Normalization and Deinstitutionalization of Mentally Retarded Individuals

Controversy and Facts

Sharon Landesman and Earl C. Butterfield
Child Development and Mental Retardation Center, University of Washington

Normalization is an ideology of human services based on the proposition that the quality of life increases as one's access to culturally typical activities and settings increases. Applied to individuals who are mentally retarded, normalization fosters deinstitutionalization and the development of community-based living arrangements. Closely allied with normalization is the concept of least restrictive environment—that the places where people live, learn, work, and play should not restrict their involvement in the mainstream of society. Some psychologists are numbered among the chief advocates of normalization and deinstitutionalization, whereas others are vocal critics. Our premise is that examining the sources of the controversy over normalization will clarify the limits of our knowledge about treatment and open the possibility of theory-based evaluation of service delivery. Such evaluation should advance our understanding of environmental influences on all human development.

Deinstitutionalization and normalization are probably the most controversial and emotionally charged issues in the field of mental retardation. Their merits and liabilities are debated passionately in courtrooms, legislative hearings, parent meetings, social and health service agencies, professional societies, and the media. Testimony invariably includes accounts of the phenomenal progress of previously institutionalized individuals after they were moved to small community homes and vivid descriptions of shameful conditions that still exist in state institutions, countered by horror stories of deinstitutionalized persons who are isolated, neglected, or abused in the community and by glowing reports of model programs conducted within institutions.

At the heart of the debate are fundamental differences in beliefs and values about the *extent* to which the environment affects the functioning of those who are retarded and what *types* of environments are best for whom. Proponents of deinstitutionalization and normalization recognize that community placement involves risk and raises complex questions about how to promote true social integration, but they do not doubt that the risk is justified and that living in the community promotes a better quality of life and safeguards human rights. Opponents stress the need of many who are mentally retarded to have protective, caring, and cheerful environments and to receive technically sophisticated training and health support systems prior to community placement. Although it is not apparent in the heat of debate, almost all would agree that minimally restrictive community living is a highly desirable *goal* for most citizens with mental retardation. As goals, normalization and deinstitutionalization are not terribly controversial; as *means* to achieving these goals, many of the current *practices* related to deinstitutionalization and normalization are.

Often absent from debate in public arenas are social scientists armed with pertinent and reliable data about why deinstitutionalization and normalization should benefit, or how these practices actually have affected, those who are mentally retarded. Perhaps because the debates frequently occur in legislative and judicial settings, legal principles and conceptions of individual rights and societal responsibility, rather than scientific observations, have been the primary reasons for changing the location and type of residential treatment services. But the relative absence of data and scientific theory may reflect other factors as well. Have investigators actively avoided or unknowingly been excluded from decision-making arenas, where polarization of beliefs is endemic and where their "factual" findings may be unwelcome, misunderstood, or ignored?

Social Reform in the Treatment of Mental Retardation: 1967-1985

The recent history of social reform in mental retardation is a complex brew of courtroom decisions and out-of-court settlements, federal legislation and standards for treatment, fiscal constraints and opportunities, and increased consumer education and involvement, spiced with strong personalities and politics. For an excellent overview, see Bruininks and Lakin's (1985) edited volume, *Living and Learning in the Least Restrictive Environment.*

In 1967, the mentally retarded population in U.S. public institutions reached a high of nearly 200,000; by 1984, the number fell to about 110,000, a 55% reduction. The average yearly cost per institutionalized resident was nearly $40,000 in 1984, totaling $4.3 billion in federal and state expenditures. Between 1967 and 1982, the bed capacity of community residential facilities increased from 24,000 to nearly 100,000, costing at least $3.0 billion in public funds in 1985.

