Deinstitutionalization of the Mentally Retarded: Is it a Viable Movement?

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DEINSTITUTIONALIZATION OF THE MENTALLY RETARDED: IS IT A Viable MOVEMENT?

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This paper is dedicated to the fond memory of my father, who encouraged educational adventures and who always wanted to know if I would ever finish with school.
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Introduction

We hold these truths to be self evident. That all men are endowed by their Creator with certain inalienable rights. Among these are Life, Liberty, and the Pursuit of Happiness.

The pursuit of and protection of those inalienable rights provides an impetus behind a movement to 'deinstitutionalize' citizens in facilities for the mentally retarded, mentally ill, and juvenile offenders. This movement has been propelled forward at an increasing rate over two decades (Joint Commission on Mental Illness & Health, 1961). Strong justification for a deinstitutionalization policy can be based on simple humanitarian theories, civil rights and economics. However, there are powerful resistancies that are dominant. Territorialities must be redefined, resources reallocated, priorities redefined, service delivery systems reoriented, legislators convinced, and the culture de-mythologized (Datel & Murphy, 1975).

On February 5, 1963, President John F. Kennedy concluded his message to the Congress of the United States with the following challenge that gave meaning and a strong push for "deinstitutionalization":

We as a nation have long neglected the mentally ill and the mentally retarded. This neglect must end, if our nation is to live up to its own
standards of compassion and dignity and achieve
the maximum use of its manpower. This tradition
of neglect must be replaced by forceful and far-
reaching programs carried out at all levels of
government, by private individuals and by state
and local agencies in every part of the Union.
We must act -

to bestow the full benefits of our society on
those who suffer from mental disabilities;
to prevent the occurrence of mental illness and
mental retardation wherever and whenever possi-
ble;
to provide for early diagnosis and continuous
and comprehensive care, in the community, of
those suffering from these disorders;
to stimulate improvements in the level of care
given the mentally disabled in our state and
private institutions, and to reorient those pro-
grams to a community-centered approach;
to reduce, over a number of years, and by hundreds
of thousands, the persons confined to these insti-
tutions;
to retain in and return to the community the mental-
ly ill and mentally retarded, and there to restore
and revitalize their lives through better health
programs and strengthened educational and rehabilitation services;
and to reinforce the will and capacity of our communities to meet these problems, in order that the communities, in turn, can reinforce the will and capacity of individuals and individual families.

We must promote—to the best of our ability and by all possible and appropriate means—the mental and physical health of all our citizens (cited in Scheerenberger, 1974, p. 3).

Fourteen years have elapsed since this statement was issued and various programs and systems have been attempted. Some have been successful, some have failed. Today, many community and residential services cannot meet acceptable levels or standards of programming. In 1960, there were 160,000 retarded persons in public residential facilities for the mentally retarded (cited in Scheerenberger, 1974, p. 3). Until 1967, the number of residents in public facilities for the mentally retarded had increased steadily to a zenith of 193,188 (cited in President's Committee on Mental Retardation, 1976(a), p. 15). By 1969, the number of retarded persons had decreased to 190,000 in public residential facilities (Office of Mental Retardation Co-ordinator, 1972). There appears to be an effort to reduce the number of mentally retarded persons in residential facilities.
Purpose of Paper

The scope of this paper deals specifically with deinstitutionalization of the mentally retarded individual and examines whether or not the deinstitutionalization process is viable. The trends, philosophies, and specific practices and plans involved in the ongoing deinstitutionalization movement will be examined.

Terminology

In its usual sense the word institution is applied to large inpatient facilities which were created to serve groups of people. The scope of this paper revolves around institutions for the mentally retarded. The current working definition of mental retardation is the 1973 revision provided by the American Association on Mental Deficiency (AAMD) which states:

Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period (cited in Baroff, 1974, pp. 7-9).

There are three components to defining mental retardation. The first deals with intellectual functioning which may be assessed by one or more of the standardized tests (typically the Stanford-Binet (Terman & Merrill, 1973) or Wechsler Scales (Wechsler, 1955). The AAMD definition states that the functioning level must be significantly subaverage; this refers to I.Q. performance of the age-related normative populations of the test. This subaverage intellectual functioning
stems from numerous factors, among which are diseases, genetic defects, impoverished health, environmental conditions and psychological deprivation. In addition to the intellectual dimension, there is a second criteria which states that there should be concurrent deficits in adaptive behavior. "Adaptive Behavior" is defined as the degree to which the individual meets the norms/standards of personal independence and social responsibility expected of his age and cultural group. The third criteria is that such deficits must occur before the age of 18 and, therefore, within the developmental period. This chronological criterion facilitates the differentiation of mental retardation from other disorders such as primary mental illness.

In this paper the author will discuss the mentally retarded person in general terms, unless specific degrees of retardation are necessary to point out differentiation in the needs of the mentally retarded. The most frequently discussed subcategories of mental retardation include: the mildly retarded who would score between 2 and 3 standard deviations below the mean; the moderately retarded who would score 3 to 4 standard deviations below the mean; the severely retarded who would score 4 to 5 standard deviations below the mean; and the profoundly retarded who would score more than 5 standard deviations below the mean. The school system denotes three categories which encompass the above degrees of retardation. The educable mentally retarded (EMR) corresponds to the mildly retarded range, the trainable mentally retarded (TMR) corresponds to a combination of moderate and severe ranges, and the profound corresponds to the profound range.
Mental Retardation might also imply the possibility that a secondary physical handicap, or multiple physical handicaps are present and might include: loss of limbs, blindness, deafness, mobile non-ambulatory, and bedridden non-ambulatory. Retardation can be viewed as a static or changing process dependent upon the cause (i.e. medical, environmental, etc.). To conclude, Gershon Berkson in discussing behavior in relation to the mentally retarded states:

Mental deficiency is a psychosocial concept emphasizing low intelligence coincident with a failure to adapt to society...current behavior and its relation to the standards of society are the critical focus for programming services...inherent in the concept of mental deficiency are the characteristics of both the individual and the society. Without a statement of both, the concept has no meaning (cited in Zipperlen, 1975, p. 268).
Deinstitutionalization

"Deinstitutionalization was born, christened, and endowed and in 1971, the presidential seal was affixed to it" (Friedman, Note 1, p. 7). The term "deinstitutionalization" has been defined by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded in the following way:

Deinstitutionalization encompasses three inter-related processes: (1) prevention of admission by finding and developing alternative community methods of care and training; (2) return to the community of all residents who have been prepared through programs of habilitation and training to function adequately in appropriate local settings and (3) establishment and maintenance of a responsible residential environment which protects human and civil rights and which contributes to the expeditious return of the individual to normal community living, whenever possible (cited in Friedman, Note 1, p. 7).

The Comptroller General of the United States, in his report to the Congress, also defined deinstitutionalization in the following way:
As the process of (1) preventing both unnecessary admission to and retention in institutions, (2) finding and developing appropriate alternatives in the community for housing, treatment, training, education, and rehabilitation of the mentally disabled who do not need to be in institutions, and (3) improving conditions, care and treatment for those who need institutional care (cited in Friedman, Note 1, pp. 7-8).

It can be concluded that institutional reform, deinstitutionalization, and the development of community alternatives are all important functions in the movement to improve the care and treatment of handicapped persons. In some cases, there seems to be a misconception that "deinstitutionalization" and "development of community alternatives" refer to an essentially identical set of events. In fact, the two are not identical; "development of community alternatives" is a descriptive title for that set of activities involved in the construction and implementation of human services programs which are designed to provide services in the local community. Institutional reform is a necessary requisite to the development of community alternatives and an essential prerequisite in a program of deinstitutionalization. The movement is broad and receives energies from many points of directions. This author will review basic concepts and theories that can demonstrate the "why" of deinstitutionalizi-
Pressures Toward Deinstitutionalization

Introduction

"Normalization" of the quality of life for the developmentally disabled person is a primary or intended goal of deinstitutionalization. The current "Zeitgeist" of changing services for the mentally retarded is reflected in the emphasis that has been placed on the "normalization principle" by the President's Committee on Mental Retardation. This principle implies providing services for the mentally retarded that strive towards achieving what is normal for the average person. It refers, not only to the individual, but to the entire system of care for the mentally retarded. "Normalization" further implies exploiting the mentally retarded person's other mental and physical capacities, so that his/her handicap becomes less pronounced and also implies that the retarded have the same rights and obligations or responsibilities as other people. "Normalization" means offering experiences to retarded persons which are as close as possible to those afforded nonhandicapped individuals, such as living in a small family environment or being able to experience privacy. The current deinstitutionalization movement receives its energy not only from concerned professionals and parents, but also from court mandates, legislative enactment, and presidential directives. Institutions for the retarded are, therefore, being compelled to modify systems which institutionalize the retarded. There is no doubt in this author's perception that this process of change is especially complex and troublesome. Albert Shafter views the dilemma of
those who must administer institutions for the retarded as follows:

It is a fact that residential facilities for the mentally retarded are currently under attack throughout the nation. Moreover, one can predict similar critical examinations will be made of other organizations that are working with the mentally retarded. If we are to survive, we must adjust to these changing demands. Most of our notions of administration must be radically altered. To those not in the residential field, I would strongly urge you to begin to re-examine your organizations under objectives of our philosophy treatment; we must develop a systematic philosophy of administration. Our present systems are inadequate and it is hoped these comments will punish us to think along the lines that we must proceed in the future if we are to survive as a social organization (cited in Budde, 1972, p. 24).

Shafter strongly sums up reasons for the need to change, the need to re-examine existing philosophies. Just what are these existing philosophies that need change and innovation? An examination of some of the underlying foundations relative to the feelings for deinstitutionalization will be reviewed to demonstrate the direction from
where the deinstitutionalization movement is receiving its energy.

Attitudes Toward the Mentally Retarded

Attitudes toward the institutions and the people residing within them, frequently govern the makings of policies and procedures which dictate management of the mentally retarded. Wolfensberger (1972) discusses attitudes in the general sense that an attitude is part of a more generalized "attitude--complex" in regards to a group of deviances or toward deviancy in its broadest sense. Wolfensberger states that the first institutions for the retarded in North America were built (1850-1870) in a period of optimism regarding mental disorder and the education of the deaf and blind and that many facilities for these other deviant groups were erected at the same time. The subsequent disillusionment about retardation was not isolated, but part of a more generalized aversion toward human deviancies. In a study by English (cited in Baroff, 1974) it was shown that negative attitudes toward blindness were related to similar attitudes toward racial and ethnic minorities. In 1950, Adorno, Frankel-Brunswick, Leiman, and Sonford (cited in Baroff, 1974) identified an "authoritarian personality" type that is particularly apt to be prejudiced. These and other studies have demonstrated that persons rarely appear to be prejudiced against only one type of deviancy, thus, in part, supporting Wolfensberger's conclusions.

Studies of attitudes toward the mentally retarded have suggested that they are frequently seen as not fully human (Wolfensberger, 1972). The retarded person has been viewed as a sick person, a subhuman orga-
nism, a menace, an object of pity, a burden of charity, a holy innocent, and as a developing individual. The goals and practices of institutions have been viewed as providing custodial care with little therapeutic services: providing practices that led to over dependency; lack of personal identity, privacy, and self-esteem; lack of individual programming; little to no integration with the community; high degree of resident control; and little to no vocational preparation. These practices were in line with the prevailing attitudes of the time (Baroff, 1974; Wolfensberger, 1972). These concepts of the retarded have guided the management and role perception of retarded individuals over the years. The characteristics of the total institution can also be seen as affected by attitudes in that it is cut off from surrounding social regions by the virtue of its architectural differences; location, size, sponsorship, and specifically the characteristics of its population (Gangnes, 1970).

