

# From Institution to Community: A Conversion Model

BURTON BLATT  
ROBERT BOGDAN  
DOUGLAS BIKLEN  
STEVEN TAYLOR

*Syracuse University*

For too long, teachers have viewed their roles in society in terms of what takes place in the schoolhouse. Although we do not believe that such a model works very well for any child or, for that matter, any teacher, it works especially poorly and leads to serious problems when the children are the so-called handicapped and the teachers have been charged with the development of responsible programs to serve these children. All education is part of a larger social context, and seldom is it more important to recognize this than in dealing with children who are at high risk for placements in institutional environments. This paper addresses itself to that larger social context and its relevance for teachers and other professionals associated with the schools.

This article begins with a brief discussion and definition of our Conversion Model, with the expectation that the reader will be receptive to the conclusion that deinstitutionalization is only one facet of any bona fide system of community options for individuals with special needs. We next describe the elements of a community model, followed by a discussion of the processes involved in conversion. The paper continues with a plan of action and, based on our analysis of relevant literature and our own investigations, an assessment of the magnitude of the problem. We conclude with a summary which sets forth the relevance of these issues for teachers and others connected with the schools. Finally, because we believe that a serious barrier to achieving a workable conversion model stems from imprecision in definitions of the population and in estimates of incidence and prevalence, the appendix delineates information on the magnitude of this problem.

## ***Conversion Defined***

If we do not reconceptualize deinstitutionalization, it will fail, either by inertia or by backlash. Deinstitutionalization is a federal policy mandated as a priority by Title XX Social

Security legislation, and by the Developmental Disabilities Act of 1975. Both as a policy and a philosophy, it has received general acceptance by state human service agencies, and by the public. Nevertheless, the practice of deinstitutionalization is occurring at a snail's pace (Conroy, 1976). The reasons are myriad, but the common denominator is our definition of deinstitutionalization.

Too often, deinstitutionalization has simply meant releasing people from state facilities by moving traditionally institutionalized people into community institutions. These have usually been nursing homes of two or three hundred people, or group homes, foster homes, and boarding homes that sometimes provide little more than bed and board. However, the goal of deinstitutionalization should not be simply to move people from one building to another, from one location to another, from a total-care institution to a partial-care one, or from a custodial-care facility to a non-care facility. The goal should be to transform a dehumanizing, segregated institutional model of services into a humanizing, integrated community model.

The task of achieving this goal has proven more difficult than first thought, mainly because it involves so much more than simply releasing people from institutions. There are several reasons for the difficulty. First, we have lacked a clearly articulated plan for community-based human services. Such a plan should address itself to these questions. Which children should enter public schools? Who will require special instruction? Who will need only resource assistance? Who will need more intense and individualized programming? What kinds of residential options will be necessary? Second, the states have vested interests in maintaining institutions whose construction has been financed by state and municipal bonds and loans. Institutional residents' Social Security, Medicaid, and insurance payments will be needed to repay lenders in the future. This mandates a continued full house in state-supported institu-

tions. Third, deinstitutionalization will require changes in attitude throughout our culture. If the community is to offer experiences different from those offered by institutions, it must rid itself of prejudice and stereotyping and of the segregating, discriminatory policies that result from those attitudes. Fourth, the conduct of service providers must conform to principles of normalization (Wolfensberger, 1972), and of human dignity.

The roadblocks to deinstitutionalization will not be overcome by either moral or legal commitments to release institutional residents. What is demanded is a systematic approach to transforming institutions—a *Conversion Plan*. By *conversion*, we mean an orderly transition from an institutional to a community-based system of services with concomitant plans to transform existing physical facilities, staff resources, institutional ideologies, community attitudes, and agency policies to alternative, more humanizing uses and postures.

When industries shift their direction and begin new production, they almost always attempt to convert existing facilities and staff to the new or alternative effort. It is time for institutions and communities to proceed in similar fashion in moving toward deinstitutionalization. Without conversion, deinstitutionalization will fail to yield its expected positive results and may possibly produce a powerful backlash.