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Another 10,000 persons who are mentally retarded reside in state and county mental hospitals, and perhaps 50,000 (most of whom are neither elderly nor medically fragile) live in generic nursing homes. Presently, Title XIX of the Social Security Act is the mainstay of the service delivery system, providing 97% of the federal aid to institutions (nearly 50% of their total budget) and 70% of federal aid for community services. Increasingly, these residential facilities are being scrutinized (at a cost of $1.9 million for auditing alone in 1984) to determine compliance with Medicaid standards for Intermediate Care Facilities for the Mentally Retarded. Not surprisingly, these on-site inspections have resulted in lengthy reviews and numerous citations—ranging from trivial to substantial—and threats of program decertification. (For more extensive facts and figures, refer to Braddock, 1981; Braddock, Howest, & Hemp, 1984; Butterfield, 1976; Gettings & Mitchell, 1980; Gettings & Salmon, 1985; Hauber, Bruininks, Hill, Lakin, & White, 1982; Lakin, Hill, Hauber, Bruininks, & Heal, 1983).

The Principle of Normalization

The concept of normalization first emerged from efforts to improve services in Scandinavia (Bank-Mikkelsen, 1969; Nirje, 1969). In the United States, Wolfensberger (1972, 1980) expanded this principle into a comprehensive ideology with detailed guidelines for providing and evaluating human services (Wolfensberger & Glenn, 1975; Wolfensberger & Thomas, 1983). Simply stated, normalization is the "utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (Wolfensberger, 1972, p. 28). Within this framework, life satisfaction, self-esteem, and personal competence are viewed as products of involvement with mainstream activities of society. Also, participation in atypical, segregated, or specialized environments and affiliation with other "socially devalued persons" are considered detrimental to an individual's development.

Normalization has captured the imagination and commitment of many professionals, service providers, and advocates. Normalization workshops are well attended throughout the country, often held as week-long retreats led by charismatic individuals whose enthusiasm and visionary certainty about how to revolutionize human services are contagious but whose bases for advocating normalization include little scientific evidence or sound theory about either mental development or institutional change. Nonetheless, normalization has been a unifying and positive force among those who have worked to end the segregation and devaluation associated with mental retardation. As Lakin and Bruininks (1985) recognized, "Normalization as a concept has endured primarily because it is elegant in its simplicity, yet it provides both a utilitarian and an equalitarian guide against which to measure the coherence of programs and services for handicapped citizens" (p. 12).

Deinstitutionalization: An Expanded Conceptualization

The pattern of deinstitutionalization has differed for mentally retarded versus mentally ill individuals (Bachrach, 1981, 1983; Braddock, 1981; Kiesler, 1982; Lakin & Bruininks, 1985). In the field of mental retardation, deinstitutionalization began 12 years later than in the mental health field, occurred more gradually and selectively, involved less recidivism (the "revolving door phenomenon"), and was accompanied by fairly stable (low) rates of new admissions. But for both mentally ill and mentally retarded clients,

> the zeal and dedication that have motivated deinstitutionalization have left in their wake a series of dysfunctional elements resulting directly from rapid, sometimes heedless, implementation of incomplete program plans. Planning for deinstitutionalization has, unfortunately, often proceeded in a sort of functional vacuum. It has certainly failed to address the needs of the diverse patient population subgroups . . . comprising the universe of mentally disabled persons. (Bachrach, 1981, p. 60)

Supporters of the normalization movement view *all* large institutions as inherently degrading and vigorously resist efforts to upgrade the quality of institutions (Center on Human Policy, 1979; Ferleger & Boyd, 1979). This has been the single most important factor in rallying the opposition. Opponents correctly note that simply releasing individuals from an institution, or closing all institutions, does not guarantee that the objectives of normalization will be achieved. They claim not to oppose deinstitutionalization per se, but rather to doubt its universal value for all individuals and to question the quality of care provided in some community settings. Their advocacy of *selective* deinstitutionalization is apparent in the 1974 definition proposed by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded:

> 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 responsive residential environment which protects human and civil rights and which contributes to the expeditious return of the individual to normal community living whenever possible, (pp. 4-5)

The above definition, later adopted in the 1975 Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103), clearly supports a continuing role for institutions in the treatment of mental retardation. This role was challenged in 1983 when Senator Chafee introduced the Community and Family Living Amendments Act (S. 2053) to phase out Title XIX Medicaid funding for institutions and to increase the financial incentives for small

Sharon Landesman is currently at the University of North Carolina.

