Will There Always Be An Institution? I: The Impact of Epidemiological Trends

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Abstract
In this two-part series of articles, it is predicted that institutions will be phased out because of five trends: development of nonresidential community services; new conceptualizations of and attitudes toward residential services; increased usage of individual rather than group residential placements; provision of small, specialized group residences; and a decline in the incidence and prevalence of severe and profound retardation due to reduction in the birthrate of high risk groups, improvement of health services for the population generally and for high risk groups specifically, increased practice of abortion, general environmental betterment, and early childhood education. In this (first) part, the impact of the predicted epidemiological trends upon residential services is discussed.

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Recently, I ventured 20 predictions about the future of residential services in mental retardation (Wolfensberger 1969d). Several of these predictions implied that the traditional institution would gradually fade away. The rationales for this prediction as well as certain related ones were enumerated and briefly discussed, but space limitations prevented more extensive elaboration of these points. Herewith, I will explore these points further, but first it is necessary to ask a very basic question.

What Is an Institution?
Both the 5,000-place institution as well as the 5-place hostel are residential services; what makes us apt to label one as an institution, and the other one as something else? Obviously, definitions are arbitrary. We are free to define institutions in such a way as to reflect the typical citizen’s opinion of what an institution is; we can impose an arbitrary definition that is more scientific or technical; or we can combine elements of both approaches.

Goffman (1961) rendered a brilliant analysis of what he called “total institutions” which he defined ultimately in terms of the barriers which exist between it and the outside, especially the barriers to departure. I suspect that even without awareness of this definition, most citizens today would similarly define an institution largely on the basis of features that emphasize separateness from the community mainstream. Yet, as attractive and useful as this definition has proven to be, I feel that such a barrier is merely a common rather than essential feature of an establishment that might be defined as a total institution, and that appears to typify our traditional mental retardation institutions. It seems to me that ultimately, an even more useful definition would be based on the deindividualization that permeates the atmosphere of a residential community. More of the features commonly associated with an institution appear to be corollaries of deindividualization rather than of separation from the “outside.” Such corollary features include the following:

1. An environment that aims at a low common denominator among its residents. For instance, because a few or occasional residents may be unstable or destructive, all residents may be subjected to an environment that appears necessary and/or appropriate to the few or occasional ones. We are all familiar with the locked doors, heavy-duty construction and furnishings, and socio-behavioral surveillance, structure, and restrictions imposed on a group for the sake of a few of its members. The fact that deindividualization can be a more significant feature than confinement is apparent from the fact that physical restraints, even when used, are usually quite
unnecessary and often ineffective in maintaining separateness and confinement.

2. Congregation of persons into residential groups larger than those typically found in the community. In American society, the most typical grouping residing together in the community is the nuclear family, which rarely exceeds six to eight members.

3. Reduced autonomy of residents, and increased regimentation, including mass movement and mass action on the part of the residents, and regimentation of their routine. Again, a surprising amount of regimentation can be attained even when there is no physical and even few social barriers to departure. The voluntary deindividualization, regimentation, and separateness of monasteries is a good example.

4. Ordinary citizens sleep, study, work, and play in separate contexts and settings, and tend to interact with different fellow citizens in each setting; in institutions, these settings tend to be physically fixed under one roof or on one contiguous campus, and sometimes programmatically unified in terms of environmental and supervisory structures. Also, the same group of persons tends to interact with each other in each such setting, resulting in an inward-directedness. Again, these features greatly reduce opportunities for individualization.

Thus, when I distinguish between institutions and other group residences in the subsequent discussion, the term institution refers to a deindividualizing residence in which retarded persons are congregated in numbers distinctly larger than might be found in a large family; in which they are highly regimented; in which the physical or social environment aims at a low common denominator; and in which all or most of the transactions of daily life are carried out under one roof, on one campus, or in a largely segregated fashion.

**Institutions Will “Fade Away”**

Both the desirability of the disappearance of the institution as well as the realism of such a prediction are controversial, and one can readily hear the argument that goes something like this: “Go ahead, start your hostels, dump the aged retarded into nursing homes, expand your community services—but when you are all done, you will still need the institution.”