#### CONVERSION TO WHAT?

We must conceptualize the problem of institutions and community programs as the *conversion* of a system, rather than as the deinstitutionalization of individuals. But what kind of system do we want? Are we advocating a transition from large institutions to smaller ones? Do we speak only for the mildly or moderately retarded? Are we asking for a new generation of enlightened professionals to decide how the retarded are to live? No. We have a vision of a world with dramatically different assumptions about the rights of people, and their potential for growth, individuality, and dignity. And we have a vision of a system of services that reflects the following principles:

1. Services must be provided as a right of citizens, rather than as a privilege (Biklen, 1974). Traditionally, services for those with disabilities have been considered a matter of charity and good will. As such, they have been denied on the basis of insufficient funds and other considerations. In the system we foresee, services will be offered to all who need them. This implies that all disabled individuals can benefit from com-

munity residential, educational, and vocational services and that they are capable of unlimited growth and development (Blatt & Garfunkel, 1969). It also means that no person will be deprived of services without due process procedures, whereby the burden of proof as to the appropriateness of any service shall be upon the service agency. All persons, regardless of nature or degree of disability, shall be entitled to a full range of appropriate programs and services.

2. Services must be provided on a *non-categorical* basis. That is, a person's needs, and not his category or label, will determine the services he receives. No agency will categorize people as "mentally retarded," "emotionally disturbed," "learning disabled," or as any other disability type.

3. Services must constitute a *continuum* to ensure that each individual's needs are met in the most appropriate manner. Programs shall be designed to fit individual needs, rather than vice versa. Rather than group homes, there will be a range of community residences—short and long term group facilities—offering foster care, respite care, and a chance for independent and semi-independent living. Rather than special schools, there will be a range of educational programs. Individuals will be able to move from one program to another as their needs require.

4. Services must be provided under the *least restrictive, most normalized* circumstances possible (Wolfensberger, 1972). Every individual must have the maximum opportunity to be integrated into the community and to be among typical peers. This implies a preference for independent, rather than supervised, living; for integrated, rather than segregated, schooling; for regular, rather than sheltered, employment.

5. The agencies providing services must be *accountable* to consumers. There must be active and significant consumer involvement in the planning, implementation, monitoring, and operation of services at agency, local, regional, state, and federal levels.

There are some who will dismiss our vision as idealistic or impractical. And they may be correct. From our viewpoint, however, there has been far too much realism and far too little idealism in the past. We have written plans without goals, provided services without a purpose, and constructed a world without a vision. If nothing else, a vision offers hope and direction.

#### *Barriers to Community Conversion*

We have presented one way of conceptualizing the problem of institutions and deinstitutionali-

zation, and some of the components of the system into which we are attempting to convert. It is also important to consider the barriers that interfere with our efforts at conversion, for it is possible that one reason for their persistence is our seeming reluctance to identify them.

#### HANDICAPISM

Handicapism has many parallels with racism. It is a set of assumptions and practices that promotes the differential and unjust treatment of people because of apparent or assumed physical, mental, or behavioral differences. Handicapism pervades our society and, overall, presents the most important barrier to the development of community programs. Prejudice, stereotyping, and discrimination are its major components. (See Yinker, 1965, and Allport, 1954, for a discussion of the use of these terms in the study of ethnic relations.)

Prejudice toward the handicapped is indicated by assumptions that they are innately incapable and naturally inferior. It is revealed in the belief that the handicapped have personalities and characteristics so extraordinary that they have little in common with non-handicapped persons, and should therefore be kept "with their own kind" (Goffman, 1963; Wright, 1960).

Prejudice is a general disposition, while stereotyping refers to the content of the prejudice that is directed toward specific groups. Thus, the mentally retarded are believed to be forever childlike, to enjoy boring, routine activities, and to be oversexed (Wolfensberger, 1975). The blind are supposed to be melancholy (Scott, 1969). Stereotypes are frequently used to justify particular modes of treatment. Thus, the retarded are often treated like children, given boring work, and isolated from others.

Despite their inaccuracies, stereotypes are maintained by many processes. They are transmitted and constantly reinforced by the culture and by peers. Since the handicapped are isolated and have few opportunities for close or sustained relations with normal people, they have little chance of disproving the stereotypes about themselves. Since handicapped people are treated in ways that correspond to their stereotypes and are rewarded for stereotypic behavior, they learn to act out the role of the handicapped and fall victim to self-fulfilling prophecies (Merton, 1957).

Prejudice and stereotyping point to the cognitive and ideological substance of handicapism and lead to discrimination. At one time, slaves and women were considered to be not unfairly treated. Laboring in the field for the

economic benefit of others, or serving their husbands was viewed as their natural condition. Similarly, handicapped people are thought to have relative equality in our society, especially since the advent of categorical social service programs. Nevertheless, their differential treatment is evidence of deep discrimination.

Recognizing handicapism in a general way is important, but we must be more specific if we are to bring down this barrier. We must recognize that prejudiced assumptions are transmitted by the mass media—television, films, books, and newspapers. For example, in horror movies we see a clear association of physical and mental handicaps with acts of violence and hatred. In children's stories, there are the inevitable hunchbacks, trolls, and other deformed monsters who frighten pretty, normal children.