Correspondence concerning this article should be addressed to Sharon Landesman, Director, Frank Porter Graham Child Development Center, University of North Carolina, Highway 54 Bypass West, Chapel Hill, NC 27514.

(six to nine persons) community-based residences. The projected impact of such legislation is enormous, involving deinstitutionalization of approximately 100,000 Medicaid recipients and expansion of eligibility to hundreds of thousands of severely handicapped individuals not currently served under Medicaid. Chafee's bill sought a major reversal of prior federal support for public residential institutions for mentally retarded individuals.

Not surprisingly, parent associations affiliated with state institutions immediately initiated efforts to block this legislation. Parents of institutionalized individuals already had united and established a national communication network (Parents Network) and organization (Congress of Advocates for the Retarded, Inc.) when they filed as *amici curiae* to the Supreme Court during the review of *Pennhurst State School and Hospital* v. *Halderman* (1977). The *Pennhurst* decision was a landmark, ordering total closure of a large public institution on the grounds that *all* similar institutions *by their very nature* violated residents' fundamental civil and constitutional rights. These parents argued the following in their brief:

> The degree of the disabilities suffered by the mentally retarded residents of public institutions is far more severe than the court believed. The reality of mental retardation is inconsistent with a presumption in favor of deinstitutionalization. It cannot be assumed that for a particular retarded individual, a CLA (Community Living Arrangement) will be "less restrictive" or "more normalizing" than an institution. For many retarded people, only an institution can provide adequate services and programs. A system relying more heavily on CLAs would be unstable and inadequately monitored, and would not assure continuity of care. (Gottesman, Weinberg, & Collins, 1980, Table of Contents)

Today, these parents use essentially the same arguments, backed by some dated and questionable findings, to support their contention that secure, state-operated institutions ("central core facilities") are the most appropriate setting for their sons and daughters. They adamantly opposed the original Chafee bill, which was endorsed strongly by the Association of Retarded Citizens/United States, the largest national parent organization. The political power wielded by parents has been a major factor in the substantial compromises that appeared in the Community and Family Living Amendments Act of 1985 (S. 873), submitted to the Senate by Chafee, and in the House bill (H.R. 2902). Chafee acknowledged the "extremely controversial" nature of his original amendments; his office alone received nearly 10,000 letters! Resulting changes in the bill included extending the time to phase out facilities that serve more than 15 residents, permitting a low level of Medicaid support for a "residual population" in larger facilities, adding a grandfather clause for certain types of community residences that now serve 9 to 15 residents, and mandating all states to provide individual and family support services for severely disabled individuals. Still, this bill makes many implicit assumptions about (a) what types of physical and social variables foster optimal development of severely disabled persons, (b) how to evaluate individuals' service needs, and (c) methods for coordinating and monitoring services to ensure appropriate living arrangements and compliance with standards. A 1987 revision of this legislation is scheduled to be introduced in Congress with even more significant compromises, reflecting a recognition of the historical role of institutions and the urgency of providing quality assurance to the community.

Because the implicit assumptions in this bill are central to the current controversies in mental retardation, we believe they should be evaluated against available empirical evidence and theories of human development and that their implications for further scientific inquiry should be considered. Some of the bill's assumptions are as follows: (a) that facilities housing more than 6 to 10 residents provide inferior care, are less well received in the community, restrict opportunities for those who live there, and are less conducive to personal development compared to smaller homes; (b) that mandated training for all residential staff and increased parent training will improve the quality of life for severely handicapped individuals; (c) that we have techniques for conducting valid external monitoring of residential programs and the progress of individuals within these programs; and (d) that an interdisciplinary team is the best means for evaluating severely disabled individuals and for developing annual individual habilitation plans. Despite their seeming reasonableness, these assumptions should be studied systematically. On the basis of prior research (see Footnote, later in this article) and recent conceptualizations of the social ecology of residential environments for mentally retarded people (Landesman, 1986, 1987; Landesman-Dwyer, 1981; Landesman-Dwyer & Butterfield, 1983; Landesman-Dwyer & Knowles, 1987) as well as for nonhandicapped individuals (e.g., Magnusson, 1981; Pervin & Lewis, 1978; J. A. Russell & Ward, 1982; Stokols, 1981, 1982), we conclude that objective and theoretical support is needed.