Some workers in the field resent the drift toward a new model because of their commitments to the past model, and because of a very understandable human rigidity. Others are free of such essentially irrational “hang-ups,” and on an intellectual level see programmatic and social benefits in patching up or salvaging the old model. For instance, they may believe that the very isolation (social or physical) of institutions serves a societal purpose by permitting society to separate itself in a relatively humane fashion from those it has rejected and discarded; that there is no other, better, or more economical alternative for the care of the profoundly retarded or multiply handicapped; or that the present institutions represent too great an investment to be discarded. Yet other workers see little merit in the old model, but while some labor optimistically for new models, some are pessimistic in regard to constructive changes; even as they support new trends in residential services, they believe that the traditional institution will still be with us for a long time, and perhaps forever.

My proposal is that institutions as I have defined them should and will disappear. The should implies a value judgment on the part of myself and many “young Turks” (both old and young) in the field. The will, however, implies a prediction on the scientific-empirical level. It is predicated on certain socio-cultural-political-fiscal realities. I propose that three trends and one phenomenon will combine to slowly evaporate the institution. The four trends are: a lowering in the incidence and prevalence of the severely and multiply damaged; increasing provision of residential alternatives; increasing provision of nonresidential community services; and a change in the ideology and conceptualization of services. The one phenomenon is the largely unrecognized fact that present institutions are not as good an investment as they are widely believed to be. Each of these points will be elaborated below.

**The Incidence and Prevalence of Mental Retardation, and Implications to Residential Demand**

Research on the epidemiology of mental retardation is voluminous. While this work has yielded some consistent findings, it has also left...
some problems unsolved, and perhaps unsolvable. One perennial problem of epidemiology has been: what is the incidence and prevalence of mental retardation? Ever since this question has been asked, workers in the field have been apt to seek “the” answer. For instance, studies that are in agreement with each other are greeted with satisfaction: studies that disagree with each other are viewed as problematic.

The search for “the” answer appears to rest on an assumption—often unconscious and implicit rather than explicitly stated—that retardation is a static phenomenon with invariable input and output events and channels. This posture is difficult to understand unless one assumes that it rests on the presumption that retardation is largely due to hereditary causes which should be relatively stable over time and space. Most epidemiologists and other workers in the field would reject such a presumption while yet continuing to assume a posture consistent with it.

Many diseases show vast fluctuations over time, space, cultures, and subcultures. So do many social phenomena such as marriages, births, divorces, crime, wealth, etc. If we truly believe that mental retardation can result from a large number of interactions of a large number of psycho-bio-socio-medical phenomena, then why should even large variations in incidence and prevalence surprise us? To the contrary, absence of such variations should surprise us.

It would thus appear that the perennial search for the incidence and the prevalence of retardation constitutes an attempt to solve a pseudo-problem of our own making. Instead, we should be concerned with the conditions under which incidence and prevalence vary, and with the ways in which causative mechanisms can and do interact.

At present, the prevalence of retardation in the United States is relatively high, especially if the operational definition of the American Association on Mental Deficiency (Heber 1959) is adopted. Even aside from this particular definition, a high prevalence is to be expected on a priori grounds. Perhaps in no other country of the world are typical cultural expectations for complex behavior as high as in ours; and yet, probably in no other advanced nation is severe deprivation of resources and opportunities as common. The interaction of these two phenomena probably explains why our prevalence of mental retardation appears to be one of the highest among advanced nations.

On the one hand, the demands for complex behavior can be expected to continue to increase, and therefore to make for an increase in the overall incidence of mental retardation; but on the other hand, there are many changes, events, and trends which are likely to reduce the incidence of retardation, and particularly so of severe and profound retardation. Thus, the question is which of the two effects is larger and most relevant to residential needs. Let us first review the factors that appear to reduce the rate of retardation.

Continuing Reduction in Birthrate among High Risk Groups

It is a well-recognized phenomenon that as nations advance economically, their birthrates decline (e.g., Berelson and Steiner 1964; Statistical Office of the United Nations 1969; Department of Economic and Social Affairs 1965). In the United States, this trend has also been evident, although some irregularities which are believed to be due to wars and depressions have occurred (Kiser, Grabill, and Campbell 1968). Generally, rates have declined since 1800 (Okun 1958; Yasuba 1961), and sharply so since about 1955 (e.g., United States Bureau of the Census 1969). Much of this continuing recent decline can be attributed to the introduction of new contraceptive means and techniques, and increasing acceptance of the practice of contraception generally.