It is from these viewpoints that the mentally retarded have traditionally been worked with. The push for more normalized procedures; therapeutic services, maximizing the residents independence, integration with the community, continued family involvement, and symptom amelioration, has led to concern with public attitudes. In a study by Sigelman (1976), community sentiments about the right of the mentally retarded to live in small group homes, marry, bear children, and enjoy equal employment opportunity were examined. A stratified random sample of 665 adults served as subjects. Several questions about laws that effect the mentally retarded were incorporated in a large-scale
survey of attitudes. The study demonstrated a high variability of responses among attitude scales. In this study, 44.7% favored the idea of homes for the retarded in residential districts; whereas a Gallup Poll commissioned by the President's Committee on Mental Retardation cited in Sigelman, 1976) found that 85% of a national sample would not object to homes for the retarded in residential areas. Respondents were more favorable toward the right of the retarded to marry, with 68.8% saying yes, but this right did not appear to carry with it the right to bear children, for only 35.6% felt the mentally retarded should not be submitted to involuntary birth control. Sixty-seven percent felt employers should not have the right to refuse hiring a mentally retarded person, if they are qualified. The positive attitudes found among younger respondents in Sigelman's (1976) survey were consistent with findings in another national survey by Gottwald (cited in Sigelman, 1976, p. 28), where age was a particularly strong predictor of attitudes across many items. In general, Sigelman's (1976) attitude survey did not generate a profile of a good neighbor for community residential programs. He further concluded that attitude studies generally do not provide much guidance to program planners in regard to actual community behavior. Many studies have been done concerning attitudes about the mentally ill or mentally retarded person. One of the best studies reflecting current attitudes of society toward the retarded was written by Lewis and concluded:

The community stance, although mixed, tends toward rejection--removal from the community
setting--of both the educable-trainable and severely-profoundly retarded child (cited in Friedman, Note 1, p. 15).

The results of this study indicate that there is a lack of communication between the governing agency and the community in regards to knowledge about the mentally retarded and their abilities. Lewis' study also showed that there is a continuing community fear in regards to the mentally retarded. This study was consistent with Sigelman's (1976) study in that it appeared there was a majority consensus toward rejection of the mentally retarded in community settings.

It appears obvious that there is a need for greater public awareness and public education regarding the mentally retarded person. Although there is judicial clearance with regard to the retarded individuals' right to live in the community; as will be discussed in more detail later on in this paper, Scheerenberger (1976b) points out that, "public awareness, knowledge and sensitivity remain critical aspects of deinstitutionalization...without community acceptance, the retarded will never attain a reasonable degree of social integration." The fact that community residences are placed in the midst of a nondeviant, normal environment does not guarantee social integration. O' Connor (1976), in her comprehensive national survey on community residential facilities, writes the following about community attitudes toward the facilities:

A good deal of concern has been expressed about the amount of community opposition a community residential facility (CRF) faces during
its establishment. Newspaper stories and experiences circulated by word-of-mouth usually focus on the efforts of potential neighbors and/or other members of the community to block the establishment of a CRF. Although it is clearly impossible to estimate the number of facilities whose establishment has actually been prevented, some idea of the amount and sources of opposition faced by existing facilities may shed light on this problem.

One-third of the CRF's studied were reported to have faced opposition by members of the community at the time of their establishment. Most of this opposition was mounted by neighbors (83%). Occasionally, businessmen, city or county officials, or other community leaders (11%) created opposition without concurrent opposition by neighbors.

In conclusion, attitudes toward the mentally retarded are effecting the deinstitutionalization movement in that these attitudes are blocking attempts at establishing more "normalized" community alternatives and are further keeping the mentally retarded person in an isolated environment. There is a definite need to educate the public in regards to the mentally retarded population.
Origin and Nature of Institutions

The concept of movement towards deinstitutionalization has frequently been viewed as a reaction against the very existence of the institution and, therefore, a brief look at the origin and nature of institutions is appropriate at this point.

Wolfensberger (1975), in an historic account of the development of institutions, demonstrates how attitudes toward deviancy have had an impact on the original rise and evolvement of institutions for the retarded in the United States. Around 1850, a number of institutions in the United States were founded for the purpose of making the deviant less deviant. The main means whereby this was to be accomplished was education. In effect, the position was to group all the deviants together in one place so that experts could retrain them on an intensive basis. Wolfensberger (1975) concluded from reviewing primary sources that the underlying impetus or goal for early institutionalization was a combination of diminishing the intellectual impairment and increasing adaptive and compensatory skills of pupils so that they would be able to function at least minimally in society. The institution was, therefore, viewed as a temporary boarding school. Wolfensberger's (1975) historical review indicates that the early prevailing opinions and practices toward the mentally retarded were community oriented. The institutions were not intended to be storehouses or permanent homes, but rather temporary training schools (see Appendix A for derivation). After the child mastered skills necessary in society, he was to be returned to his family. For example, Samuel
Gridley Howe said in 1851 of what is now Fernald State School: "This establishment, being intended for a school, should not be converted into an establishment for incurables." (cited in Wolfensberger, 1975, p. 25). The early founders held to a number of other beliefs and practices including the belief that these "schools...are organized on the family plan." The pupils sat at the same table with the principal and were under constant supervision. Nearly all the institutions were located near the state's capitals or in the very heart of the community so that legislators could oversee their operations. This leads to the belief that the founding of the early institutions was accompanied by pride, hope, and a euphoria that can scarcely be comprehended in this day and age where the institution has been viewed as a storehouse for the mentally retarded.

The year 1876 is the year that dates the beginning of the social indictment of mentally retarded individuals in the United States and the concomitant change in institutional philosophy from educational and moral treatment to incarceration and total segregation (Wolfensberger, 1975). I suggest that this change in philosophy can, in part, be attributed to the fact that social programs increasingly became the responsibility of the government and this made the abdication of the individual responsibility for the handicapped easy and socially acceptable. The term "school" began to disappear from the names of institutions, being replaced by the term "asylum". For example, in 1893, the "Custodial Asylum for Un teachable Idiots" was founded in Rome, New York. The theory that public institutions would serve as instruments to
"protect the individual and protect society" is, therefore, young. By 1920, workers in the field began to recognize two facts. First, studies of the community adjustment of the retarded showed that they were not the menace as had been thought; and secondly, it was realized that the aims of segregation could not be achieved (Wolfensberger, 1975). According to Scheerenberger (1976), the majority of public residential facilities for the mentally retarded have been established since 1950. Wolfensberger (1975) notes that before 1950, the mentally retarded were generally grouped with other mentally ill persons. Differentiation between the mentally retarded and mentally ill was slight and resulted in management systems that treated both groups as indistinguishable. It is not infrequent to see the dual diagnosis of mentally retarded and mentally ill.

In conclusion, the previous review indicates a circular movement in regards to management of the mentally retarded. Historical accounts picture the management and goals for the mentally retarded as moving from a community orientation to an institutional orientation and, more currently, back to the community. The move to depopulize institutions and relocate the mentally retarded within the community is what deinstitutionalization is all about. It is important at this point to further speculate on what the reasons for institutionalization are, as these factors do effect the deinstitutionalization movement.

Factors Leading to Institutionalization

The history of public residential care of mentally retarded in the United States is a chronicle of horrors repeated and rediscovered.
The extreme social ostracism connected with having a handicapped child, coupled with the guilt-reducing push from the professionals for institutionalization, reached such proportions that families turned their eyes away from the ugliness of the sterile institutional surroundings, closed their noses to the stench, and blocked their human reasoning ability. Society's keen perception of fear and rejection of the handicapped person made the integration of the mentally retarded into the larger family picture impossible.

The most extensive investigation dealing with factors leading to institutionalization was conducted by Saenger (cited in Baroff, 1974, pp. 353-356). In a New York City population, he identified four major determinants of institutionalization: (1) degree of retardation, (2) degree of behavior problem, (3) family intactness, and (4) availability of community services. Saenger's (cited in Baroff, 1974, pp. 353-356) sample consisted of mild, moderate, severe and profoundly mentally retarded individuals. He used statistics from the community and the institutions to determine factors related to those mentally retarded individuals institutionalized.

1. Degree of retardation in terms of an I.Q.: Saenger (cited in Baroff, 1974, pp. 353-356) found that about 75% of persons in the profound range of mental retardation are placed in New York institutions annually. In contrast, only 11% of individuals classified as mild are placed in institutions. Assuming that these findings aren't unique to New York alone, the primary basis for composition of an institution is apparent. Although only a small proportion of
all retarded persons have I.Q.'s in the profoundly retarded range, it is this group that has by far the greatest probability of being eventually institutionalized and is least likely to be returned to the community.

2. Saenger (cited in Baroff, 1974, pp. 353-356) distinguishes two kinds of behavior problems that affect institutional admission—those of the community and those in the home. Community behavior problems include delinquency problems and are largely limited to the mildly retarded person. Home-type behavior problems appear to involve the severely handicapped person to a greater degree.

3. Family intactness refers to the presence or absence of one or both parents and parental inadequacy. Retarded persons living in homes with both parents were less likely to be institutionalized than those coming from homes with only one parent. Of retarded individuals who were not institutionalized, 90% lived in homes with both parents, while this was true for only 40% of those who had been institutionalized. The highest scale of institutionalization was found in youth with both behavior problems and inadequate parents. Eighty percent of those with this combination of problems had been placed in state facilities.

4. Community services for retarded persons, except those purely educational, were meager; therefore, institutionalization was a necessity for services and training.

The determinants that Saenger (cited in Baroff, 1974, pp. 353-356) identified have also been found in related studies (Maney, Pace & Mor-
rison, 1964; Maney, Plummer & Pace, 1969; Tarjon, Wright, Dingman & Sobaugh, 1961). Tarjon et al. (1961) found two main groups being admitted to an institution in California: preadolescents with severe handicaps, often physical as well as mental, and mildly retarded adolescents with severe behavior problems. The reasons for their admission basically correspond to those Saenger noted (cited in Baroff, 1974, pp. 353-356); i.e. mental level and behavior problems. Maney et al. (1964, 1969) also noted the significance of mental level, but she and her colleagues centered on the 'behavior problem' group and noted this factor as being significant for institutionalization. A further study by Saenger (cited in Wolf, 1975, p. 3) investigated 1,050 families in New York City and found that the majority of persons in institutions had come from low-income families. This factor has been repeatedly demonstrated in a number of studies concerning institutionalization (President's Committee on Mental Retardation, 1976(a)). Wolf (1975) further supported the conclusions of Saenger (cited in Wolf, 1975) when she and her colleagues demonstrated that the more the child is perceived as disruptive, the more likely he/she will be institutionalized. Also the gender of the child was found to influence the likelihood of parents defining the retardate as problematic and thus resulting in institutionalization. The last suggestion by Wolf (1975) regarding gender of the child was upheld in studies by Sabagh & Windle, Zarfus, and Churchill (cited in Wolf, 1975), where the male was seen to be admitted earlier and admission rates to be greater than females over time.

Jaslow, Kine, and Green (1966) suggest that institutions for the
retarded should not be required to serve those whose real problem is not retardation; it is presumed that reference here is to mildly retarded youth and the culturally deprived child who is institutionalized due to the inadequate home environment. Jaslow and his colleagues have proposed four criteria to be applied to prospective admissions as a means of avoiding unnecessary institutionalization and reducing heterogeneity. Jaslow et al. (1966) view the heterogeneity of institutional populations as one of the causes of their difficulty. The criteria Jaslow et al. (1966) have proposed also correlate with the factors leading to institutionalization. The criteria noted by Jaslow et al. (1966) include: (1) degree of physical handicap as determined with a medical model; (2) degree of antisocial behavior after age eight; (3) mental level with severe and profoundly retarded persons eligible for admission subject to age provisos and (4) family intactness where the child is eligible if he/she is at least four years of age, severely or profoundly retarded, and where there is not more than one parent in the home. Jaslow's proposed criteria were applied post facto to the resident population of a midwestern institution. Of 300 children under age 11 who were in the institution, only 96 (32%) met these criteria when admitted, 99 (33%) were eligible at some date following admission, and 105 (35%) should not have been admitted at all when these criteria are applied. Jaslow further concluded that at least one-fourth of the children committed to this center did not belong there and would not benefit from it while another third were committed prematurely. Jaslow's criteria for admissions are recommendations that could lead to
an overall decrease in populations in institutions, if, as he answers, his studies can be generalized to other institutionalized populations.

In conclusion, the factors that relate to institutionalization are factors that need to be systematically evaluated. It is imperative that we be aware of the dynamics that bring the mentally retarded person to the institution in the first place in order to progressively move on with the process of deinstitutionalization. The need and adherence to appropriate criteria for admission to institutions is a necessary first step in attempting to provide greater community services for the mentally retarded.