The Role of Social Science in Policy Formation and Evaluation

Baumeister (1981) characterized the relationship between mental retardation policy and research as "the unfulfilled promise":

> My conclusion is that in the short run science is not a major factor in the formation of social policy.. . . Over the long run, however, the impact of science on policy is much more significant, for the methods of science are well suited to the extended analyses of causes and effects. No other method of knowledge generation can rival the scientific method to produce systematic and replicable information, (p. 454)

Before considering our current knowledge base, we will answer our earlier questions about the interests, activities, and products of scientists in mental retardation.

Are Social Scientists Interested in Policy-Related Topics?

Scientific interest in what types of environments foster positive development is a century old (Crissey, 1975; Kanner, 1964). Dedicated investigators documented painstaking efforts to treat children who were unresponsive to conventional socialization and educational efforts. Special asylums for the "feeble-minded" were created to provide a simplified and supportive social community and attracted behavioral scientists and clinicians eager to test new training techniques, many based on theories about central nervous system functioning. The ideology of the times implicitly underscored the ecological principle *of person-environment fit* by designing a social world in which the consequences of mental deficiency appeared less obvious and less devastating than they did in the mainstream community. Studies of deinstitutionalization and determinants of successful return to community life were an integral part of the early institutional caretaking system. Predictive research was underway by the turn of the century. By 1960, considerably before the recent wave of social reform, more than 100 empirical studies about community placement had been published. Despite this interest, Windle (1962), in a scholarly and detailed review, concluded that serious problems in conceptualization, design, and data collection prevented discovery of fundamental principles about who does well in what types of residential settings. Sadly, Windle's conclusions are still correct (Butterfield, 1985).

Recent resurgence of interest in scientific study of deinstitutionalization and community placement is reflected in articles published in the *American Journal of Mental Deficiency* between 1970-1975 and 1980-1985. Over this decade, there was a twofold increase in the proportion of articles concerning community placement—from 7% to 14%—and a dramatic shift in the sources for all research subjects. In the early 1970s, nearly 74% of the 83,771 subjects included in 544 research reports came from institutional populations; by the 1980s, only 13% of 136,074 subjects (456 articles) lived in public residential facilities. Begab and Richardson (1975), Bruininks, Meyers, Sigford, and Lakin (1981), Edgerton (1984), and Landesman and Vietze (1987) have edited informative volumes of original research on deinstitutionalization and community services.

Mental retardation investigators seldom cast even their directly relevant research as a test of normalization ideology or as an examination of the bases of current public policies toward treatment. In part, this reflects differences in theory, style, and social rewards between the scientific and service delivery worlds. Consider, for example, Bachrach's (1985) analysis of the notion of "least restrictive environment":

> This concept generally rests upon the uncritical acceptance of at least three assumptions that are logically weak and largely unwarranted: first, it is assumed, for all practical purposes, that the quality of restrictiveness resides outside the client and in the environments; second, that the quality of restrictiveness is primarily a function of class of residential facility; and, third, that there is a relationship between restrictiveness and residence that may be expressed in terms of a continuum, (p. 30)

After further consideration, Bachrach concluded that these assumptions lack empirical support. Similarly, other researchers and policy analysts find the normalization ideology seriously deficient as a *scientific theory,* viewing it as "a conceptual disaster" (Aanes & Haagenson, 1978, p. 55) and "right ends, wrong means" (Throne, 1975, p. 23). Wolfensberger (1983) proposed the new label "social role valorization" to replace "normalization." He believed that "in part because of its name, people have failed to take the principle of normalization seriously as a tightly-built, intellectually demanding, and empirically well-anchored megatheory of human service and, to some degree, relationships" (p. 234). This name change is unlikely to motivate scientists to conduct inquiry into Wolfensberger's human services philosophy, although many studies of attitude formation and change, social interaction patterns, self-concept, and personal competence of those who are mentally retarded have been and, it is hoped, will continue to be conducted. These studies pertain directly to this ideology and to public policy formation.

