning authorities find it necessary to compile registers of the mentally retarded, and to maintain "waiting lists" for services of various kinds. Sometimes authorities postpone taking any action to improve their services until, they have first instituted surveys to ascertain just how many cases they would have to provide for if their services were fully adequate to meet all the demands that might be placed upon them. When this happens, years may pass with nothing done while elaborate surveys of prevalence and needs are carried out. The cost in human terms of such procrastination is incalculable, and to refuse to begin to meet urgent and manifest human needs until one has "assembled all the facts" is quite unjustifiable. Nevertheless, the facts do need to be assembled.

The Demand for Residential Places

The number of residential places which are required for mentally handicapped persons per thousand of the population is not determined solely by the prevalence of mental retardation. Two other factors are of great importance, namely: (1) the adequacy of the mental health, education and welfare services for the mentally retarded living at home, and for their families, and the amount and quality of residential provision; (2) the attitudes of the public, and of the medical and educational professions in particular, towards mental retardation and residential care (Tizard, 1964). We also know that the demand for residential places is influenced by: the number of places available, and thus the possibility of obtaining one, the quality of residential care, which at present is often so poor that it deters parents from parting with a child who is proving difficult to manage at home; the amount and quality of the community services for retardates living in their own homes (domiciliary services); the age of the child; the age and handicaps of his parents and other members of his family; the aptitude of family physicians, teachers, other professionals, and the general public; the social and economic circumstances of individual families and of the communities in which they live; and finally, the criteria of

mental retardation. One cannot, therefore, give a general answer as to the amount of provision which is required.

A Continuum of Services for the Mentally Retarded

Against this background let us consider the services themselves. The President's Panel on Mental Retardation (1962, pp. 14-15) gave an outline of the main needs:

1. Research into the causes of retardation and in methods of care, rehabilitation and learning.
2. Preventive health measures, including (a) a greatly strengthened program of maternal and infant care directed first at the centers of population where prematurity and the rate of "damaged" children are high, (b) protection against such known hazards to pregnancy as radiation and harmful drugs, and (c) extended diagnostic and screening services.
3. Strengthened educational programs generally, and extended and enriched programs of special education, closely coordinated with vocational rehabilitation, specific training and preparation for employment; education for the adult mentally retarded, and workshops geared to their needs.
4. More comprehensive and improved clinical and social services.
5. Improved methods and facilities for care, with emphasis on the home and the development of a wide range of local community facilities.
6. A new legal, as well as social, concept of the retarded.
7. Helping overcome the serious problems of manpower, as they affect the entire field of science and every type of service, through extended programs of recruiting with fellowships, and increased opportunities for graduate students and those preparing for the professions to observe and learn at firsthand about the phenomenon of retardation.
8. Programs of education and information to increase public awareness of the problem of mental retardation.

It will be noted that in this broad statement of objectives, most attention is paid--and rightly so--to services for retarded persons living in their own homes. As a statement of what is required to meet their needs, the "Report to the President" could hardly be bettered. However, it is in regard to residential care that new models are most needed, and the writer believes that in dealing with residential provision, the President's Panel was less farsighted and bold in its recommendations than it was when dealing with nonresidential services. The rest of this paper discusses factors bearing on residential services, and outlines one new model of residential care.

Institutional Care Today

Having considered some of the main factors bearing on the amount of residential provision required, and the part played by residential care in a total pattern of services, let us now look at the type of residential care that is currently provided, and the type that is required.

The usual type of residential care for the mentally retarded, in the United States as well as in most of the rest of the world in which services have been provided, is the large comprehensive hospital, training school, or institution which contains both adults and children on all levels of retardation. In the United States, at least 95 percent of all institutional retardates live in establishments with more than 500 residents (Sheerenberger, 1965). In the past, the justification for the large size and heterogeneity of institution populations was mainly economy. Large institutions were believed to be cheaper to run than smaller ones, and in institutions containing mildly and severely handicapped residents, the less handicapped were able to contribute very substantially to the care of the more handicapped and to the general running of the institution. More recently, smaller institutions and establishments of about 500 beds have been regarded by many authorities as being of optimum size.