Cartoons, too, are important carriers of handicapist images. "Stupid idiot," "moron," "dumb," and "crazy" dot the landscape of such comic strips as *Beetle Bailey* and *Archie*. These comics not only confirm prejudicial and stereotypic attitudes, but also prove that disability labels have become general terms of derogation.

In hundreds of ways, the mass media transmit and reinforce negative concepts of the handicapped that create barriers to their placement and acceptance in the community. (For a full discussion of the concept of handicapism, see Biklen and Bogdan, 1976. Authors who have described various categories of the handicapped as minority groups include Dexter, 1964; Wright, 1960; Yunker, 1965; and Gellman, 1959.)

#### ECONOMICS

Special education is big business. The Rand Corporation recently reported that government agencies expend \$2.8 billion annually to serve mentally retarded youth (Kakalik, 1973). Mental health is also big business. Governor Carey of New York has recommended a \$924 million Department of Mental Hygiene budget for the 1977 fiscal year, "part of the Governor's \$10.7 billion austerity budget . . ." (*Mental Hygiene News*, January 30, 1976, p. 1). Contrast this with the \$640.2 million appropriated for fiscal year 1973 in New York State.

Institutionalization is big business in New York, and in a fundamental sense, New York, our case example, reflects the national situation. The 1975 appropriation for the Willowbrook Developmental Center was approximately \$62 million, more than a \$20,000 expenditure per resident. In 1965, the per capita expenditure at Willowbrook, and at virtually every other state institution for the mentally retarded, was less than \$4,000 a year.

Even deinstitutionalization is big business, for those engaged in trust-busting and monolith-wrecking and for others who create and manage community alternatives to institutions. There is no way to avoid the fact that special educational health-mental retardation is big business. We can, in fact, talk of a handicap industry (Blatt, 1976).

And it is sacred business too! How many people noticed recently that a presidential candidate's ill-fated \$90 billion federal budget cut proposal avoided assault on allocations for the handicapped? Our pariahs have become holy untouchables, for the most part segregated and lacking normal opportunities, but surrounded by government and philanthropic agents who are committed to protect to the end their right to be different, and to back that right with big dollars. In this modern era, we seem to insist on creating problems, and then on spending heavily to support them.

The handicapped are big business, although the business resembles more closely the game of Monopoly than the work of people who buy, or sell, or grow. Like Monopoly, the handicap business appears unreal, the money expended seems like paper, the promises not really meant or taken seriously. Handicap monopolies are easily created and almost as easily destroyed; this moment's idea is the next moment's joke; today's victory is tomorrow's embarrassment.

When Rockefeller, Carnegie, Mellon, and others invented the philanthropy business, their efforts led to significant changes in the extent and manner in which the federal government aids those in need. Big business has taught us how to organize our philanthropies to serve the people and, further, how to organize the people—the state—to serve both business and philanthropy.

This is America. There is enough for everyone, for the rich and the poor, the healthy and the sick, the sound and the unsound, the philanthropist and the businessman. Some data:

*Item.* In 1965, New York State embarked upon a five-year \$500 to \$600 million mental hygiene construction program as part of a master plan for the mentally disabled (Legislative Commission on Expenditure Review, 1973). Forty major projects were approved, at a construction cost of \$320.3 million. Furthermore, the program included an additional \$188 million for modernization of existing facilities, plus \$100 million to help construct community mental health facilities. By 1972, 23 of the original 40 major projects had been completed or were under construction; these exceeded cost estimates by 50% (\$94

million), a discrepancy that inflation in construction costs cannot fully explain. When the revised total plan is implemented, 28 projects will have been completed at a cost of \$343.5 million, \$23 million over the original estimates. If there are no further delays, inflationary increases, union demands, or bright new ideas, the 7,500 beds that will be the basic product of New York's master plan will cost the state's taxpayers approximately \$45,000 each for construction, and an additional one and one-half to two times that amount (\$65,000 to \$90,000) to meet fund obligations, to the banks, foundations, and other bondholders who underwrote the cost.

*Item.* A recently completed study by the New York State Department of Mental Hygiene disclosed that residents in group homes for the mentally retarded required expenditures of \$6,700 yearly, while institutionalized residents required \$34,000.

*Item.* A recent report issued by the New York State Assembly (Swift & Melby, 1976) revealed that family care for the mentally ill and retarded requires approximately \$7 a day, while residential services cost from \$50 to almost \$90 a day. While family care and other community placement admittedly may require additional educational and treatment services, such services are frequently available through resources provided by insurance, city, county, or state programs.