Effects of Institutionalization

Numerous studies have reviewed the effects of institutionalization on the development of the individual. Results are diverse and have been used both for or against the deinstitutionalization movement. Balla, Butterfield, and Zigler (1974) examined 103 children in four institutions to determine mental age and intelligence quotient. Additionally, they examined responsiveness to social reinforcement, verbal dependency, imitation of experiment or behaviors, and effectance of motivation or change seeking. Approximately 2½ years later the children were retested and decreases were significantly found in verbal dependency, imitation, and behavioral ability scores. These authors suggest that these findings imply that the environment of institutions negatively influences individuality and speech. Balla et al. (1974) attempted to control for extraneous variables and further found the pre-institutionalization experiences, institutional environment, sex, and diagnosis significantly
affected the child's response to the institution. To conclude, this study demonstrated that institutions provided practices that lead to overdependency as seen with decreases in behavioral ability scores. No significant change was seen in relation to intellectual functioning as a result of institutionalization. Sternlicht & Siegal (1968) demonstrated the impact of four years of institutionalized care on children and adults at a state school. There was a significant decrease in measured I.Q. of mentally retarded children, but the negative change in test scores for adolescents and adults was not as great. Institutionalization is seen to effect the younger child greater because of the great amount of learning and training that takes place during the developmental years versus the adolescent or adult years. This study suggests that the effect of institutionalization on the developing younger child is greater than on the adolescent or adult. Further studies indicate that early institutionalization usually has an increased adverse effect on the individual's mental and emotional development (Baroff, 1974, p. 349). There are few studies which document that the institution has had a positive effect on development. In a study by Klaber (cited in Baroff, 1974, pp. 350-353), six state institutions for the mentally retarded were studied for effects of institutionalization. He demonstrated that the institutions differed in terms of their effects on comparable populations and further identified factors associated with such differences. The population Klaber (cited in Baroff, 1974, pp. 350-353) studied consisted of two series of matched triads of severely and profoundly retarded children and youth residing
in six institutions. One series consisted of 51 children who were divided into three institutional subgroups of 17 each and matched as to age, age at institutionalization and I.Q. The second series consisted of 132 in number and were relocated five years prior to the study. These individuals were transferred to other centers and through retrospective matching determined the effect of different institutional placements on their current mental status. The quality of care provided by the institution was judged in terms by degree of independence in self-help skills (feeding, toileting, dressing), general adjustment (affect), and degree of growth in mental age since transfer to the institution. The atmosphere and environment of the six institutions did differ and these differences appeared to be related to measured differences in independence, adjustment, etc. Klaber (cited in Baroff, 1974, pp. 350-353) investigated the following areas to demonstrate this difference: daily life on the ward, interviewing parents of residents, size of staff-child ratio and general staff-resident interaction. The Klaber research provides an important contribution to our understanding of institutional services for the severely and profoundly retarded persons. His study demonstrated the variability in services that exist across a number of institutions for the mentally retarded. Other findings included: frequency of parents' visits as unrelated to distance traveled, larger population size of the institution negatively effects residents being treated like individuals, the picture of the institution as a reservoir of knowledge and services cannot be assumed with large institutional populations, and that severely retarded children
appear happier when relatively more time is spent with normal adults than with peers or retarded adults who serve as ward helpers. This, too, is consistent with Wolfensberger's (1972) encouragement of maximal integration of retarded with nonretarded persons. It is possible that mentally retarded persons cannot relate to each other in supportive peer-friend relationships. Numerous studies have demonstrated that institutionalization has had a negative effect on development; whereas other studies show little to no change and even positive effects of institutionalization (Baroff, 1974). In reference to this, Klaber's study suggests that these different findings are dependent upon the unique characteristics of each institution. He further identified a set of criteria (Program Analysis of Service Systems) that offers a potentially incisive means of program evaluation.

To conclude, a major power behind the movement to deinstitutionalize stems from the effects of institutionalization on the individual. Authors of research studies purport and demonstrate that institutionalization, in general, has a negative effect on the development of the individual. This "institutionalized effect" hinders development in areas such as: self-help skills, socialization skills, perceptual-motor skills, and language skills; and serves as a force behind the concept to decentralize and move toward "normalization".

Instruments and Patterns of Change

The deinstitutionalization movement, as noted earlier, receives its momentum from various sources. In 1958, Friedman (Note 1, p. 1) presented one of the first organized deinstitutionalization plans in
this country to the Department of Institutions and Agencies in the state of New Jersey. Apparently, it was read, reviewed, and simply disregarded.

Then came President Kennedy, newspaper investigations, legislative inquiries, the visit of Bobby Kennedy to Willowbrook, the investigation of the New Jersey legislature, the President's Committee on Mental Retardation, and the first Mental Retardation Facilities and Community Mental Health Centers Construction Act. The nation was literally shocked into acknowledging one of the darkest aspects of its history. Institutions and services for the mentally retarded people are changing and so are prejudices and public attitudes; as seen with the growing trend toward "normalization" in various programs and services for the mentally retarded. The mentally retarded person is now referred to as a 'person', an 'individual', and a 'resident'. The term hospital is being replaced by, 'center', 'facility', and 'residential facility'. These changes can be seen in current reports, studies, and books by professionals that acknowledge the rights of the retarded. In the middle of all this are the retarded persons themselves with their handicaps and their knowledge of being handicapped and different.

The following pages review some of the instruments and patterns that are affecting a change in the management and handling of the mentally retarded person and that have provided part of the impetus for deinstitutionalization.

Normalization Principle

A trend that is challenging institutions for the mentally retarded
is that these institutions adopt programs based on principles of "normalization". Allowing mentally retarded residents the right to function normally in society, of course, seems to attack the very raison d'être of the more recent institutional tradition. The process of continuous change and innovation in this nation is a fact of life; however, it can be concluded that it carries with it threats to nearly every tradition.

Wolfensberger (1972) describes the changing attitudes of the 19th and 20th centuries and the evolution of the large institution for the mentally retarded. The rights of all mankind, regardless of race, sex, or creed, have begun to be a matter of general concern. The principle of normalization, especially as expressed by Wolfensberger (1972), appears to be an honest attempt to translate this concern into a practical philosophy. "The maintenance of, or attainment of, non-deviant or normative behavior is the ultimate concern of the normalization principle." (Wolfensberger, 1972, p. 13).

The normalization principle has a wide array of meanings and implications as discussed in a definitive review of the subject by Wolfensberger (1972) in his book: *Normalization: The Principle of Normalization in Human Services*. In a chapter entitled "Evolution of a Definition", Wolfensberger traces the history of the concept back to its origins in Scandinavia. The different formulations form an interesting progression: Bank Mikkelsen, "letting the mentally retarded obtain an existence as close to the normal as possible", Nirje, "making available to the mentally retarded, patterns and conditions of everyday
life which are as close as possible to the norms and patterns of the
mainstream of society" (cited in Wolfensberger, 1972). And finally,
Wolfensberger refined the definition to fit the North American scene
as follows: "Utilization of means which are as culturally normative
as possible in order to establish or maintain personal behaviors and
characteristics which are as culturally normative as possible." (Wolf-
ensberger, 1972, p. 28). This concept has also received endorsement
from a report from the President's Committee on Mental Retardation in
1969. It further means avoiding excessive sheltering and protection
of allowing what Perske (1972) has called the "dignity of risk". Perske
(1972) contended that denying an individual exposure to normal risks
commensurate with his/her functioning tended to have a negative effect
on the mentally retarded person's sense of human dignity and also de-
layed the development of a sense of responsibility. In addition, the
removal of all risk also diminishes the individual in the eyes of others
who imagined him to be without ability (Perske, 1972).

Zipperlen (1975) discusses the controversy surrounding the norm-
alization principle and finds that it stems from deep-seated and widely
differing preconceptions of what is considered normal. Mikkelsen's
and Nirje's definitions emphasize the 'environment', while Wolfens-
berger introduces "behavior and personal characteristics". Wolfens-
berger (1972) then states that "the normalization principle is culture-
specific, because cultures vary in their norms", also that "the term
'normative'...could be equated with 'typical or conventional'." Zip-
perlen (1975) wonders if one can understand the normalization principle
to mean the modification of the behavior of those persons perceived as
deviant; in an attempt to make them as indistinguishable as possible
from anyone else in the mainstream of conventional culture? Herein may
lie the seeds of varying reactions to the concept: from Wolfensberger's
"a captivating watchword standing for a whole new ideology of human
management" to the opinion of some experienced workers in the field,
that normalization represents "an unrealistic fad like so many--it will
pass" (Zipperlen, 1975). Throne (1975) suggests that the normalization
principle ignores the fact that the mentally retarded do not develop
normally in response to normative procedures. Procedures which imply
ordinary conditions will perpetuate maintainence of the mentally re-
tarded person's developmental rates and will tend to stabilize the
mentally retarded in their retarded states (Throne, 1975). Throne fur-
ther states the need for specialized techniques designed to speed up
the developmental rates of intelligence and related skills. Nirje
(cited in President's Committee on Mental Retardation, 1976(a)) em-
phazizes the logic of the normalization philosophy and points out that
the principle applies to all retarded people, whatever their degree of
handicap and wherever they live. He further states that the application
of the principle will not "make retarded people normal", but rather that
it will make their life conditions as normal as possible, respecting the
degrees and complications of the handicap, the training received and
needed, and the social competence and maturity acquired and attainable.
So, he further asserts, the aims of care and services and goals of
training, in striving to develop a better adjustment to society, are
also a part of normalization. It is this common sense approach to understanding the normalization principle that is strongly supported by this author.

Baroff (1974) states that the right to "normalization" is the essence of the declaration of general and special rights of the mentally retarded. Vitello (1974) recommends that positive and optimistic thinking in terms of education be combined with realistic predictions of outcomes and he proposes cautions on the road to normalization; as did Nirje. The success story of normalization in a 19-year-old boy with Down's syndrome is presented by Frank (1975), in which he discusses the steps to success that one mentally retarded person, Marc, went through. The independence and skills achieved by the young man are attributed to his parents' treatment, expectations, and their belief in normalization at a time when institutional placement was usually advised. The normalization principle alone does not appear to be the total answer, but it is a step in a positive, more humane direction than has been seen in the history of treatment of our mentally retarded.

Basic Personal and Civil Rights

Judicial processes that once promoted institutionalization now provide the strongest impetus for deinstitutionalization, through decisions on due process, right to treatment, right to minimum wage, right to education, and welfare rights (Datel, 1975). Dramatic changes in the law and in public attitudes toward the mentally retarded can be seen when we speak of the mentally retarded as citizens. Until a very few years ago, the mentally retarded were referred to as 'children',
regardless of their age, abilities, or individual potential. Acknowledgement has been given to the mentally retarded citizen's right to habilitation and to life in the least restrictive environment. Basic civil rights that have long been ignored, relative to the mentally retarded population, are finally being recognized and are current issues within the judicial system.

In a Master's Thesis at Florida Technological University, Kathy K. Barraclough (Note 2) surveyed the 50 states' supervisors of the Department of Health, Education, and Welfare--Division of Retardation, and the Executive Directors of the major office of the Association for Retarded Citizens; concerning knowledge of legislation for the mentally retarded. Barraclough concludes from her results: people working with the retarded do not know the laws in their states and do not consistently handle the mentally retarded in the same fashion. "No two states have the same guidelines, laws, practices, or procedures" (Barraclough, Note 2, p. 161).

The past few years has seen an explosion of litigation on behalf of mentally retarded persons (President's Committee on Mental Retardation, 1976(b)). Most cases have focused on the minimum standards of humanness and treatment that must be accorded persons who are institutionalized after someone has decided they cannot function in the community. Ross (cited in President's Committee on Mental Retardation, 1976(b), p. 3). characterizes the traditional legal treatment of the mentally retarded as exhibiting high levels of denial and finds that through these mechanisms, the law has condoned the concept of mental retardation as
encompassing levels of functioning relative to levels of humanity.