The institution of today is also achieving status as a hospital rather than an institution, and progressive authorities are attempting to staff it accordingly. The Technical Planning Committee of the American Association for Mental Deficiency (1964), for example, recommends that a 500-bed institution for the retarded should have "consultant physicians in pediatrics, psychiatry including child psychiatry, electroencephalography, neurology, neurosurgery, orthopedic surgery, physical medicine and rehabilitation, internal medicine, general surgery, anesthesiology, ophthalmology, otorhinolaryngology, radiology, and pathology" who are to make regular visits to the institution and conduct clinics and ward rounds in it. Other personnel and services recommended by the AAMD Technical Planning Committee are on a similarly lavish scale.

Two questions should be asked about a model such as that proposed by the AAMD: Will it provide what is needed? And is it feasible to do so?

It appears to me that the AAMD model of comprehensive, up-to-date hospital-type care has been put forward without sufficient thought having been given either to the role which such an establishment should serve in the general community or to the needs of the residents who will live in it. Remarkably few of the residents in mental deficiency institutions today require hospital treatment; very few even require basic nursing. This latter fact was brought out recently in the Wessex survey (Kushlick, 1967), and in a study in the Birmingham (England) region (Leek, Gordon and McKeown, 1967) investigating the medical needs of all 1652 residents in 13 institutions for the retarded in that region. These residents were similar in most respects to those in England and Wales

as a whole. Each resident's requirements were assessed by a hospital physician and the nurse in charge of each ward. In this region, "in . which pediatric and psychiatric centers do a considerable amount of investigation which might elsewhere be done in hospitals for the subnormal," there were only seven residents who required investigation or active medical treatment of a kind which would make it necessary for them to be in hospitals. About half (851) were considered to need no medical treatment of any kind. Approximately 40 percent needed "mental nursing," with or without basic nursing (washing, dressing, feeding, etc.). About 13 percent required only basic nursing. The remainder needed no nursing services. "Some of them required simple personal attentions (such as advice concerning washing, dressing, time-keeping, etc.) but most needed only a sheltered environment with opportunities for training and occupation., Nineteen percent of the patients were considered suitable for work outside hospital or in hospital service departments, and approximately 50 percent required therapeutic occupation or vocational rehabilitation." (Leek, Gordon and McKeown, 1967, p. 121).

Similarly, Kushlick (1967) found that in Wessex, about 70 percent of the children in institutions were ambulatory and continent, and almost the same proportion of severely retarded adults were ambulatory, continent, and without severe behavior disorders; 50 percent could feed, wash, and dress themselves without help. A substantial minority of the mildly retarded adults had behavioral disorders requiring primarily social treatment.

While it may be that the findings obtained in these surveys would not be typical of what would be found in other areas, nevertheless the general conclusion is inescapable. Few retardates need hospital treatment; all need education, employment, a satisfying social and cultural environment, and, in the case of retardates who cannot live with their own families, a home in which they can live as normal a life as possible.

In the large institution, it is difficult to provide for these needs. Because of the expense, and because land is simply not available in cities, large long-stay institutions are necessarily placed outside the main centers of population. In consequence, they tend to become isolated from the rest of the community. They are difficult to staff adequately, since they have to provide large numbers of nursing and supervisory staff, and also specialists to deal with possible contingencies; and because they have only tenuous links with other services for retardates and people who live at home, they have to provide for all of the needs of the residents--board and lodging, medical care, education, employment, recreation.

Again, because the institutions are large, they draw residents from a very wide geographical area. Hence, visiting by families is difficult, and contacts between the retardate and his home are weakened finally lost. It is also difficult to rehabilitate higher functioning residents , many of whom come from urban slums and for whom a period

of residence in a sheltered environment in rural surroundings is hardly a good preparation for the city life they will have to live when they return to their own environment.