There are fixed costs, some of gigantic proportions, which are not accounted for above: pension costs, government and other grants, various kinds of interest rates, and hidden costs that even the most penetrating search has yet to uncover. The question that crops up again and again is: Why New York State (and other states) continue to construct and support segregated facilities? Perhaps because there are currently 64,000 union employees in the New York State Department of Mental Hygiene, an increase of 10,000 in little more than three years. Perhaps because there are also contractors, builders, architects, real estate entrepreneurs, and many other people anxious to provide the best construction to any state for any purpose. Perhaps because there are merchants and manufacturers who would rather sell carloads of merchandise to institutions than run corner five-and-dime stores.

In 1963, at the behest of Governor Rockefeller, the New York Legislature created the Health and Mental Hygiene Facilities and Improvement Fund (HMHFIC), an organization that has had several name changes since, but has remained steadfast in its mission to execute

the construction program of the Department of Mental Hygiene (Legislative Commission on Expenditure Review, 1973). Its original responsibilities included completing work on a \$350,000,000 mental hygiene bond issue. However, since its January 1964 takeover date, HMFIC (or you may use its new name, the Facilities Development Corporation), has spent over one billion dollars on mental hygiene construction. Financing is arranged through the State Housing Finance Agency, which issues bonds to institutional and individual investors, who purchase them because they are tax-free and offer the lender a virtually fail-safe guarantee of earning from 3½ to 7% interest on his money. You must remember that these bonds are tax-free (an important benefit to those in high tax brackets) and are rated as very safe by Standard and Poor and by Moody, even in the face of New York City's and New York State's various fiscal crises. One reason for the safety of these bonds and their high ratings is that income to mental hygiene facilities (income directly from patients or their families, or from federal or third-party sources, such as income from Title 19 of the Social Security Act) is *pledged first to the mental hygiene facilities improvement fund*. The bondholders must be paid first, as in any good business.

How do we convert segregated facilities for the handicapped and the elderly to useful purposes? How can these thousands of people return to normal community life, without the state's bankrupting itself in attempts to meet bond obligations and other commitments to the business community? First, we must recognize the depth and extent of commercial involvement in supposedly non-profit, philanthropic, and service agencies. Second, we must seek to interest other clientele in the segregated facilities and programs we have set up for the handicapped and the aged. A modest beginning might be to explore with business and state officials the possibilities for converting segregated facilities to new uses. To carry out the conversion, institutional operating budgets would be transferred to the community as each segregated facility is evacuated by so-called mental patients, state school residents, and the aged. This may require public support, special tax measures, and other inducements. The farmers have these advantages and so do others. Why not the handicapped?

#### THE SCHOOLS

In its first five years (1971-1976), the Center on Human Policy (a Syracuse University facility

devoted to the promotion of community-based environments for people with special needs) received over 4,000 requests for assistance from parents of children with disabilities and from teachers and other professionals in education. The vast majority of these requests concerned school placement and the right to education. The requests and complaints fell into several groupings. Some involved children who were excluded from school for behavioral reasons or because of severe disabilities. Others came from parents and guardians who sought to improve the quality of school instruction, or desired more specialized instruction. There were complaints about absence of auxiliary services, such as transportation and speech therapy. There was a recurring pattern of non-service; institution and social service agency professionals often found local school districts reluctant or unwilling to accept "state" children.

This last category is particularly significant. We found that, while parents were often willing to advocate tirelessly and for months on end to secure adequate services for their children, professionals were often as concerned with interagency harmony as with the fate of an individual child. Consequently, agency professionals often gave up trying to place institutional children in local schools, for fear of jeopardizing interagency harmony. These findings have been reiterated in several local and national reports (Task Force, 1971; Children's Defense Fund, 1974), as well as in our own research (Biklen, 1973; Blatt & Blank, 1971).

Numerous parent and professional cases brought the *Center on Human Policy* staff into frequent contact with school officials. Here we learned the language of exclusion, and its familiar ring from school district to school district, from professional to professional. We began to catalogue the many phrases that signalled exclusion. In some instances, they were typical bureaucratic doubletalk; in other cases, they reflected not so much the bureaucratic ethos as the social context in which prejudice toward the disabled is commonplace. *Taken as a whole, these phrases and the attitudes they reveal constitute a formidable barrier to successful deinstitutionalization.*

In the bureaucratic tradition, we frequently heard:

"We do not have the funds to create a program for your child."

"We agree with your philosophy, but we must be practical."

"The child is not in our jurisdiction. It is beyond our sphere of influence."