The decline in birthrate should mean a decline in the relative number of damaged infants generally. However, of even more significance should be the decline in the birthrate of certain “high risk” groups which have been particularly apt to produce impaired offspring. Among these groups have been the poor and disadvantaged (and consequently a large proportion of the noncaucasoid population); very young and older women; mothers in poor health, with numerous previous pregnancies, and with a history of reproductive problems; and unmarried women. Impaired children from such groups appear to have accounted for a disproportionate number of our institutional residents.

In the past, it was assumed (with only limited documentation) that mild retardation was especially prevalent among lower socio-economic groups, while more severe retardation was relatively equally distributed across all socio-economic strata. Today, we do not only know that poverty is one of the major correlates of retardation generally, but with
perspicacious hindsight we can now recognize that we should have expected all along that factors making for severe impairment should be especially prevalent among the poor and disadvantaged (e.g., Hurley 1969; Kosa, Antonovsky, and Zola 1969; Mooring 1968; President’s Committee 1969). Some high risk groups (e.g., the poor, the disadvantaged, and the noncaucasian) have also had much higher birthrates than more favored “middle Americans.” However, while in the past the birthrates of high risk groups have not fallen either as rapidly or as low as that of middle Americans (e.g., Kiser, Grabill, and Campbell 1968), the gap will probably narrow rather rapidly.

For instance, a study of tentative Omaha data found that if Omaha birth rates are examined by census tracts grouped according to average family income, the most affluent tracts in which birthrates were already very low showed no further decline in rates between 1960 and 1967; in the second quartile tracts, rates declined by 17%; in the third by 24%; and in the fourth by 37%. Within the Negro ghetto, some census tracts showed a decline of 63%. The overall non-white birthrate dropped from 47.3 per thousand in 1957 to 26.5 (equivalent to 44%), while the white rate dropped from 27.4 to 17.5, or only about 16% (Omaha World Herald, June 11, 1969).

Another high risk group is that of unmarried mothers. From Sweden (Karl Grunewald, personal communication) comes a finding that had been unforeseen though quite expectable, i.e., that increased practice of contraception by the unmarried had had a sizeable effect in reducing the relative incidence of impaired infants from this source.

The implications of these phenomena and trends are that we can expect substantial declines in birth rates among high risk groups even after the birth-rate of middle Americans levels off; and in turn, this means a substantial reduction in the relative number of impaired infants.

Preventive Health Services to High-Risk Groups

Not only is the birthrate of high-risk groups relevant to our discussion, but also the health of and health-related services to such groups. One index of the health of a population group that is relevant to severe impairment is neonatal and infant mortality. Such mortality, prematurity, and high risk status are highly related to each other as well as to infant damage and to the incidence and prevalence of severe and multiply damaged children.

Neonatal and infant mortality rates in the United States have dropped steadily since 1915 (Shapiro, Schlesinger, and Nesbitt 1966; United States Department of Health, Education, and Welfare 1969). However, two phenomena stand out.

1. Relative to other nations, the United States has been falling behind, and for 1966, there were 22 nations reported to have had lower infant mortality rates (Statistical Office of the United Nations 1968). While some artifacts may be involved, the data are probably correct for at least twelve of these countries. Tentative data for 1967 (Statistical Office of the United Nations 1969) suggest that the list had grown to at least thirteen nations, and the rates of Scandinavian countries (e.g., 12.9, 13.3, and 14.2 per 1000 births, and thus 60–70% of U. S. rates) point the way to a minimal goal that can be achieved.²

2. Infant mortality rates differ greatly between various population groups in this country. They tend to be very low in advantaged, and very high in disadvantaged groups. For instance, white-nonwhite differences have been near 100% for years (United States Department of Health, Education, and Welfare 1969), and another example from Omaha is very informative. In Omaha, as in most urban centers of the United States, residential areas of wealth and of poverty are clearly defined and differentiated. In recent years, the infant mortality rates in some of the wealthier residential areas have been less than a third of the national average, while in certain census tracts in the poverty and Negro areas, they have been over three times the national average. In other words, the chances that an infant in a poor family would die were occasionally ten times higher than that of infants of privileged backgrounds. Again, the current rates for advantaged population segments can be viewed as minimal targets that can be achieved for the entire population.