The President's Committee on Mental Retardation convened a conference in 1973 and from that meeting drew together a comprehensive review of recent progress in ensuring the legal rights of the mentally retarded. The document produced from this conference is entitled, *The Mentally Retarded Citizen and the Law* (1976(b)). Numerous court cases are discussed relative to concern over the mentally retarded citizen and his rights. Legislation has been cited for example, in the state of Florida which permits physicians in state hospitals to allow children with Down's Syndrome and severely retarded persons to die, simply by withholding life sustaining procedures and drugs. The author of the bill states that of 1,500 severely retarded patients in Florida institutions, 90% should be permitted to die. "Why not let them die," urge components of such legislation, "when the money for their care could be used for such good social purposes." (cited in President's Committee on Mental Retardation, 1976(b)). The sponsors of this bill call it "Death with Dignity" for the mentally retarded person. It was not difficult to find reams of legislation that invited questionable morality. In 1976, a helpless mongoloid infant was denied life-saving assistance in a hospital in Decatur, Illinois. The events became tragically familiar. The film "Who Should Survive?", produced by the Kennedy Foundation, related a similar incident that occurred several years ago at the John Hopkins University (cited in President's Committee on Mental Retardation, 1976(b)). In general, these cases are rarely clear-cut with respect to evidence for the defense or prosecution; yet, they do
document the need for greater concern or acknowledgement for the retarded person's rights. Currently, misconceptions about the mentally retarded are still common in this society, and these misconceptions are shared by many lawyers, legislators, and judges. Too often legislatures adopt and reflect inappropriate and inaccurate stereotypes and beliefs. The mentally retarded appear to be among the first to have their human rights denied; the first to be experimented upon, to be placed in institutions, to be sterilized, to be allowed to wither, and even to be destroyed (Baroff, 1974). Environments as found at Willowbrook State School, New York; and Partlow State School, Alabama; have given a new impetus for a "Bill of Rights for the Mentally Retarded...which will enforce a commitment to a minimal standard of decency." Javits presented this vow for legislation while on a tour at Willowbrook State School (see Appendix B for further derivation).

**Fundamental Rights.** The basic fundamental rights to which the President's Committee on Mental Retardation (1976(b)) addressed itself, and the court cases associated with those rights will be examined.

The first right is the right to life itself. The second, the retarded person must have the right to an education in his or her immediate environmental setting. This principle has wide implications in the movement of deinstitutionalization and will be discussed in a little more depth than other civil rights. The starting point began with the court case of Brown v. Board of Education in 1954, which demonstrated that the federal judiciary showed special concern with the constitutional rights of minorities who had been unable to assert their inter-
ests in the political process. The decree set forth from this infamous and precedent setting case implied that there is no separate and equal education. The right to an equal education was awarded. The implication from this case for the mentally retarded was long in coming, but in 1972, in Mills v. Board of Education, the court held that: "shall be provided to each child of school age a full and suitable publicly-supported education, regardless of degree of the child's mental, physical, or emotional disability or impairment", and "the Board of Education has an obligation to provide whatever specialized instruction that will benefit the child." (cited in President's Committee on Mental Retardation, 1976(b)). In the court case of Pennsylvania Association for Retarded Children (P.A.R.C.) v. Commonwealth of Pennsylvania, the courts recognized the learning needs of the mentally retarded and acknowledged that every retarded person is capable of deriving some benefit from education. The Mills v. Board of Education court case unequivocally settled constitutional issues brought about by previous court cases and stated that retarded children have a right to education and rehabilitative services. To date, the highest judicial authority to recognize the rights of mentally retarded to equal educational opportunities is the Supreme Court of North Dakota. In re H.G., A Child, the case followed P.A.R.C. and the Mills decision and concluded that the state constitution and the equal protection clause of the fourteenth amendment of the United States Constitution requires the state to make educational opportunities available to all children (President's Committee on Mental Retardation, 1976(b)).
A federal law which adds credence and support to these previous cases was signed by Congress and became effective November 29, 1975 and is referred to as Public Law 94-142, better known as The Education for All Handicapped Children Act of 1975. Under this law is the stipulation that by 1980, all states will have mandatory school attendance for the retarded. Presently, states are drafting negotiations with the federal government so as to meet the minimum requirements as set forth by Public Law 94-142 in order to receive federal funds for assistance for these special programs.

A nationwide concern for the basic right of the retarded to treatment was reviewed and established that they have the right in; Donaldson v. O'Connor. This right to treatment issue involved two Florida physicians held personally liable for failure to treat a state hospital resident. They asserted that they did the best they could with resources available to them (President's Committee on Mental Retardation, 1976(a)). Should the doctors have had to show the good faith effort to secure sufficient resources in order to escape liability? It was found that a Pennsylvania case suggests that the answer is, yes! The superintendent of a state hospital was fired for dereliction of duty and allegations included unsanitary conditions. His defense was lack of funds, overcrowding, and understaffing. On a finding that the superintendent had made inadequate protest of inadequate resources, the State Civil Service Commission upheld his firing (President's Committee on Mental Retardation, 1976(a)).

The right to habilitation and to life in the least restrictive
environment possible is also seen in Wyatt v. Stickney (cited in O'Connor, 1976). This Alabama right to treatment case was begun by 93 employees of an institution who were fired due to state tax cuts. The terminated employees asserted that the residents would not receive adequate treatment, and as the case developed the claim and issues changed. The focus changed to the fact that even with these employees reinstated, Alabama's institutions still did not provide adequate treatment. This case establishes the adoption of minimum quantitative standards to give content to the duty of the court and found in the Constitution to provide "adequate treatment" to all involuntarily committed residents. This case reflects on the mentally retarded and mentally ill as well. It should be noted that the definition of "adequacy of treatment" was avoided (President's Committee on Mental Retardation, 1976(a)). Inherent is also the right of each resident to a "...habilitation program which will maximize his human abilities and enhance his ability to cope with his environment...;" the second is that "no mentally retarded persons shall be admitted to the institution if services and programs in the community can afford adequate habilitation;" and third, each resident has "...the right to the least restrictive conditions necessary...". (President's Committee on Mental Retardation, 1976(a)).

The right to fair classification has become another issue still pending. Cases like Dina and Larry P carry with them the issue of labeling and classification of children based on Intelligent Quotients derived from, what the defense claims, are culturally biased tests. These labels (EMR, TMR, etc.) have been shown to provide no gain at all
from services which carry the label (President's Committee on Mental Retardation, 1976(a)). Litigation concerning this particular issue has occurred in California: Larry P is still pending in court at the time of this writing.

As a result of these efforts, institutions are modifying current programs to meet these decrees and to "normalize" as much as possible. The court cases not only affect large institutions, but also the general public educational system across the nation as well. The public school system is being forced to provide greater services to the severely and profoundly retarded. Inherent in this demand is the reallocation of resources and the training of varied professionals in dealing with a predominately new student population. This is where Public Law 94-142 hits home and also where Wyatt v. Stickney indicates a potential for great expansion in community placement.

Deinstitutionalization, while worthy of implementation in the case of many institutionalized retarded persons, may be fraught with personal and legal problems for others. Legal arguments have been advanced to support the need for careful examination of the management and rights of the retarded. It is anomalous to speak of the law and deinstitutionalization without at the same time speaking about the law and institutionalization, for what is at stake either is a decision as to the person's appropriate life style, a decision as to what is the "best" placement of that person, whether in an institution or within the community in some smaller institution. There are innumerable legal issues in deinstitutionalization. A brief review of these issues is
Deinstitutionalization and the Law. Deinstitutionalization and the law encompasses many legally unresolved implications in the deinstitutionalization process. This author will present some additional considerations which directly affect the mentally retarded citizen. Turnbull and Turnbull (1975) present a discussion relating to the law and deinstitutionalization in a rather speculative and argumentative manner. The following is a condensed summary of their speculations with appropriate comments.

The "due process" issue; a 'right to confront the public or its representatives and be heard by an impartial arbiter before the public takes action with respect to that individual', has been found to be granted to the mentally retarded only with respect to the placement of the mentally retarded in special education programs (Turnbull, et al., 1975). There is apparently no "due process" available to the mentally retarded person in regards to voluntary admission to an institution or to voluntary discharge to a community setting. This is based on the traditional assumption of the courts that the mentally retarded person is unable to participate in these decisions because it is assumed that the mentally retarded person is not capable of the level of functioning needed to comprehend these decisions. The courts, along with many of the service systems for the mentally retarded, have let the impressions and abilities of the severely and profoundly retarded individual govern their decision making practices (Mamula & Neman, 1973). Nevertheless, parents and/or guardians (including the courts) are the primary decision
makers for the mentally retarded. Yet, as this author has noted through work in an institution for the mentally retarded, the best interests of the retarded person are not always the same as, and indeed frequently conflict with, the wishes of the parents or administrators. A prime example is the parent who states that their mildly mentally retarded child will not be placed in a foster home and further asserts the reason is that the child is 'safer' and more 'secure' in the institution.

Baroff (1974) demonstrates that the mildly retarded person can function more adequately in community facilities. The legal assumptions in favor of parental custody or the parental veto need strict examinations. Parents who have not visited or communicated with their retarded child in years, still have the authority to veto possible transfer to a group home or training program. Where do the parents' rights end and the child's or "adult" retardates' rights begin? No courts have yet addressed this question formally. There are many retarded people in institutions simply because their parents feel it is a safe and/or a convenient placement (Turnbull, et al., 1975).

The numerous persons involved with placement decisions—parents, administrators, social workers, psychologists, physicians, teachers—have enjoyed substantial immunity in that their decisions with regard to the mentally retarded individual are not appealable. Litigation is underway that is attempting to make this immunity obsolete, with parents and legal advocates for the retard persons being able to sue the decision-making professionals (Turnbull, et al., 1975) when it is felt that decisions made are not in the child's best interests. Parents
have frequently placed their children in institutions based on advice from general practitioners of medicine, who have often admitted to having little knowledge of mental retardation (Turnbull, et al., 1975). Upon examination of reports done by licensed clinical psychologists in the institution where this author works, the following was classic: "This child, with an I.Q. of 48, will never be able to do much for himself and will be totally dependent on others for his needs. Institutionalization is strongly recommended before parents become too emotionally involved." This psychologist had little knowledge of the abilities of a person with an I.Q. of 48. A person functioning within the moderate range of intellectual deviation has the abilities to develop a maximum of self-help skills (eating, toileting, dressing), and basic education skills at the pre-kindergarten to kindergarten level (Baroff, 1974; Sattler, 1974). The parents, based on the psychologists findings, institutionalized the retarded person. It is felt that alternate community or home placement may have been a viable alternative that was prematurely ruled out.

An emerging legal problem is to define the role of the institution in preparing parents, the resident, the receiving facility and the community in general for deinstitutionalization. These issues are not yet recognized as legal responsibilities of a deinstitutionalizing facility. Scheerenberger (1974), Datei et al. (1975), and Jasper (Note 3) presents models for deinstitutionalization as requiring collaborative preparations by state and community agencies. These models show the degree of integration of work necessary for an effective process. The under-
standing of a need for total co-operation has been identified, and yet the proper litigation is inherently necessary to ensure pressure for adhering to these standards. It is further unclear whether or not the rights possessed by a resident of an institution survive his deinstitutionalization and carry over to the community. As noted before, Public Law 94-142 does extend the right to education and individual education plans as a global entity encompassing institutions and communities. Turnbull et al. (1975) notes that without necessary legal safeguards, deinstitutionalization will not be a satisfactory answer to the problems of institutionalization. In short, we do need to supply the legal protections that retarded persons in the institutions are partially receiving to those who are being deinstitutionalized.

Advocacy

Throughout this paper, maximal feasible integration of the mentally retarded into the cultural mainstream has been and will be discussed. Generally, a child in our society has one or two parents who provide for his/her physical and emotional needs, who socialize him/her into the larger culture, and represent his/her interests. As time passes and the child matures, society expects the individual to function with competent independence and to solve his/her own problems. This functioning is perceived as "normal". Inevitably, there are people who cannot develop to a "normal" state of functioning. In relation to the mentally retarded, the services of "advocacy" groups are essential to fair and humane management of the mentally retarded. Advocacy groups, in general, strive toward provision of better and more "normalized"
services for the retarded. They are giving energy to the deinstitutionalization movement since in theory deinstitutionalization is suppose to provide that which they strive for; more and better humane services to the retarded. Their role can be viewed as guardians who oversee programs to maintain accountability.

