

Normalization and Deinstitutionalization of Mentally Retarded Individuals:

Controversy and Facts

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Running head: NORMALIZATION

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, while others are vocal critics. Our premise is that examining the sources of the controversy over normalization clarifies the limits of our knowledge about treatment and opens 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 matters 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 phenomenal progress of previously institutionalized individuals after moving 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. While not apparent in the heat of debate, most 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, the current practices of deinstitutionalization and normalization are exceedingly controversial.

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 reason 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

Recent history of social reform in mental retardation has been a complex break of courtroom decisions and out-of-court settlements, federal legislation and standards for treatment, fiscal constraints and opportunities, and increase consumer education and involvement, spiced with strong personalities and politics

For an excellent overview, -see-the volume edited by Bruininks and Lakin (1985) c  
Living and Learning in the Least Restrictive Environment.

In 1967, the mentally retarded population in U.S. public institutions reached  
high of nearly 200,000; by 1984, the number fell to about 110,000, a 55 percent  
reduction. The average yearly cost per institutionalized resident was nearly  
\$40,000 in 1984, totalling 4.3 billion dollars in federal and state expenditure:  
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 p ublic dollar  
in 1983.

Another 10,000 persons who are 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 percent of the federal  
aid to institutions (nearly ,50 percent of their total budget) and 70 percent of  
federal aid for community services. Increasingly, these residential facilities are  
being scrutinized (costing 1.9 million dollars for auditing alone in 1984) to  
determine compliance with Medicaid standards for Intermediate Care Facilities for  
the-Mentally Retarded .dCF/MR). 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 (Nirje, 1969; Bank -Mikkelsen, 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 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 of tan 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 aggregation 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 mental retardation deinstitutionalization began 12 years after that in mental health, occurred more gradually and selectively, involved less recidivism {the "revolving door phenomenon"), and was accompanied by fairly stable

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{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 doubt its universal value for all individuals and question the quality of care provided in some community settings. Their advocacy of selective deinstitutionalization is apparent in the 1974 definition proposed by the N a t i o n a l 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 when Senator Chafe\* introduced The Community and Family Living amendments (s. 2053) to phase out Title XIX Medicaid funding for institutions and to increase the financial incentives for small (6 to 9 persons} community-based residences. The projected impact of such legislation is enormous, involving deinstitutionalization of approximately 100,000 Medicaid handicapped individuals not currently served under Medicaid. Chafee's bill seeks a" major reversal of prior federal support for public residential institutions for mentally retarded individuals.

Not surprisingly, parent associations affiliated with state institutions  
i 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 Halderman v. Pennhurst State School and hospital (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<sup>1</sup> fundamental civil and constitutional right<sup>3</sup>. 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

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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, 1990, 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 oppose the Chafee bill, which is endorsed strongly by the Association of Retarded Citizens/U.S., the largest national parent organization. The political power wielded by parents has been a major factor in the substantial compromises that appeared in the new Family and Community living Amendments of 1985 (S. 873) submitted to the Senate last April, 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 from 10 to 14 years 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 (1) what types of physical and social variables foster optimal development of severely disabled persons, (2) how to evaluate individuals' service needs and (3) methods for coordinating and monitoring services to insure appropriate living arrangements and compliance with standards.

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; (1) that facilities housing more than 6 to 9 residents provide inferior care, are less well received in the community, restrict opportunities for those who live there, and are less conducive to person; development compared to smaller homes, (2) that mandated training for a residential staff and increased parent training will improve the quality of life for severely handicapped individuals; (3) that we have techniques for conducting val. external monitoring of residential programs and the progress of individuals with these programs. and (4) 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. Based on prior research and recent conceptualization of the social ecology of residential environments for mentally retarded people Landesman, in press; Landesman-Dwyer, "1981 Landesman-Dwyer & Butterfield, 193 Landesman-Dwyer & Knowles, 1985) as well as for non-handicapped individuals {e.g. Magnusson, 1981; Pervin & Lewis, 1978; Russell & Ward, 1982; Stokols, 1981, 1982 [we conclude that the objective and theoretical support for these assumptions ranging from non-existent to weak. 1 to 4 above

### 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 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 product 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 care taking 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 conceptualizations, 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 versus 1980-1985, Over this decade, there was a twofold increase in the proportion of articles concerning community placement — from 7 to 14 percent — and a dramatic shift in the sources For all research subjects. In the early 1970s, nearly 74 percent of the 83,771 subjects included in

544 research reports came from institutional populations; by the 1980s, only percent of 36,074 subjects (456 articles) lived in public residential facilities, Begab and Richardson (1975), Bruininks, Meyers, Sigford, and Lakin (1981), Edgerts (1984), and Landesman and Vietze (in press) have edited informative volumes 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 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 "Lea: 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 environment second, that the quality of restrictiveness is primarily a function class of residential facility; and, third, that there is a relationship between restrictiveness and residence that may be expressed in terms of continuum, (p. 30]

After further consideration, Bachrach concluded these assumptions lack empirical support. Similarly, other researchers and policy analysts find the normalization ideology seriously deficient as a scientific theory "a conceptual disaster" (Aan & Haagenon, 1979) and "right ends, wrong means" (Throne, 1975). Wolfensberg (1983) proposed the new label "social role valorization" to replace "normalization He believes that;

in part because of its name, people have failed to take the principle normalization seriously as a tightly-built, intellectually demanding, a

empirically well-anchored mega theory 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 hopefully 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 less than 20 percent presented empirical data\* As Crissey (1975) admonished in her APA presidential address to 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 de-institutionalized 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 post-institutional 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 (Landesmam-Dwyer, 1985; Landesmam, in press}- 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, Landesmam (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 post-placement 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., Landesmam, in press; Landesmam-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 mental retarded individuals reflect biases (often unacknowledged) 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 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 variations 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 expediences of residents can differ in important ways. attributable to differential treatment by staff and to individual differences in residents responsively;
- (3) The consequences of a particular residential environment on an individual will depends 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 potentate 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 1ft 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 deterained:

{ 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 (bath real and perceived) for engagement with and control over the environment.

He recognize that many other relevant findings exist (see reviews by Heal, Sigelman, Switzky, 1978; Janicki, 1981; Landesmam-Dwyer, 1981; Landesmam-Dwyer & Buttertield, 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 De-institutionalized and Mainstreamed)?

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

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 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 colleague 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,  
consumer;, 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 non-technical language, supplemented by discussion of potential  
policy utilization of such basic principles about human behavioral development.

He 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  
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 (1985) extended a valuable  
invitation in his introductory remarks to his new bill:

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

We hope that at least three classes of research will occur. 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 insure 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 setting 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 v. Mashburn, 1984) can be valuable. When service delivery systems are examined in relation to key questions about social policy, such studies may contribute to and 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 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 level. 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 narrow 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 insure 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. Do not give up because the controversy continues. To professional service providers, and policy makers, we extend our appreciation for asking how scientific data might be used to guide decisions about service delivery. We hope you will help us become better informants in public arenas.

FOOTNOTES

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

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