The question may also be asked whether it is really feasible to attempt to provide a modern hospital-type environment for the retarded on the lines recommended by the American Association on Mental Deficiency. Many, and perhaps most, residential establishments for the retarded fall far short of the standards advocated. On the contrary, they tend to be isolated, overcrowded, understaffed--and cheap to run only because they provide a poor environment. But to bring them to an acceptable standard would require an enormous outlay in cost, and even leaving cost aside, it is doubtful whether it would be possible, even if it were desirable, to provide in every institution however large, the equipment and personnel recommended by the AAMD Technical Planning Committee. Even today, the few specialists that there are in mental retardation (especially physicians and psychologists) spend a disproportionate amount of time dealing with routine problems of institutional retardates, so that they are not able to provide the services needed by retardates who live in their own homes--services which in some instances might help to obviate the need for residential care. If more specialists are centered on institutions, the needs of the rest of the community are likely to suffer still more. Elsewhere, I have attempted to discuss this matter more extensively (Tizard, 1968).

Residential Alternatives to Institutions

Generally, residential institutions were the first form of public provision for the mentally retarded. It is only recently that the problems of retardates who live in their own homes have begun to be studied seriously. Today, as the President's Panel pointed out, it is recognized that an adequate community service should provide, for the retarded who live at home or for their families, good antenatal and obstetric facilities and other preventive services; adequate mental and child welfare clinics; counseling services and practical social help; education; sheltered employment; vocational guidance and training for adults; organized provision, in which voluntary societies and local endeavor participate, for leisure-time activities; etc. The mentally retarded who cannot live in their own homes require these services also; their only additional need is for a home. Thus, it can be argued that the primary job of the residential services is to provide a home; and all the other needs of the retarded should be provided equally for those who live in their own homes and those who have no homes, through the same facilities and personnel.

If we accept these premises, there is much to be learned from studying the organization of residential care for orphans and other dependent children. A great deal of thought has been given to the problems of bringing up dependent children, particularly since the second world war, and there has been much experiment and a careful scrutiny of policy. While institutional policy for the mentally retarded has remained

rather static for the best part of this century, that for dependent children in care has changed out of recognition in two decades. The quality of care given to such children far surpasses that which is found in most institutions for the retarded.

In considering what would be the best type of residential provision for the subnormal, one cannot, therefore, fail to be impressed by what has been done for dependent children, the more so as the pattern of care which is favored by those in charge of residential services for children has also been found to be applicable to other groups who may need residential care, notably old people. For just as there has been a turning against the large institutions for children, so large workhouses and institutions for old people are today being replaced by smaller homes.

Following the example of those who have been concerned with, the residential care of dependent children, one can envisage an alternative to the large mental deficiency institution in the form of a series of foster homes and small hostels, which would be situated in the centers of the population that they serve. The hostels would be conveniently placed so that the residents would attend the same schools or day training centers as attended by those living in their own homes. The residential centers could also serve as social centers for handicapped persons in the neighborhood. Thus, not only could maximum use be made of the residential facilities, but it would also follow that a retarded person who came to need residential care would not be required to make a complete break with what was familiar to him, while one who was discharged into the community would not have to learn to adjust to a completely new environment.

Some examples of residential services that constitute alternatives to the traditional institutional pattern follow.

Residential provisions for children. Profoundly retarded and perhaps multiply handicapped children might best be placed in a long-stay annex attached to a children's ward or hospital, while the less severely handicapped children capable of attending training centers would be in special residential homes. Alternatively, units for about 15 severely and profoundly retarded children might be established if no hospital annex is available. An example of a homelike residence on which various researches were conducted is the Brooklands model (Lyle, 1959, 1960; Tizard, 1964). Yet another form of residential provision is foster care. Efforts to get foster homes for severely or profoundly retarded children have not in the past met with great success, possibly because the social workers making the enquiries have themselves been half-hearted about them. More experience is needed in this area.