Current descriptions of advocacy range from narrow definitions of individual case representation (e.g. by a parent, lawyer, administrator, court, etc.) to the broad field of generally speaking and acting on behalf of the mentally retarded as a group. There is also considerable diversity when it comes to the role of the advocate and the objectives of advocacy within a particular advocacy model. Advocacy is seen by Wolfensberger (1972) as a means through which "normalization" will be aided. He speaks of citizen advocacy as, "a mature, competent citizen volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention" (cited in President's Committee on Mental Retardation, 1976(b), p. 597). The safeguarding of rights of the mentally retarded is a concern of mankind perhaps as old as mankind itself. Wolfensberger notes that although the word "advocacy" has its historical connotations, the way in which it is used today and the intensity of its meaning are relatively new (cited in President's Committee on Mental Retardation, 1976(b), p. 618). Wolfensberger states that inherent citizen advocacy is the concern with providing the "least restrictive environment" to the mentally retarded and only such protec-
tion as consistent with normalization concepts. The advocate can fulfill many roles which include: adoptive parents, guardianship successors, and so on.

A study in Hamilton, Ontario confirmed something about guardianship that many people have suspected for some time. In this study, it was found that the need for guardianship was inversely related to the quantity and quality of available informal social supports. When there are strong informal and social supports, there rarely is a need for formal guardianship, and vice versa. This finding is highly supportive of the least restrictive alternative principle (cited in President's Committee on Mental Retardation, 1976(b), p. 620).

Wolfensberger (1972) discusses his view of what the role of the advocate is. Advocacy roles can range from minor to major, formal to informal, short-term to long-term. This includes: formal advocacy as seen with adoptive parenthood, guardianship, and trusteeship for property; informal roles include friends and guides. Advocacy service agents also include: federal, state, and local services as provided by law, e.g., Social Security benefits, Veterans' benefits (children of servicemen), guardianship, and legal counsel (Baroff, 1974, p. 125). In the development of advocacy, it was considered critical that advocates have a stable administrative source for backup. The advocacy office was "invented" to be this mechanism. The first two advocacy services were initiated in Nebraska in late 1969 and early 1970 (Wolfensberger, 1972). A youth advocacy service was established in Nebraska around the same time to give continued support to mentally retarded
residents discharged into the community. Both of these services have been noted to be widely imitated across the nation.

The New York State Committee for Children views "advocacy" as "a strategy to reduce the discrepancies between the services which are presently available to cope with problems. Advocacy is not a blueprint for the future, but a means of implementing better service systems for children." (President's Committee on Mental Retardation, 1976(b)). It appears then, the the view of government held by the initiators of the advocacy program will be a decisive factor in how the agencies and advocates work together. If the government is viewed as in need of prodding and friendly reminders, then the New York strategy to reduce discrepancies between services and needs makes sense. If the government is viewed as the enemy ally, then advocacy is differently defined. The adversary situation exists and bargaining or promoting arbitration is needed (President's Committee on Mental Retardation, 1976(b)).

An appropriate question at this point is "What are we advocating for?" The obvious reply: "For the good of the handicapped." The advocate attempts to obtain that which is beneficial for the handicapped person. To obtain any such benefit, the advocate employs any number of available "tools". "Tools" are needed to be able to provide advocacy and the legal system is usually viewed as the best. Professionals may select "tools" from their areas of expertise and non-professionals from common sense or just plain concern. A federally funded project, located in South Bend, Indiana; the National Center for Law and the
Handicapped, was formed to fight for and establish legal rights for the handicapped. Its scope is broad and includes all handicapped persons. Besides promoting litigation, it aids in getting favorable rulings from the legal system. There exists federal legislation such as Public Law 90-480 which provides for removal of architectural barriers in new or remodeled buildings that are built by the federal government. Originally, no provision for enforcement of this law was available. Recently, Public Law 93-112, was enacted and is designed to solve the problem by adding an enforcement agency to make sure builders comply with legislation (President's Committee on Mental Retardation, 1976(b)). This is an example that demonstrates how advocates and advocacy agencies are attempting to normalize conditions by first addressing institutional reform: which serves as a requisite to community alternatives and as a pre-requisite in a program of deinstitutionalization.

The National Association for Retarded Citizens, American Association on Mental Deficiency, Council for Exceptional Children, and Human Rights Advocacy Committees on the state or local level, are vehicles that have emerged over the years and are critical to the goal of and process toward deinstitutionalization. In general, they define their roles as asserting, establishing, and maintaining the rights of the mentally retarded or handicapped. Wolfensberger (1972) outlines the philosophy of the National Association for Retarded Citizens as the responsibility of friends of the retarded to obtain, rather than provide services. This was found to be the philosophy of the Riksfoerbundet for Utvecklingsstoerda Barn (F.U.B.); the national organization
of parents of the mentally retarded persons in Sweden.

With the previous discussion of advocacy for the mentally retarded, a growing recognition of the term and need for advocacy is occurring. Undoubtedly, the mentally retarded person is in need of a stronger advocacy. If there had been a good, strong advocacy base, then the problems and horrors that are continually brought to the public's eye, especially regarding institutional care and treatment of the mentally retarded, would not be in existence. Safeguarding the mentally retarded, specifically, has not been a strong point in the history of the mentally retarded, nor has it been an easy service to provide. Many professionals, particularly social service and institutional professionals, have been hostile to citizen advocacy. Some dissatisfaction toward advocacy groups is legitimate as these groups are an inconvenience. Yet, we must realize that there is a tremendous limitation in the capacity of paid human services, professionals, and attorneys to meet the needs of the handicapped (President's Committee on Mental Retardation, 1976(b)). Advocacy groups address problems relevant to the institutional setting and community setting as well. Their basic role in the deinstitutionalization process is that of assuring the rights of retarded persons within the context of making programs and services for the retarded more humane.
Alternatives to Institutions

The limited economic, social and human resources of the modern family have made public and private social agencies an indispensable and essential form of service for those who are severely mentally handicapped. Many forms of services are possible for these agencies, including large institutions and/or residential homes. This paper has, to this point, discussed the background for deinstitutionalization by reviewing concepts such as normalization, the basic civil rights of the retarded, and advocacy. These concepts have helped to foster the growing change in attitudes toward the care of the mentally retarded. These concepts emphasize placing institutionalized residents in community living situations rather than having them remain in large institutional settings (Silva & Faflak, 1976). The efficiency of small specialized residences as a substitute for institutional residences is complementary to the normalization principle. In theory, the push for deinstitutionalization is seen as being able to provide equalities of life more like family living with personalized attention, fewer caretakers, and increased civil liberties and responsibilities.

Currently, in many areas of the nation, and inherently also within every state, there are few alternative living accommodations with social and rehabilitation backup services to meet the needs of the clients. There is also obvious competition among the duplication of services as well as a lack of co-ordination among the various community resources.
Many issues of concern are still pending in the courts, legislature, and even state and local agencies. This process is not and has not been an easy one, it encompasses all sorts of barriers. States across the nation are fumbling, first to find merit in deinstitutionalization and secondly, to set up a logically oriented design for the process. The question, "Is deinstitutionalization a viable process and what has been accomplished?" will be addressed in the following pages of this paper.

A Beginning

The push for deinstitutionalization can be seen as a relatively new movement to some, and as a relatively old one to others. Wolfensberger's (1972) concepts were stimulated from the Scandinavian countries long before the United States acknowledged thoughts of normalization or deinstitutionalization. As noted previously in Wolfensberger's historical review of the origin of institutions, the earlier viewpoints (1800's) stressed that the institution serve as a temporary training school. It appears that at that time in history, an orientation toward community placement can be seen. This orientation changed with time as the institution developed into a permanent home for many of the mentally retarded. Today, the shift is moving back to community placement. It is felt that the United States has made a circular movement in regards to philosophy and management of the retarded.

Dr. Alexander L. Britton (Note 4), who teaches at California State University at Long Beach, presented his findings on care for the mentally retarded persons in Sweden. He and his wife toured Sweden in June
and July of 1976 and expressed gratitude to Dr. Karl Grunewald, the M.D. who is head of the Division of Care of the Mentally Retarded of the Swedish Board of Health and Welfare in Stockholm. Dr. Grunewald works extensively with the normalization principle and its concepts. Sweden has functionally adopted this concept with both logical and systematic implementation with their mentally retarded populations. The philosophy of Dr. Grunewald emphasizes upward mobility; i.e. assisting retarded citizens towards as much independence as possible, toward living as normal a life as possible in as normal a setting as possible (Britton, Note 4). Dr. Britton notes with admiration the dignity that the Swedes give their mentally retarded. This dignity is well documented and exhibited in their residential facilities. These facilities have been described by Britton (Note 4) and Grunewald (cited in President's Committee on Mental Retardation, 1976(a), pp. 253-265) as relatively small, modernly furnished, comfortable, and conducive to dignified caring. Grunewald (cited in President's Committee on Mental Retardation, 1976(a), p. 259) provides a table of statistics to document some of these findings and statements (see Appendix C for further derivation). Sweden is in a position now to decentralize and integrate its institutions for the retarded more now than ever before. The percentage of Sweden's population that is mentally retarded is estimated at .6%. This figure does not include those who are mildly retarded, because most of them attend school or find work and are absorbed into the society. In Sweden, the people regard the mentally retarded as people. No one seems to question or wince at their rights. Britton (Note 4) asserts the possibility
"that providing this welfare service is a protection of self; that is comfortable knowing that the service is available while one hopes that it will never be needed." Isn't it almost like the Americans' philosophy towards life insurance?

The findings and feelings presented by Dr. Britton (Note 4) suggest the reality of the possibility for dignified caring for the mentally retarded. The deinstitutionalization process has already taken a major leap forward in Sweden. I have visited Sweden several times myself, and have seen first hand the cultural emphasis of giving the handicapped and aged due respect and dignity.

The Scandanavian countries appear to have taken the lead in normalizing environments for the mentally retarded. Denmark is another country which has statistically demonstrated that its' efforts have been received and have been successful. N. E. Bank-Mikkelsen, currently director of the department for the care and rehabilitation of the handicapped, received the Kennedy Foundation award in 1968 for recognition of his program development work. Under his direction, Denmark experienced a surge of growth in services for the mentally retarded and a growth in community alternative programs. In both Sweden and Denmark, the medical model of mental retardation has been supplanted by a social model placing responsibility for management of the mentally retarded with a variety of disciplines. By no means are the efforts complete, but they are established (cited in President's Committee on Mental Retardation, 1976 (a), pp. 241-252).

Ontario, with a population of approximately eight million, has also
experienced a change in the focus of dealing with the mentally retarded as presented by Donald Zarfus (cited in President's Committee on Mental Retardation, 1976(a), pp. 267-276). Two major changes include: moving away from the large institution toward the unit system, and having the Ministry of Education assume responsibility for all educational programs for the mentally retarded. The unit system, designed to replace the medical-nursing model, introduced the concept of grouping together retarded persons of both sexes into units where their needs would be related to four components: (1) hospital care for chronically ill persons, (2) educational unit for all children attending school programs supplied by Ministry of Education, (3) activity unit for those not requiring medical care, but not qualifying for school programs, and (4) adult training and rehabilitation unit for vocational training. The de-emphasis on the medical model is seen with a move toward emphasis on a training model. With the Ministry of Education owning the responsibility the level of the teaching competency has reportedly improved, as did the programs. The deinstitutionalization movement is viewed as ongoing with hopes that the present inflation and recession will not cripple the push for better services.

Great Britain is yet another country that has shown attempts and successes in their push to decentralize institutional care for the mentally retarded. Albert Kushlick presents a discussion centered on Wessex, England. He cites that research has been carried on since 1963, and includes a six stage program involving, locating, defining, developing, refining, and carrying out needed services for the retarded. The
British have discovered that they can provide better services with locally-based programs and appear to be positively headed in that direction. Locally-based programs include: domestic settings near the retarded person's home and small living units (hostels) within the community setting (analogous to America's foster/group homes). Based on Wessex, England; the use of institutions as centers for consultation and training professionals to work with the retarded has developed (cited in President's Committee on Mental Retardation, 1976(a), pp. 297-312).

It is not within the scope of this paper to present in any further detail the process of deinstitutionalization in other countries besides the United States. Comparative statistics have been supplied to show the downward change in the census of institutions in Sweden, Denmark, and Ontario (see Appendix C). The fact to be recognized here is that other countries are well versed in the philosophy of normalization for the mentally retarded. The experience of these countries should dispel doubts about the feasibility of decentralization in the treatment of the mentally retarded in this country.