Are There Relevant Data?

Reams have been published on deinstitutionalization and normalization since 1967. In reviewing more than 500 such documents for the President's Committee on Mental Retardation, Landesman-Dwyer (1981) found that fewer than 20% presented empirical data. As Crissey (1975) admonished in her presidential address to APA's Division 33 (Mental Retardation),

> The issue is really not institutions versus community. The issue is where can the most suitable care be provided? *Most suitable* will of course depend on what the need of the individual is, as well as on the bias of who decided what is *suitable.* And these needs will change with time, circumstances, and the individual's own characteristics, (p. 807)

Edgerton (1984), an anthropologist who has provided sensitive portrayals and insights into the lives of deinstitutionalized mildly retarded persons over the past two decades, concluded,

> Success is reported here, failure there; deinstitutionalization continues, but so does reinstitutionalization. Some mentally retarded persons do very well in their adjustment to community living; others do less well. Some do well at first and encounter problems later on. Others have trouble initially but, as time passes, become more successful. Some fluctuate throughout their lives. Perhaps the most accurate appraisal that anyone can make of community adaptation is that it is a highly complex and changing phenomenon, one that we know far too little about. It is also an intensely human phenomenon, filled with joys and sorrows, boredom and excitement, fear and hope. (p. 1)

Beyond such a sweeping, and certainly true, picture of postmstitutional adjustment, what relevant facts are at hand? To allow fair assessment of the data, three chronic problems that plague the field must be considered. First, there is no standard terminology or nomenclature for describing and evaluating residential environments (Landesman, 1986; Landesman-Dwyer, 1985). This means that different terms are applied to highly similar facilities and vice versa. The lack of uniform labeling of environments prevents valid comparisons of results across studies and contributes to errors in grouping studies. For example, states' licensing standards and the demographic characteristics of their service providers and recipients vary so widely for foster care and group homes that few, if any, common outcomes can be expected. To remedy this situation, Landesman (1986) proposed use of a theory-based classification system that includes structural, functional, and historical-developmental characteristics of home environments.

Second, the vast majority of studies are flawed in design by inadequate attention to pre- and postplacement measures, biases in selection and/or assignment of subjects to environments, and insufficient objective description of the actual residential treatment received (Butterfield, 1967, 1985; Heal & Fujiura, 1982; Windle, 1962). Such problems are not unique to mental retardation. Kiesler (1982), for example, found only a score of studies in which mentally ill individuals were assigned randomly to institutional or community treatment facilities, and multiple methodological problems prevented straightforward conclusions about treatment effects. Although reasonable design solutions and compromises have been advanced, and sometimes implemented (e.g., Landesman, 1987; Landesman-Dwyer, 1984; MacEachron, 1983), opportunistic and uncontrolled field studies still dominate the literature.

Third, the concept of "quality of life" is inherently multidimensional and value laden; accordingly, the data available about the adjustment of mentally retarded individuals reflect biases (often acknowledged) of the investigators and may ignore other, equally important, effects. Classic examples of this limitation abound in all areas of psychology—such as studying only changes in the rate of a single targeted behavior while ignoring the occurrence of other theoretically related behavior. To provide answers to most policy-motivated questions, multiple perspectives and multiple outcome measures are essential.

Despite these constraints, there *is* a substantial body of relevant findings, but the data cannot be organized readily around the big questions "Should there be any institutions at all?" and "Is normalization really an attainable or desirable goal for everyone?" Instead, research over the past three decades has confirmed (convincingly, in our judgment) at least 10 important observations

1. Even within one type of residential care, significant variation can occur across individual facilities, sometimes greater than that observed between different forms of residential care.

2. In a given residential treatment program, the actual experiences of residents can differ in important ways attributable to differential treatment by staff and to individual differences in residents' responsivity.

3. The consequences of a particular residential environment on an individual will depend, in part, on his or her prior residential history—what comprises a relatively enriched environment for one person may be comparatively barren for another.