Figures cited above have profound implications to the incidence and prevalence of severe and multiply damaged children. Now, that Omaha poverty areas are beginning to receive extensive

²These and other data were the most recent ones I could obtain at the time the paper was submitted. They are slightly outdated because of publication lag.
services for handicapped children, the prevalence of damaged children from disadvantaged backgrounds is beginning to become visible for the first time, and appears to be staggering. With some variation, the Omaha situation is repeated across the nation.

Another index of great relevance here is the rate of maternal death associated with childbirth. This rate, of course, had declined phenomenally over the years (e.g., Shapiro, Schlesinger, and Nesbitt 1968; United States Department of Health, Education, and Welfare 1969). In 1915–1919, the overall rate was 728 per 100,000 live births; by 1967, the rate was down to 28, and still declining. However, while in 1915–1919, non-caucasians had a rate that was 179% higher than that of caucasians. The difference between these rates increased dramatically as the maternal death rates for caucasians dropped much faster than that of noncaucasians. By 1957, the difference was 430%, and in 1967, it was still 356%. Once more, such data demonstrate dramatically the progress we can, must, and will make, and the tremendous unrealized preventive vistas that still lie before us. These vistas, we should note, do not even involve new discoveries, new drugs, new surgeries, etc.; they involve no more than applying what we know and have the means of doing right now!

Fortunately, the last few years have seen extensive improvements in the health care of high risk groups. For instance, mother-child centers, maternal and child health programs, and children and youth programs have served the poor, unwed mothers, and other special risk groups. Such services undoubtedly will be expanded further.

However, health services are not enough, since social and health factors interrelate in intimate but ill-understood patterns. Therefore, it is comforting to know that the socio-cultural factors which can obviate health services are also improving. In time, the effects of these combined trends should be expressed in a significant reduction in the incidence of severe retardation and multiple handicaps.

### Increased Legalization and Practice of Abortion

Although the practice of abortion involves complex questions of morality—even to an extent contraception never did—there is every reason to believe that in the future, high-risk women who do conceive (perhaps because of contraceptive failure) will have relatively ready access to abortion. There are strong grounds for predicting that within a generation, abortions may be performed as readily in the United States as in countries with highly liberalized abortion laws, such as Japan, although probably not as widely. In Japan, abortion is utilized as an equivalent to contraception, while it is to be expected that in this country, effective contraception will be practiced so universally that abortion will be employed mostly for other reasons.

A significant proportion of severely and multiply damaged infants are products of hereditary, genetic, and intrauterine damage. In many cases, the presence of such damage can be suspected and increasingly even confirmed prenatally. As the practice of abortion in high-risk pregnancies becomes widely accepted, we can expect a very significant decline in the birth of damaged infants. In fact, in order to fully visualize future trends, we must recall that infants with prenatal abnormalities make up a large proportion of the visibly, severely damaged, such as we now encounter in our present institutions, and in community programs for the severely retarded.

### Improvement of Health and Preventive Services Generally

It is to be expected that health services generally will improve, and that some preventive measures will have special relevance to the reduction of severe impairment. Significant recent advances in the latter category include rubella and measles vaccination, and Rh desensitization. Other noteworthy developments are improved and increased genetic counseling, prenatal diagnosis of fetal abnormalities, prenatal exchange transfusions, and numerous improvements in early postnatal management. Many advances, though of relatively minor effect upon retardation by themselves, do add up. Better standards for drugs, improved auto safety, and better control over X-ray usage and sources are a few examples. Many other preventive improvements can be reasonably expected.

### General Environmental Betterment

Adverse environmental factors interact with each other and with yet other factors in a number of ways which have implications to the incidence
and prevalence of mental retardation. However, many of these adverse conditions appear to yield to increased material prosperity and progressive social enlightenment. Poverty, and the culture of poverty, are perhaps the two conditions which both have extensive implications to retardation, and which also appear to be on the decline.

That poverty is a significant factor is readily apparent in the indices which accompany poverty in this country, such as poor medical care and nutrition. However, much more subtle, but perhaps even more significant than poverty itself, is what has been called the “culture of poverty” (Lewis 1959). When a poor, expectant mother does not have the money for a baby-sitter or for bus or taxi fare to go for a prenatal examination, then her poverty may contribute to the birth of a damaged child; when she has a baby-sitter, and gets free transportation, but fails to go for her examination because of low motivation or superstitious beliefs, then we may say that her risk is higher because of her cultural ways which are associated with poverty. When she is too poor to nourish herself or her children properly, her poverty may well result in stunted and damaged children; when she has enough money for food, but serves mostly starchy foods and ill-balanced meals, her culture rather than poverty may cause ill effects.