Planning Alternatives

There is a great concern over the issue; How is deinstitutionalization to come about? The concepts reviewed earlier in this paper do not address the pragmatic problems of individuals who must implement programs or of the management systems needed. Several prominent people in the field of Mental Retardation and Psychology have proposed models to deal with this issue. It is important to keep in mind that the
basic objective of residential normalization is the development of small group homes which provide residents with as near a family environment as possible. Also, a viewpoint held by many officials indicates that community alternatives will cost less than large state-run facilities. The following is by no means a complete review of these models, but it is intended as illustrative and as an overview.

Scheerenberger (1974) notes that all states are attempting to meet the needs of the mentally retarded, and at the same time resolve some of the critical problems confronting most residential facilities through the dual process of deinstitutionalization and institutional reform. His primary focus is on deinstitutionalization. By definition and practice, the residential facility in the community must be considered an integral part of the community. The degree to which it is a successful member of that community is dependent upon its interaction and involvement with the community (Scheerenberger, 1974).

The community placement that is available to the mentally retarded should provide the "least restrictive environment"; however, placements in foster homes, group homes, or nursing homes frequently are more restrictive than residential living in a public facility. For example, Murphy, Pennee, and Luchins (cited in Scheerenberger, 1974, p. 4) examined foster home placement in Canada and concluded: (1) there was little to no interaction between residents and family; (2) regimentation and uniformity were common; and (3) little to no interaction between residents and the community occurred. It appears then, that foster home placements can have the same stigma that has been associated
with large institutions, without some of the benefits of the institution. Luchins summarized his observations by stating:

> it is my opinion that those who think foster home placement enables a patient to escape the disadvantages of an institutional life are mistaken. Foster homes can be as institutionalized as hospitals are, while lacking the compensatory advantages that hospitals might possess (cited in Scheerenberger, 1974, p. 4).

California is mentioned time and again as an example of poor planning for community alternatives (President's Committee on Mental Retardation, 1976(a). *Time* magazine described deinstitutionalization efforts in California:

> chronically ill patients have been returned to communities poorly equipped to provide adequate treatment. With no one to care for them, former patients have ended up on Welfare rolls, in boarding houses, cheap hotels, and even jail (1973, p. 74).

Such reports are not made to condemn community placements, but rather to show that others have tried to place their retarded without proper planning and have not necessarily succeeded in providing any greater dignity to the mentally retarded.

Scheerenberger (1974) points to five ingredients for successful deinstitutionalization: (1) local authority, (2) standard-setting,
monitoring agency, (3) back-up services, (4) adequate financial support, and (5) effective advocacy program. An examination of our efforts in these areas follows. First, local authority: Scheerenberger notes that there must exist an agency to be responsible for planning, implementing, and co-ordinating the services for the mentally retarded; it should have statutory authority and be legally accountable. Currently, there appears to be an incredible bureaucratic maze involved in this first step (Friedman, Note 1). Secondly, after a prospective group home developer has gone through this maze, he is confronted with independently determined standards (Friedman, Note 1). After finding a comparable place, he is faced with the state code, the city code, regulations for intermediate care facilities for the mentally retarded, national life safety code, safety inspectors, fire inspectors and many others (Friedman, Note 1). Inherent in having all of these organizations involved is the fact that each carries with it different standards. The process is complex and confusing. Periodically, back-up services are needed and are difficult to identify. Adequate financial support appears lacking, as Butterfield's report indicates (cited in President's Committee on Mental Retardation, 1976(a)). Friedman (Note 1) cites double standards of deinstitutionalization that he collected from a detailed report to the Congress of the Comptroller General of the United States, 1977. In this report, Friedman (Note 1) points to ways in which contradictory federal regulations have hindered effective deinstitutionalization programs, and at the same time he notes ways in which such road blocks can be alleviated.
As noted in the preceding review, current federal and state operations have created obstacles and disincentives to the development of desirable and effective programs that place the mentally retarded in the least restrictive alternative available, such as own homes and group homes. It is clear that if deinstitutionalization is going to take place and be successful, a variety of programs must be available to each community. It is equally clear that if appropriate community-based programs are not available in sufficient number and of high quality, that many deinstitutionalized people will meet with frustration and failure and possibly be returned to the institution. That is what had happened in, for example, California. It is the prevention of that kind of catastrophic occurrence which requires us to analyze the deinstitutionalization process very carefully and which leads us to believe that institutional reform is an essential ingredient.

Models for Deinstitutionalization

Several states have provided papers and systematic planning alternatives for the mentally retarded or disabled individual. Availability of papers and materials limits this discussion to a few states, yet does demonstrate some working models for deinstitutionalization and implies that interest and progress is occurring in relation to the deinstitutionalization movement.

An integration-of-services model being tested in Virginia features a coalition of institution and community workers to assess the client's needs and prescribe services (Datel & Murphy, 1975). Grant monies awarded in 1972 from the Social and Rehabilitation Service, DHEW, were
utilized to study service integration strategies across 12 states. Datel et al. (1975) describes the model of service integration for deinstitutionalization (SID) that resulted from the funded proposal to be applied to the residents of state institutions. In concept, the procedure is applicable to any institutionalized citizen in any state. It purports to try to overcome the pitfalls of the deinstitutionalization process. The SID procedures rest upon collaboration of all state human service agencies and community counterparts. The model has five "socio-technical" components, each a "service-integrating" mechanism in client processing: (Datel, et al., 1975).

1. Assessment and Prescription (A&P) Team: a coalition of institutional staff and community delivery staff.
2. Broker Advocate: acting for the client in arranging and maintaining service delivery.
3. Automated Information System: for the case manager as well as for the program administrator.
4. Quality Control Team: project staff who evaluate, develop, and co-ordinate the system as well as identify problem issues.
5. Committee of Commissioners: the governing body for the model's operation.

This model includes program activities not directly related to the resident, but are essential to the model's integrity and viability. Datel et al. (1975) present a precise flow diagram that demonstrates the main client-processing sequence. The progress of this model to date appears to be rather positive. The model has been in operation
since May 11, 1973. Approximately 376 clients have been processed with this model system. Some 65 percent were recommended for community placement with 22 percent actually being placed. Lack of community resources to meet prescriptions accounts for the large discrepancy between number of clients prescribed for community placement and the number actually placed (The gap is largest for mentally retarded persons) (Datel, et al., 1975).

As clients are processed, needs become known, information is distributed, plans can be drawn; as service deliveries cooperate, mutual objectives are defined; as public awareness grows, public support is increased; as state agencies collaborate, funds are consolidated (Datel, et al., 1975). Unlike The Right to Choose publication authored by the National Association for Retarded Citizens, (N.A.R.C.); Datel, et al., (1975) give a systematic service-integrating procedure. In the National Association for Retarded Citizens handbook are guidelines that are brief and present central issues and concerns to a beginning interested party; in a step-by-step process. The handbook presents its basic view from the developmental model in regards to a treatment approach system. This model's central concept is that the mentally retarded should live in a home-like environment. From this concept the handbook gives the step-by-step procedures in achieving residential alternatives in the community. No statistics or success of using this approach are presented. This model is not as complicated as Datel's, yet provides a good overall picture of the processes involved in the deinstitutionalization movement.
Mamula and Newman (1973) developed a comprehensive handbook for community agencies and social work practitioners dealing with community placement of the mentally retarded individual. The concise handbook provides information to aid in the development and maintenance of community placement programs. A discussion of the history of the development of community programs is presented and discusses current and future trends in community placement programs. I found its practicality refreshing as actual examples of the how-to-do-it are presented. Mamula and Newman (1973) view the concept of community placement for the mentally retarded as a preferred mode of rehabilitation and treatment. Although community treatment has received considerable emphasis, few community alternatives have developed the necessary facilities and concomitant supportive services for the successful community adjustment of the mentally retarded (Mamula & Newman, 1973).

The Minnesota's Governor's Planning Council on Developmental Disabilities (Note 5) developed a model to serve as a guideline for persons responsible for directly implementing programs for clients. The Community Alternatives and Institutional Reform (CAIR) project, the model proposed by this council, gives a detailed sequence for the deinstitutionalization process. Working materials and models are presented as aids. No conclusive research with this model has been done.

Thomas (Note 6) discusses the deinstitutionalization process and reviews why, in his opinion, failures and frustrations occur in the process of preferred placement. He states that community-based programs will cost as much as institutional care, if they provide the same level
of service. This issue of economic gain or loss has been noted to be a currently debatable issue (Mamula & Newman, 1973). Thomas (Note 6) states that it will be very difficult to provide effective services and obtain enough money to operate two complete service systems; one in the institution and one in the community. Further, even if monies were available, there simply are not enough trained people in the field to provide services for two complete systems. Therefore, Thomas (Note 6) offers a practical solution in dealing with this one aspect of deinstitutionalization. He states that realistically institutional programs and personnel must be rearranged, decentralized, and relocated in community-based programs. Through the development of the "Minnesota Learning Center Model" (MLC), Thomas (Note 6) presents a plan that demonstrates that decentralization is possible and effective results can be obtained. Reorganization as an institutional reform is possible and has been accomplished with the MLC. The organizational revision which occurred with implementation of the MLC model had certain positive effects, as cited by Thomas (Note 6). A summary of the effects include: (1) decrease in time MLC youth spends in institution from a mean of 407 days to a mean of 227 days; (2) dramatic increase in the rate of academic progress as measured with a pre and post test using the Wide Range Achievement Test; (3) increase in community placement and success of MLC youths as shown with comparisons during the departmental structure and during MLC structure; percentages increased from 35% placed and remaining in the community during departmental structure to 70% placed and remaining in the community with MLC structure, and (4) a
33% decrease in the use of sick leave by MLC staff. It would be misleading to attribute all these beneficial effects to the implementation of the MLC structure. Thomas (Note 6) states that there he found no sure way to be certain what effects were due to reorganization and what were due to other variables. He cites the need for replication of the MLC in other institutions before beneficial effects can be said to be the result of the MLC structure. Thomas (Note 6) suggests that institutional reform need not be destructive of existing institutional programs. Overall, institutional reform can lead, according to Thomas, directly to deinstitutionalization and allow institutional personnel to contribute to the development of community-based alternatives.

The recommendations made by the New England Case Conference on issues particular to the state of Maine concern the means of implementing deinstitutionalization (Note 7). Because of the numerous difficulties encountered in implementing a deinstitutionalization program, the Regional Developmental Disabilities (DD) Advisory Committee, Department of Health, Education and Welfare, Region 1, (Conference, Note 7) suggested a conference to discuss a particular case that possibly could be generalized across states. The conference was pre-planned with participants receiving communication regarding the particular case prior to coming to the conference. The results of the conference can be divided into three main categories: definitions of deinstitutionalization, recommendations on national issues, and recommendations on the issues in Maine. The conference centered on the particular case of the one major institution, once synonymous with mental retardation in Maine,
Pineland Center. The major problems discussed at the conference fall into two categories: those dealing with attitudes and those dealing with resource allocations. The conference members concurred that the nation, as a whole, is not committed to a positive, supportive role in aiding the developmentally disabled and inherently the mentally retarded. The need for massive community education was strongly recommended. Resources were cited as being unevenly distributed across the nation. Bureaucracy was cited as resisting deinstitutionalization in their lack of reassignment of employees and lack of open communication. A need for better transportation was cited along with legal reform. As deinstitutionalization continues, institutions will have to provide a highly specialized type of service. At that time, it will be especially necessary to prevent unwarranted institutionalization, as Jaslow (1966) spoke of. This can be aided by improvement in the diagnostic and evaluation system (Conference, Note 7). The participants response was favorable with strong recommendations that conferences be set up similar to this one, due to its productiveness in defining and brainstorming issues in a cohesive fashion that leads to greater awareness.

Community Alternatives

For the past few years, one aspect of an institution's connection with the community has been expressed by the term deinstitutionalization. The residential alternatives to the institution, developed as a result of the increasing criticism of large institutions and the thrust of normalization, consist of various community-based living situations. As we all know, the cornerstone of successful adjustment in the
community is the appropriate development of local services for the resident. The community alternative is presently viewed by most people involved with the mentally retarded as being an optimal placement as compared to the large, state-run institution.