4. Social interaction within a facility (amount, nature, and distribution) appears to influence resident behavior more than does size, staffing ratio, location, or cost.

5. Successful adaptation to a new environment is not highly predictable from formally measured intelligence or "adaptive behavior" skills, age, sex, family involvement, length of prior institutionalization, or formal training received *prior* to moving.

6. Accurate assessment of an individual's potential or full range of abilities is *not* possible because of the narrowness and psychometric weaknesses of assessment devices and because the environment itself may suppress or potentiate the expression of certain behavior.

7. The initial fears and negative attitudes of parents and local communities toward deinstitutionalization and new community homes almost always dissipate quickly once placement has occurred, and objective bases for these fears do not exist.

8. Given adequate support systems, most severely and profoundly retarded individuals, even some with severe behavior or health problems, can progress in settings other than large, traditional institutions.

9. Physical renovation and increased staffing levels in institutions have resulted in modest improvements compared to more positive changes observed for apparently similar types of individuals who moved to small, independently owned community homes. We stress that reasons for this difference have *not* been determined.

10. Over time, "good" community places can become "bad," perhaps because of changes in staff commitment, administrative style or support, and day-to-day opportunities (both real and perceived) for engagement with and control over the environment.

We recognize that many other relevant findings exist (see reviews by Heal, Sigelman, & Switzky, 1978; Janicki, 1981; Landesman-Dwyer, 1981; Landesman-Dwyer & Butterfield, 1983) and that we have not cited the substantial relevant advances made in the technologies for training cognitive, vocational, and social skills of retarded individuals (Berkson & Landesman-Dwyer, 1977; Bricker & Filler, 1985; Butterfield, 1983; Ellis, 1979).

How Do Scientists Fare in the Real World (or, Can Scientists Be Deinstitutionalized and Mainstreamed)?

In a fascinating and well-written social history of New York's Willowbrook litigation, Rothman and Rothman (1984) commented on the performance of the mental retardation "experts":

> The courtroom, however, was not the place to analyze precisely what was and was not known. The experts did not lecture on the state of the discipline. They did not tell (Judge) Judd that community care for the retarded was an experiment, that one could not be confident of its outcome, although given the history of institutions, the risks seemed worth taking. Instead they delivered unqualified opinions, as though deinstitutionalization were the only legitimate option. *When social science entered the courtroom, the litigant might win but the discipline did not. Testifying and carrying out research . . . are activities more*

Complete citation of the documentation for these conclusions is not possible within the scope of this article, but a list of selected references for each major conclusion is available upon request from the first author.

> *antithetical than anyone who does both would like to admit,* (pp. 111-112, emphasis added)

Considering the litigation-related experiences of our friends and colleagues, as well as our own, we conclude that many of us have been naive, ill-prepared, or not sufficiently scholarly in presenting scientific findings effectively (Butterfield, 1979). We know that courtroom testimony has created bad feelings among colleagues and that many have condemned any participation of researchers in such controversial cases.

We rate psychologists' performance in public hearings about proposed legislation as somewhat more responsible and effective than that in courtrooms, but success in dealing with the printed and audiovisual media has been uneven. There are disappointingly few responsible documents to assist the general public, consumers, decision makers, or direct service providers in understanding the scientific literature on deinstitutionalization and normalization. A valuable service, consistent with the long-term impact on policy that Baumeister (1981) envisioned, would be to translate some of the *basic behavioral findings* about the effects of environmental variables and about theoretically guided training strategies into *nontechnical* language, supplemented by discussion of potential policy utilization of such basic principles about human behavioral development.