Although we still have a shameful amount and distribution of poverty, not only the proportion but even the number of the poor has declined steadily and substantially in the 1960s, and it has done so in almost all segments of the poor population (e.g., National Advisory Commission on Civil Disorders 1968; United States Bureau of the Census 1969; United States Department of Labor 1969). For instance, between 1960 and 1967, the number of poor persons had declined from 38.9 to 26.1 million overall, and from 10.7 to 8.4 million among non-caucasians (United States Bureau of the Census 1969). Particularly encouraging is the fact that employment gains made by Negroes have been even larger than those made by caucasians (e.g., National Advisory Commission on Civil Disorders 1968; United States Department of Labor 1969). This trend appears to hold up even at this time of recession.

While the culture of poverty may linger long after poverty itself has ended, we can still expect a significant long-range decline in both proportion and number of mothers and infants who are at risk because of poverty and its culture. This, of course, should express itself in a reduced incidence of retardation.

**Early Childhood Education**

Growing acceptance of the fact that man is most shapable early in life has led to a number of trends, six of which will be mentioned because of their relevance:

1. **The private early education movement**, manifested in the explosive growth of private Montessori schools, kindergartens, and similar establishments. Many such schools have accepted retarded youngsters.

2. **Operation Headstart**, intended to reduce the shock of school entry for disadvantaged youngsters. Appropriately, goals have been raised to actually prevent scholastic and mental retardation, and accordingly, Headstart has expanded from a three-month summer program to a one-year and even longer program for many children.

3. **Lowering of school entrance age for many types of handicapped children**. For instance, until recently, severely retarded children in Nebraska public schools had to be eight years old; today, they are accepted at age six, and some are accepted as early as age three.

4. **Mandatory education for the severely retarded**. Formerly, lack of mandatory provision meant that the child might have received no education until his teens, if ever; now, he will be exposed to intensive shaping in his more plastic early years. To cite Nebraska again: education for the severely retarded was mandated as late as 1967, and was not effectively implemented until 1969. In a few years, all states will mandate and implement such education.

5. **A new emphasis on enabling mothers on welfare as well as others to work**, which is resulting in a rapid growth of day care centers. Since standards for these day care centers are being tightened, one can increasingly refer to them with justification as developmental day care centers. They may well be the transition to universal school entry at an earlier age.

6. **Increased provision of kindergarten programs in the public schools**. Here, we see movement from no provision to permissive to mandatory services; from half-day to full-day programs; and from one year to two-and even three-year programs.
A recent government report (Nehrt and Hurd 1969) showed that 8% of three-year-olds, 23% of four-year-olds, and 66% of five-year-olds were enrolled in preprimary programs of a developmental nature. Although these figures are probably much larger than most citizens would suspect, they are still too small. There can be little doubt that we will and indeed should lower our age for universal public education. Within one generation, we shall probably see first grade entry at age three and four, and some kind of developmental program for two-year-olds.

One major implication of these trends to mental retardation is clear. Early education will contribute substantially to a reduction in the prevalence of mental retardation, both by reducing the incidence of retardation that results from environmental deprivation, and by reversing such retardation in many instances. However, the effect is likely to be most marked in the reduction of mild retardation. Its greatest impact upon demand for residential places is not likely to come from this reduction, but from the relief and hope that early education offers to parents of the more severely retarded.

Conclusion

For years, writers in the field have called for more and better preventive efforts and measures. However, medically-oriented workers have had a “hang-up” on the inborn errors of metabolism. Because here, an apparently successful paradigm had been established in what was otherwise a sea of pessimism, the paradigm was glorified out of all proportion. However, the payoff to this paradigm so far has been negligible, while the ongoing and relatively rapid implementation of the vastly more significant near-eradication of measles and rubella, for instance, was not well foreseen. Even the much more readily foreseeable reduction in the incidence of retardation due to contraception was virtually unforeseen, and is probably not fully grasped even today. The effects of liberalized abortion have long been predicted, but their impact on programs for the multiply impaired and more severely retarded are probably also not fully grasped.