Changes have been noted in management systems and services for the mentally retarded. These changes will be discussed in the following section.

Changes in Residential Facilities

Earl Butterfield (cited in President's Committee on Mental Retardation, 1976(a)) has reviewed some basic changes in public residential facilities across the United States. Information about the number of residents in public residential facilities was collected for the first time in 1950. In that year there were 128,145 residents in public residential facilities for the mentally retarded. Since 1950, similar information has been published for every year until 1971. From 1955 to 1967, statistics indicated an increase in admissions from 143,548 to 193,188 and then a decrease to 181,058 in 1971. Butterfield (cited in President's Committee on Mental Retardation, 1976(a)) noted that official statistics have not been released for 1971 to 1976. He estimates a decrease in the institutional census during 1971 to 1976, if 1971 to 1976 is indicative of earlier time periods. Scheerenberger's (1976(a)) study of 192 public residential facilities (PRF) indicates that there are 10% fewer mentally retarded persons in public residential facilities today than in 1969, or approximately 15,000 persons less than 1969.

Butterfield and Scheerenberger's studies indicate, in general, that
states are decreasing their institutionalized populations. Butterfield cites 31 of 50 states as decreasing their institutional populations between 1967 and 1971. Yet, he speculates on the statistically significant consistancy of admission rates over the years suggesting an overall relative decrease. A possible hypothesis is that the people working in institutional settings view the normalization principle and community placement as positive trends. It further appears that the public, including the parents of the mentally retarded, still maintain many of the old traditional attitudes toward the mentally retarded that have aided in maintaining admission rates.

Scheerenberger (1976(b)) found that the older the facility, the greater the bed capacity and, therefore, the greater number of residents. An overview indicates that newer facilities are much smaller in bed capacity and thus have smaller resident populations. This trend toward less populated facilities can be viewed as consistent with the normalization principle, and possibly indicates attempts at community placement or deinstitutionalization. Butterfield's (cited in President's Committee on Mental Retardation, 1976(a)) research demonstrated significant decreases in the number of residents per employee and the number of new institutions to indicate an effort at providing better care for the mentally retarded.

Butterfield's (President's Committee on Mental Retardation, 1976(a)) study uses rates of admission per 100,000 population, daily maintenance costs and number of residences per 100,000 population, to give a national comparative picture from 1960 to 1971. The state with the
worst statistics was Alabama. Alabama's rates of expenditures were the lowest; its per capita number of residents increased while its per capita first admissions decreased to practically zero. Alabama's institutions were severely overfilled, yet discharge rates were not as rapid as other states. Alabama also rated the lowest on Butterfield's ranking of states according to a score reflecting effort to provide effective residential care. Unlike Alabama, New York has a respectable relative standing, yet also has had its shortcomings as seen in the 1970's with the disclosure of the Willowbrook facility. Connecticut has been hailed as outstanding. It releases its institutionalized at a faster rate and has higher expenditures allocated per capita. According to Butterfield's formula for reflecting effort to provide effective residential care, with a scoring range of (highest) +5 to (lowest) -4; Illinois was the only state with a +5. Connecticut, Michigan, and Pennsylvania had a +4; California, Colorado, Hawaii had +3,...to Alaska, Florida, Louisiana with -1; and South Carolina, South Dakota, and Alabama with the lowest of -4. The scores on which these ratings are based do not reflect any absolute standards of treatment, but do give a comparative viewpoint on the status of states. Butterfield concludes with the opinion that we still lack objective information on the quality and outcomes of care provided by residential facilities. Also, he found it easier in 1969 to obtain this data than in 1975. In 1969, there was a two-year lag, now there appears to be a four-year lag. Scheerenberger (1976(a)) supports Butterfield's contentions that the development of comprehensive community services for the
mentally retarded has not progressed as rapidly as one would desire; nor, in Scheerenberger's opinion, does the data collected demonstrate any significant effort or impact relative to the deinstitutionalization movement. His study was also based on the 1971 statistics gathered from the states; the current picture may be assumed to be changing.

Processes are slow due to the many cogs in the wheel of progress. Bureaucratic mazes hinder movements left and right as the movement toward providing more normalized efforts for the mentally retarded continues. The outlook is viewed as optimistic and there have been successes. The following sections are presentations more specific to the effectiveness and nature of the community alternatives.

Economics

Foster-family case homes, for example, are one type of community placement program which offer a community-based, family-type living pattern. If used appropriately, this environment may be more conducive and less discomfort to the mentally retarded. Small group homes, boarding homes, apartments, intermediate care facilities for the mentally retarded (ICF/MR) are all alternatives that have the potential of providing the mentally retarded with a greater environment for learning and for coping. A community-based residential service is some type of housing, other than the individuals natural home, usually designated for not more than 12 persons having similar needs in terms of age, independence and/or ability (N.A.R.C., p. 8, 1973). The community's resources are more appropriately used and economic gains to the community have been documented, both in terms of human resources and costs of
operation (N.A.R.C., p. 7, 1973). Mamula et al. (1973) states that the actual monies saved without compromising the quality of the placement is still being debated. For example, a study by Cox and James (cited in Mamula, et al., 1973, p. 4) indicated that the foster-family care placement of twenty-four children saved a particular state $200,000 in one year. In California, the State Department of Social Welfare estimates that family care placements save the state in excess of $3,000 per individual per year over the costs of institutionalization (cited in Mamula, et al., 1973, p. 4). Consequently, because of its economy, the concept of community placement has gradually emerged in social work practice replacing the older traditional model of institutionalization (Mamula, et al., 1973).

Current National Perspective

Scheerenberger (1976(a)) studied the makeup of current institutional populations of mentally retarded. He found that 55% of the total population were multiply handicapped, 63% of the new admissions were severely and profoundly retarded with 37% mildly, moderately and borderline retarded. More often than not, the multiply handicapped severe and profound are the most difficult to provide treatment for and are thus placed in institutions as cited in a previous study by Saenger (cited in Baroff, 1974, pp. 353-356).

According to a survey performed in New York state, one-third of the mentally retarded persons living in institutions could have remained in the community if alternative local services had been available (cited in Birenbaum, et al., 1976, p. XVI). There are few studies that show
the utilization of community-based services for the mentally retarded because efforts to create effective halfway houses and group or foster homes are very recent in most states.

Nihira and Nihira (1975) completed a survey of adaptive behaviors of 426 community placed residents. From 1344 incidents collected, 194 were of positive or normative behavior. Of these, 123 involved gains in acquired skills and 71 involved gains in approved interpersonal relations. The findings were felt to be representative of the kinds of normative behaviors the mentally retarded are involved with in community placement. The findings were derived from a single incident with time limits and, therefore, should be viewed as explorative rather than as inclusive (Nihira, et al., 1975). It appears that the caretakers were primarily concerned with the self-help skills and socialization skills of the residents and that gains toward independence in any area were positively approved. This study reveals the fact that by letting the mentally retarded person fully develop the self-help skills that he/she has the abilities for, an allowance is being made that enables the mentally retarded person realization of his/her personal potential. Community clients can, and do, reach for a more normalized life in a more normalized environment. This demonstrates the philosophy of the "normalization principle" and the "right to the least restrictive environment".

A report of an experimental program was done by Birenbaum and Seiffer (1976). Their book examined the progression of events that happened to 63 men and women who left three large and isolated state
schools for the mentally retarded and went to live in a community that they called Gatewood. Birenbaum et al. (1976) give a comprehensive picture of the process. Forty-eight residents remained at Gatewood and were interviewed at successive points. The transition had its problems, but the presentation gives the origins of Gatewood, the selection of clients, and the philosophy that adheres to a positive view of deinstitutionalization. The overall picture presents a well planned and thought out process. Success is indicated in that the residents adapted to the environment of Gatewood; a planned, small, residential facility. Their lives were considered to be more normalized than their previous setting in the large institution. This book further demonstrates that the movement toward greater community placement is not a phantom movement. The fact does remain that not all attempts are as positive (President's Committee on Mental Retardation, 1974).

Jasper (Note 3) presents a paper that reflects the need to examine whether or not deinstitutionalization has served the residents well or not. Birenbaum et al. (1976) advocates yes it does; if it has been well planned. This is the concensus of opinions across varying disciplines as noted by this author. The qualifier, of course, is "well planned". Jasper (Note 3) notes that to some deinstitutionalization is "a new handle on an old teakettle", as the response over the country has varied considerably. His study looked at Mental Retardation Centers and Intermediate Care Facilities which housed residents discharged from an institution. Questionnaires were used with parents and community agency personnel in order to obtain responses concerning the residents
progress. There was also a section for the resident to respond on, if physical or medical limitations were not hindering. Interviews with the residents were carried on by social workers in conjunction with the institution and community staff. Fifty-six residents compiled the final sample. The residents' progress was measured in terms of recreation, activities of daily living, work, and happiness. Overall, the residents and questionnaires provided favorable responses. The community appeared to present the resident with a greater opportunity for development in the areas cited. Jasper (Note 3) notes that the idea of relocating the residents acted as a motivator to them. Why get ready, if there's no place to go? Staff personnel appeared to be rewarded when residents "grew" or accomplished more. Furthermore, Jasper (Note 3) notes that a number of residents revealed social and psychological problems existing in conjunction to their mental retardation and effected their ability to adapt to institutional services or community ones. This author feels that treatment and attention has been neglected in this area and is highly needed. Jasper (Note 3) strongly feels that even with the ups and downs the deinstitutionalization movement has had, it appears to be a part of the American society and is here to stay. He also views the movement as not eliminating the institution but that it is essential to the strengthening of the programs and services within the institution. As his paper denotes, "hook-up" refers to the necessity and future of hooking-up the institution with the community.

As noted earlier, Nihira (1975) found positive results as did Jasper (Note 3). Negative results are indicated, but there are too few
studies on community placements of residents that are appropriate and available. Therefore, it appears logical that those studies available will paint a positive picture.

In her excellent national survey on community residential facilities, O'Connor (1976) summarizes the following as major findings:

(1) Community residential facilities (CRF's) were located throughout the United States; however, one-half of the facilities were located in six states. These states ranked high to low: Michigan, New York, Nebraska, California, Washington, Minnesota. Florida ranked sixteenth.

(2) The most common profile of CRF's was a large older home in a residential or combined residential and business area, and located within walking distance of stores and shops.

(3) Most residents shared a bedroom with only one or two other persons.

(4) Over two-thirds of the facilities were considered "normalized". However, since normalization of the facility was related to facility size, over one-half of the residents were living in "non-normalized" facilities.

(5) Community opposition, mostly by neighbors, at the time of development was faced by about one-third of the facilities; attitudes were reported to have improved because of residents' behavior and staff efforts.

(6) There were two primary staffing patterns: a) full-time administrators and direct-care staff principally in large
facilities and those serving children; and b) houseparents most common in small facilities and those serving older residents.

(7) The average staff-to-resident ratio was .52 or one staff person for every two residents. This ratio was higher for children and adolescents, and lower for adults.

(8) Primary causes of staff turnover were low pay, long hours of responsibility and little privacy, especially for live-in staff.

(9) Virtually all facilities used one or more types of community services; the most satisfaction was expressed with religious, medical, and dental services.

(10) Transportation was the most needed, but inadequate or unavailable, community service.

(11) Ninety percent of the residents lived in facilities reporting a need for one or more of the 15 types of community services; nearly one-half were living in facilities in need of four or more services.

(12) One-third of the facilities reported a need for educational services and vocational training.

(13) Residents range in age from very young to very old, although most are between 17 and 34 years of age.

(14) Most residents had basic self-help skills and 80% were estimated to have an I.Q. of 40 or above.

(15) Over one-half of the residents moved to the CRF directly from
an institution, and an additional 10% had a history of institutionalization.

(16) For those residents with a history of institutionalization the median length of stay in the institution was 10 years, and one-quarter of them had lived in an institution for 30 years or more.

(17) Two-thirds of the residents had periodically reviewed developmental plans, although the content and complexity of the plan varied considerably.

(18) Of the residents, 14% had paid jobs in the community; 43% were in work training programs; 26% were in sheltered workshops; 47% were attending some school classes; 31% attended school as their principal program; 8% were in non-vocational activity centers, and/or on-grounds training; 4% were not reported to be in programs or receiving any skill training.