We reluctantly extend an invitation to our colleagues to direct increased efforts toward fulfilling the role of "scientist-practitioner" (Barlow, Hayes, & Nelson, 1984) and toward assuming the social responsibility discussed so eloquently by B. Russell (1960) and Glass (1965), among others. We are reluctant because we know firsthand how time consuming and frustrating these efforts can be. We also appreciate how much effort is needed to conduct sound research so there *will* be relevant findings in the future. The positive side-effects of such involvement in the "real world" include increased opportunities for conducting collaborative research in service delivery settings and direct challenges to our academic world perspectives. Many of our best hypotheses had embryonic beginnings in the form of interesting stories and opinions shared by those in the settings we seek to understand. Our ability to appreciate the ecological perspective (Cronbach, 1975) and the multidimensional nature of ecosystems (Bronfenbrenner, 1977) has increased exponentially with our exposure to the controversies and with our direct participation in the lives of clients, their families, and those who work to improve home and training environments. Senator Chafee (1985b) extended a valuable invitation in his introductory remarks to his new bill:

> [T]he provisions in my legislation are open to discussion.. . . (the) goal of this legislation is to provide a mechanism for the development of the most appropriate and effective system of long-term care for those in our society who are severely disabled. I desire any input which will further that goal.

What Next?

Controversy about normalization and deinstitutionalization will continue and will not be abated by any amount of scientific inquiry. The controversy is based on differences in faith, experience, and values, and the relative validity of the different positions is untestable. More data relevant to the care and treatment of those who are mentally retarded, however, can be collected.

We hope that at least three classes of research will be conducted. First, we hope that the National Institutes of Health and other federal research sponsors will continue to fund field-initiated studies into factors that influence development, learning, and habilitation of mentally retarded individuals. Continued support of investigator-initiated studies is perhaps the best way to ensure that diverse approaches are taken to the thorny problems of mental retardation. The difficulties of conducting sound research into issues germane to residential care and treatment can be overcome, and the rewards for theory and practice can be high. Second, there is a need for carefully designed outcome and evaluation studies of various treatment programs. Such studies afford opportunities to investigate person-environment relationships in ways that permit generalizations well beyond the treatment settings studied. Wariness and scientific integrity are needed, however, when interpreting data from applied/evaluation studies, especially when they are atheoretical, descriptive, or not prospective. For this reason, we favor theoretically motivated outcome studies with longitudinal designs. Third, we believe that scholarly and comparative historical studies of service delivery systems (e.g., Dokecki & Mashburn, 1984) can be valuable. When service delivery systems are examined in relation to key questions about social policy, such studies may contribute to an improved understanding of the decision-making processes that ultimately affect the everyday lives of retarded citizens and their families.

Whether or not these and other sorts of research are done, our states must continue to provide residential care. Increasingly, this public care will be monitored, with the threat of loss of federal funds if the care does not meet mandated standards. These standards are detailed and comprehensive, allowing little room for alternative means of achieving the objectives they seek to promote. A strict audit probably could dictate the loss of federal monies to all state programs. Many states already question the rationale for some of the federal standards, such as whether all residents should receive active daily treatment to increase their skill levels. Presently, the only valid way to determine whether an individual will benefit is to provide treatment. The only logically defensible position is that if one treatment regimen does not work, another should be tried. The number of treatment options is such that there is no practical limit to how many must be tried before concluding that a person cannot benefit. For these reasons, we endorse the federal mandate that all individuals receive active programming.

Protests will continue that not everyone will benefit more in small, community-based homes than in large institutions. Diversity in quality of programming among community facilities can be as great as that among institutions. The size and location of a residence are not what matter most; what does matter is the actual care and treatment an individual receives. Rather than prematurely narrowing our treatment approaches, we should encourage the development of diverse and innovative residential programs.

There is a grave need to examine the relationship between service quality and the standards designed to ensure quality. With good reason, funding agencies seek to establish responsible use of their monies consistent with their program goals. Unfortunately, it is questionable whether presently mandated standards, when met, actually assure desired quality (Bible & Sneed, 1976; Repp & Barton, 1980). We suspect that clarifying how to create standards and monitoring systems that actually improve services will benefit not just individuals who are mentally retarded, but all who receive human services.

We close by extending thanks to our colleagues who have braved the controversy to learn more about deinstitutionalization, normalization, and how to match people and places. We exhort them not to give up because the controversy continues. To professionals, service providers, and policymakers, we extend our appreciation for their asking how scientific data might be used to guide decisions about service delivery. We hope they will help us become better informants in public arenas.

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