Residential provisions for school leavers and young adults. Few mildly retarded adolescent school leavers (drop-outs) and young adults will need residential provisions. Those that do could live in small

hostels having between ten and twenty places. Even for this group, foster homes should not be ruled out completely. English experience suggests that it is desirable to have separate hostels for higher functioning retardates who are working out and for lower functioning dependent retardates. The hostels for the mildly retarded should contain both young men and young women. Their function should be to prepare school-leavers and young adults for independent living in ordinary lodgings or in their own homes. At the same time, they should serve as social centers to which other young people living at home could come. Most residents of hostels for the lower functioning would be expected to attend sheltered workshops and similar day services.

Residential provisions for other adults. The number of mentally retarded adults who are of violent or dangerous propensity is exceedingly small. Their special needs can best be met by the same services provided for the care, treatment, and detention of mentally disordered offenders and other mentally disordered persons who are a danger to themselves or the community. The greatest need for residential accommodation for adults is for long-stay homes for the moderately and severely retarded. In the future, these are likely to comprise three-fifths of the total for whom residential care is required. However, very few adult retardates will be grossly handicapped, physically or behaviorally. It is suggested that the needs of these people could best be met in small family-type units separate from but reasonably close to the main sheltered workshops in which many of them would be employed during the day. The hostels could also serve a wider community function as a club and meeting place for other retardates living at home. There is much room for experiment and innovation here.

Costs. The question of costs is one of great importance in the planning of a service. It is also a matter on which it is difficult to generalize from one country to another. Some observations can, however, be made. The main reason why large institutions have been cheap to run has been that they have been grossly understaffed. This applies particularly to the primary care workers and to teachers, youth leaders, and social workers. The question arises whether fewer personnel are required for adequately staffing of large units than of small ones. It is usually assumed that this is so, and that small units are more expensive both to build and to maintain. Recent (unpublished) evidence collected for the Wessex Regional Hospital Board challenges this assumption. To build a new 450-bed hospital could cost 2.5 million British pounds, while building 17 hostels containing the same number of beds would cost 1.3 million, i.e., only about half as much. If a service of adequate quality is provided in our residential establishments, annual running costs are unlikely to be significantly greater in the small units than in the large, and they may even be less. The writer can see no reason why a similar state of affairs might not be found in American conditions, but detailed empirical enquiries would need to be undertaken before realistic estimates could be made about the comparative cost of establishments of different sizes.

General Considerations. There is, in principle, nothing at all novel in any of these proposals, but their implementation would result in a mental deficiency service very different from that which exists in most parts of the world today. It is likely to be very much cheaper than the elaborate alternatives proposed by advocates of modern hospital-type care. Specialist medical and other staffs would be shared with general domiciliary (nonresidential) services. Most of the staff running the hostels would need little nursing training; their training should rather be in child care and development if they are to work in children's units, or in youth work supplemented by some instruction in the special problems of the mentally retarded if they work in adult units. The medical arrangements made for residents who were sick would be the same as those made for retardates living in their own homes in times of sickness. Staff ratios in the proposed units would need to be high enough to cope with minor illnesses as well as the minor physical and social incapacities of the residents.

Conclusion: The Need for Experiment

The case made out for a different kind of residential service is based on earlier studies carried out by the writer and his colleagues and reported in more detail elsewhere (Kushlick, 1966; Tizard, 1968). The .n need, however, is for experiment—for planned variation in the pattern of a service which is expanding, and for evaluation of the result's obtained from different kinds of administrative practice. The ' Wessex study, still in progress, is an example of this type of experiment, in that it subjects residential services of various sizes and based on a variety of models to empirical evaluation. The writer believes that it is through such survey and experiment that the greatest advances in our knowledge of how to provide the most effective form of service will come. The opportunities for such, experiment are now numerous, and the techniques of social science are sufficiently well-developed for us to be able to make use of them.

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