(19) Most residents had home responsibilities. The proportion of residents having a household task decreased as the complexity of the task increased; only 7% of the residents i.e., the young or severely disabled, had no responsibilities in the home.

(20) The most popular community activities were visiting restaurants and snack bars, shopping, and recreation, both indoor and outdoor.

(21) One-half of the residents had regular contact with their families.
(22) Fifty-seven percent had friends outside the facility which they both visited and entertained as guests.

(23) One-fifth of the residents dated.

(24) Facility managers felt that four out of every ten residents would be able to live independently in the community in the future.

As can be seen from the above points, we have not yet made the major commitment needed for truly integrated deinstitutionalization programs. These findings are supported by Jasper (Note 3), Nihira et al. (1975), Birenbaum et al. (1976), and many others. Their support is given on a smaller scale and indicate that the movement can be positive even with all the needs in areas of finance, the government, the laws, etc., etc.
Summary and Conclusion

It has been noted that only a small proportion of the mentally retarded require the special facilities of a hospital set up on the medical model (President's Committee on Mental Retardation, 1976(a)). It appears logical that a move from the traditional, clinically centered view of the mentally retarded as being incurable, with organic etiology, and primarily involving subnormal intellect to that of the developmental and training models is becoming a reality. Wolfensberger's historical account of institutions implies that this nation's earlier foundations, in regards to treatment of the mentally retarded, was oriented toward the community and in favor of more normalized procedures. During the early 1900's, the philosophy of treatment appeared to change. The change represented a trend to retain the mentally retarded in institutions with sustained medical care. Currently, the movement of deinstitutionalization can be viewed as circular in nature, in that it once again favors greater community placement, normalization, and more therapeutic services for the mentally retarded.

The very intent of our Declaration of Independence implies that everyone should have the opportunity to develop his/her potential to the fullest possible extent and to establish the opportunity to live in the least restrictive environment possible.

The courts have found that institutionalized mentally retarded persons have a constitutional right to a humane physical and psycho-
logical environment, to dignity, privacy, and humane care. The legal emphasis is seen in regards to development of special educational programs and public laws; as Public Law 94-142. Numerous court cases have recently given rise to greater civil rights for the retarded. Provision of these opportunities is also the intent of institutional reform as defined earlier by the National Association of Superintendents of Public Residential Facilities. The judicial process, along with the philosophy of "normalization" has added power to the deinstitutionalization movement. The growing role of advocacy is further demonstrating a greater awareness of the needs of the mentally retarded.

The move toward deinstitutionalization has not been approved by all professionals and parents. It appears that the underlying fact of relocation appears to clash with improvement of current programs and service systems. One specialist in mental retardation services observed that:

Opponents of the view to totally abolish institutions point to the experience in many states of moving individuals into group homes, with consequent worse care and far less supportive services than the large institutions provide. In some states, increased placement in the community is accompanied by markedly reduced admissions and thus rapid overloading of the service delivery system. The diversion of state and federal funds from the institution
to the community tends to further deteriorate the quality of care in these facilities and exacerbate the very conditions in urgent need of remediation (cited in Birenbaum, et al., 1976, p. XVII).

It is a much cited fact that deinstitutionalization will require a vast outlay of additional resources, both financial and personnel. If deinstitutionalization is important to the resident, it is life-giving, I believe, to the institution. Deinstitutionalization does not mean eliminating the institution. It is essential to it and its training and treatment program should continue to be strengthened. Institutional reform, deinstitutionalization, and the development of community alternatives are all important factors in the movement to improve the care and treatment for handicapped persons. For practical, as well as logical reasons, it will be necessary to reorganize, decentralize, and relocate institutional personnel. The institution should be used as a consultation center regarding management of the mentally retarded. Thus, institutional reform is an essential prerequisite to deinstitutionalization and the development of adequate community programs.

Communities are unbelievably uninformed about developmental disabilities in general. Lewis' (cited in Friedman, Note 1) and O'Connor's (1976) studies and observations pointed directly to this community unawareness of the mentally retarded person. Yet, there is little evidence to support the notion that the government is sincerely attempting to remedy this factor. Greater interest is needed in this area of
attitudes toward the mentally retarded before adequate support can be assumed from the community. Possibly, some facet of responsibility for deinstitutionalization can be given to the community.

There is little available data to support any plan for deinstitutionalization. Therefore, it is important that any recommendations for a service model be systematically evaluated. Research by Klaber (cited in Baroff, 1974, p. 353), represents an important contribution to understanding institutional services to the severely and profoundly retarded person. Perhaps the most fruitful aspect is the identification of criteria by which programs can begin to be evaluated. This is essential to institutional reform and the development of deinstitutionalization programs. In combination with rating scales such as PASS (Program Analysis of Service Systems), an instrument designed to assess quantitatively "normalization", the Klaber criteria offer a potentially incisive means of program evaluation.

Scheerenberger's (1974) ingredients to successful deinstitutionalization: (1) local authority, (2) standard-setting, (3) back-up services, (4) adequate financial support, and (5) effective advocacy programs; offer a plausible hypothesis. The hypothesis offered is that the intensity of these efforts, in recognizing these factors, could serve as the real measure of how much our attitudes have undergone change and, as a result, how much the movement toward deinstitutionalization will succeed.

It is my conclusion that every service model should at least include: (1) services that are equal or superior to any existing ones,
(2) responsibility for assessing, evaluating, and monitoring client needs, (3) provision of services through local community agencies, (4) encouragement of the development of services not available, and finally (5) some type of systematic integration of all disciplines.

Wolfensberger cited that earlier philosophies concerning the mentally retarded were rooted with wide and deep hopes for a great state institution that would redeem and train the mentally retarded individual. Now, it almost appears we are placing a great faith in a "new institution"-the community itself. Is this a real substantive, or an illusion? Are we just moving from one system of service to another with no great changes in basic philosophies or actual quality of care? The current evidence is incomplete and not conclusive. The provision of programs and services for students with exceptional needs is severely hampered by the national shortage of trained and skilled personnel at all levels; government mazes hinder progress; community attitudes are generally unaccepting of the mentally retarded; development of community alternatives has been inadequate; financial resources are inadequate, etcetera. Yes, there are many needs as cited by many authors. There should be no doubt that change and reform are involved processes. Currently, the deinstitutionalization movement is in the middle of defining and establishing priorities. Inherently, it appears as though we are still questioning the worth of such a movement. Many authors have noted that with sufficient planning, appropriate program implementation, and careful monitoring; community placement may be able to provide excellent oppor-
tunities for our mentally retarded.

We should value and nurture above all, the "normalization" principles which teach us that all human beings are equal in law, and those with greater gifts have the greater responsibility and that indeed those with the least must be entitled to the most compassionate society--and that every human being must count as one whole person.
Appendix A

Historical Summary
Appendix A

Wolfensberger's graphic summarization of the evolution of institutional rationales and practices.

Appendix B

Bill of Rights
Appendix B

The following is an extension of the 'Bill of Rights' for the mentally retarded in the state of Florida. The bill reaffirms all those inalienable rights guaranteed in the U.S. Bill of Rights, while setting forth 13 specific rights for the retarded citizens:

1. The right to dignity, privacy, and humane care.
2. The right to religious freedom and practice.
3. The unrestricted right to communication.
4. The right to personal possessions and effects.
5. The right to education and training.
6. The right to prompt and appropriate medical care and treatment.
7. The right to social interaction.
8. The right to physical exercise.
9. The right to humane discipline.
10. The right to physical examination prior to subjection to a treatment program to eliminate bizarre or unusual behaviors.
11. The right to minimum wage protection and fair compensation.
12. The right to be free from physical restraint.
13. The right to a central record.

Appendix C

Statistics:

Table 1 - Sweden
Table 2 - Denmark
Table 3 - Ontario
Appendix C

Table 1: Sweden

Forms of living of all the mentally handicapped receiving provisions and services

<table>
<thead>
<tr>
<th>Form of Living</th>
<th>Number of persons 1969</th>
<th>Number of persons 1973</th>
<th>Percentage 1969</th>
<th>Percentage 1973</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental homes</td>
<td>9,580</td>
<td>13,490</td>
<td>35.7</td>
<td>42.0</td>
</tr>
<tr>
<td>On their own</td>
<td>340</td>
<td>1,350</td>
<td>1.3</td>
<td>4.2</td>
</tr>
<tr>
<td>Other private homes (foster homes).</td>
<td>900</td>
<td>1,060</td>
<td>3.3</td>
<td>3.3</td>
</tr>
<tr>
<td>Boarding schools and group homes</td>
<td>2,640</td>
<td>2,240</td>
<td>9.8</td>
<td>7.0</td>
</tr>
<tr>
<td>(children)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group homes (adult)</td>
<td>350</td>
<td>1,170</td>
<td>1.3</td>
<td>3.6</td>
</tr>
<tr>
<td>Residential homes</td>
<td>10,100</td>
<td>10,790</td>
<td>37.7</td>
<td>33.6</td>
</tr>
<tr>
<td>Special boarding schools</td>
<td>180</td>
<td>120</td>
<td>0.7</td>
<td>0.4</td>
</tr>
<tr>
<td>Special residential homes</td>
<td>280</td>
<td>220</td>
<td>1.0</td>
<td>0.7</td>
</tr>
<tr>
<td>Special hospitals</td>
<td>2,030</td>
<td>1,450</td>
<td>7.6</td>
<td>4.5</td>
</tr>
<tr>
<td>Other forms of living</td>
<td>420</td>
<td>240</td>
<td>1.6</td>
<td>0.7</td>
</tr>
<tr>
<td>Total</td>
<td>26,820</td>
<td>32,130</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Note. Tables 1, 2, 3 from, President's Committee on Mental Retardation. Changing Patterns in Residential Services for the Mentally Retarded. Washington D.C.: Government Printing Office, 1976, Table 1 - p. 259, Table 2 - p. 250, Table 3 - p. 273.
### Table 2: Denmark
Number of facilities and clients

<table>
<thead>
<tr>
<th></th>
<th>Number of facilities</th>
<th>Number of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Residential facilities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Central institutions (regional centers)</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Local institutions</td>
<td>14</td>
<td>28</td>
</tr>
<tr>
<td>Relief and holiday homes</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Special treatment homes</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Homes for children</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Treatment home (delinquents)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Boarding schools</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>School homes</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>Youth boarding schools</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Hostels</td>
<td>1</td>
<td>32</td>
</tr>
<tr>
<td>Semiprivate care homes</td>
<td>26</td>
<td>19</td>
</tr>
<tr>
<td><strong>Total residential facilities</strong></td>
<td><strong>54</strong></td>
<td><strong>126</strong></td>
</tr>
</tbody>
</table>

2. Day facilities:

<table>
<thead>
<tr>
<th></th>
<th>Number of facilities</th>
<th>Number of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schools</td>
<td>19</td>
<td>72</td>
</tr>
<tr>
<td>Kindergartens</td>
<td>5</td>
<td>51</td>
</tr>
<tr>
<td>Workshops</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Youth schools</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total day facilities</strong></td>
<td><strong>27</strong></td>
<td><strong>176</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Number of facilities</th>
<th>Number of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>81</strong></td>
<td><strong>302</strong></td>
</tr>
</tbody>
</table>

2. Population by age groups in above:

<table>
<thead>
<tr>
<th>Age</th>
<th>1966</th>
<th>1969</th>
<th>1972</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>1,033</td>
<td>573</td>
<td>438</td>
</tr>
<tr>
<td>10-17</td>
<td>2,674</td>
<td>2,374</td>
<td>2,051</td>
</tr>
<tr>
<td>18-39</td>
<td>2,750</td>
<td>3,175</td>
<td>3,365</td>
</tr>
<tr>
<td>40+</td>
<td>835</td>
<td>740</td>
<td>633</td>
</tr>
<tr>
<td>Total</td>
<td>7,292</td>
<td>6,862</td>
<td>6,487</td>
</tr>
</tbody>
</table>


5. Total population of above facilities by year: 1966, 10,300; 1969, 10,137; 1972, 9,660.
Reference Notes


References


Jaslow, R. I., Kime, W. L., & Green, M. J. Criteria for admission to institutions for the mentally retarded. Mental Retardation, 1966, 4, 2-5.


Scheerenberger, R. C. A study of public residential facilities. Mental Retardation, 1976(a), 14(1), 32-35.