In attempting to assess the meaning of the various trends traced and predicted above, one may conclude that in mental retardation, the medical advances will be manifested most spectacularly by a reduction in the incidence of the more severely retarded and multiply handicapped. Social and educational prevention will probably have its most spectacular effects in mild retardation. That there should be such an equivalence (medical prevention of the severely retarded versus socio-educational prevention of the mildly retarded) is not new. What is new is that we now can predict with confidence that these effects will be strongly manifested in the future. The medical effects will probably be manifested much sooner and stronger and, indeed, are already in evidence; however, the socio-educational ones will have greater significance to our society.

For a long time, a common conjecture has been that there was a kind of balance between the number of infants saved by medical advances from damage, and those damaged but saved by the same or other advances from death. We have no way of knowing how true this conjecture was, but today, I believe that circumstantial evidence weights the scales strongly in favor of infants saved from damage over those damaged ones saved from death.3

The predicted trends toward lowered incidence and prevalence of damaged children could be reversed by an unforeseen disaster, equivalent to the Thalidomide tragedy or the rubella epidemic. However, even the impact of such disasters upon the prevalence of retardation is very likely to be blunted by the increased practice of abortion.

While the incidence of damaged infants will probably decline considerably, the prevalence of the aged retarded is apt to increase. At present, the life expectancy of severely and multiply damaged children and adults still appears to be well below that of the population as a whole. This gap can be expected to be narrowed, which will result in a higher prevalence of such individuals of advanced age. Also, the effects of the preventive measures mentioned can be expected to be offset in part by the increasing complexity of our society, and the greater likelihood that increased behavioral demands will make many persons retarded. However, persons who will pass into the retarded zone because of such social changes will be considered mildly retarded. Even if their number should outweigh

3Grunewald (1969) discusses several of the above points in regard to the Swedish scene. In a personal communication (October, 1970), he also felt that the data coming in now indicate a definitely lowered incidence of profound retardation in the 0–5 age group.
the number of those whose retardation is prevented or reversed, they are not likely to contribute significantly to the demand for residential places. Instead, they are likely to increase the demand for certain community services, particularly special education, vocational training, and personal guidance.

In evaluating the likely effects of preventive measures upon residential demand, it is important to consider two points.

1. In all likelihood, there is a high correlation between the severity of impairment, and the degree to which residential demand is met. In other words, among the most impaired, the demand for residential places is probably much more completely met now than among the more moderately impaired. For instance, as medical improvements prolonged life, and as institutions modified their admission criteria, the rate of admission of more severely retarded persons to public institutions began to increase in about 1945 (e.g., Goldstein 1959). However, the annual institutional movement reports of the United States Department of Health, Education, and Welfare suggest that in approximately 1958, such admissions reached a peak and have declined gradually, at least through 1967, which is the last year for which complete data were accessible to me as this article was written.

2. Over the years, as attitudes changed, there has also been a change in what constitutes a reasonable demand for residential placement. Only now are we about to agree that a newborn infant should not be placed merely because he has Down’s Syndrome. Only fifteen years ago, even a minor community problem was enough to institutionalize a mildly retarded person.

From the above it appears to follow that even though a specific preventive measure may prevent many more cases of mild than of severe impairment, it is exactly this latter effect which would have the more significant implication to residential provisions. Even modest preventive successes may have noticeable effects upon the demand for residential places, and the demand should decline most and first for the more severely impaired, and then “work its way” upward.

One might think that a survey of studies of waiting lists for institutions would be of assistance in clarifying this situation, but as noted in a recent review (Wolfensberger and Halliday 1970), such studies suffer from a number of artifacts which appear to render their conclusions irrelevant to the issue.

In sum, a number of current and predictable trends appear to make for a lower incidence of severe retardation. Prevalence of severe retardation is likely to decline for children, remain more stable for mature adults, and perhaps increase for the aged. While a possible increase in the prevalence of mild retardation will have little effect on residential service demand, the trends in severe retardation imply a significant reduction of such demand for children. There is apt to be an increase in demand for such services for the aged severely retarded, but such a demand can be met largely through generic residences for the aged.

The concluding article in this two-part series discusses the impact that the newly developing service model in mental retardation will have upon institutions.

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