"Sorry, we do not make the rules."

"The unions will never buy it. They will not take on any extra work."

"We cannot change all at once. It will take time. We do not want to rush into things and possibly make it worse for everyone."

"We need evidence before we can act."

"We will need more time. You must learn to be patient."

There were other built-in biases against disability, expressed in exclusionary language:

"This child is an exceptional child among exceptional children. She just doesn't fit any category of student in our schools."

"Your child is too severely disabled."

"The schools cannot solve every need. We are not a babysitting service."

"If we included your child, we would have to cancel an art teacher for the typical children."

"We have always sent such children to the institutions or to private schools."

"We need at least ten of them with the same disability before we can set up a specialized program."

"We do not have a program for children at that level."

"We would like to help, but we need teachers first."

The effect of such phrases is immense (Task Force, 1971). Schools provide the core of every child's developmental experience, apart from home life. School exclusion, perhaps more than any other agency policy, threatens the whole deinstitutionalization process. Without schooling, community placement becomes a kind of custodial placement. So we must again turn to conversion, this time with an eye to overcoming prejudices, stereotyping, and bureaucratic red tape.

In part, that has already occurred in the form of court rulings, such as the *PARC vs. Commonwealth of Pennsylvania* litigation and the *Mills vs. Board of Education* case; national legislation, such as PL 93-380 and PL 94-142 (Abeson, 1974; Abeson, et al., 1975; Gilhool, 1973); and consumer advocacy (Biklen, 1974, 1976; DesJardins, 1971; Ruskin, 1975). Court decisions like these and laws established on their basis insist on the right of children with disabilities to public education in the least restrictive (most integrated) setting possible. Children and their parents have also won due process rights by which they may question and challenge placement and exclusion decisions. Thus, there is an emerging new language replacing the language of exclusion. We are beginning to hear more about "rights":

"every child can benefit from an education," "least restrictive services," "zero reject," "mainstreaming," and "individualized planning." These new words and phrases can be regarded as part of the conversion process.

#### PROFESSIONALISM

Ironically, those who have been given the responsibility to provide services to the handicapped often erect additional barriers to changing our categorical service-segregated system to an integrated non-categorical one. Many professionals working with the handicapped think in terms of categories and segregated services. This is the way they have been taught to diagnose and prescribe. Thus, they may not have the philosophy or the skills needed to meet the requirements of conversion. Retraining can provide only a partial remedy; professionals do not change easily. Furthermore, not only is retraining a technical problem, but professional resistance to it can lead to a major undermining of conversion efforts.

Next, there is the brick-and-mortar, formal organization of the professions—physical and organizational elements that stand as defenses against the onslaught of change. For example, our buildings have been constructed to foster segregation and isolation. State schools dot the landscape of our countrysides, and day schools for the handicapped form part of the skyline of our cities. These represent great financial, as well as career and life, investments. Similarly, professional societies and professional schools have been organized in ways that may be detrimental to conversion, i.e., according to diagnostic categories. There is, for example, the American Association on Mental Deficiency. Special education departments have specific programs in emotional disturbance, mental retardation, learning disabilities, speech and hearing disorders, and so on.

Another barrier to conversion is the profession's insistence that special children need specially trained professional people to take care of them. While, to some extent, this is true, it is not wholly or always the case. A major challenge for the professional lies in demystifying himself and freely sharing some of his understanding with others, so that they too can join in helping the handicapped.

#### BUREAUCRATIC STRUCTURES

As we have seen, deinstitutionalization means nothing more than the exodus of individuals from an institution. Usually, it has resulted in

"dumping" and re-institutionalization (Conroy, 1976). But who is responsible for the failure of deinstitutionalization? Is it the institution that sends people into the community? Or the community that fails to provide local services? Or perhaps the private agencies that refuse to serve the formerly institutionalized? The institution points to the local community, the local community to the institution, the private agencies to both, and all to the legislature that balks at additional appropriations, in an endless display of buck-passing and rationalization (Biklen, 1974).

This brings us back to our original question. Who is responsible for the failure of deinstitutionalization? Perhaps everyone in general, yet no one specifically. The deinstitutionalization process has been based on faulty assumptions and models. In this section, we identify three major deinstitutionalization models and show how they have been doomed to failure (see also President's Committee on Mental Retardation, 1976). Most states have adopted one of these models with only slight variations. Some have combined two or more, to further complicate matters. Still others have adopted no model at all.

*Institutional expansion.* In many states, the same agencies that operate institutions have been expected to develop community-based programs. However, whether for ideological, economic, or pragmatic reasons, these agencies remain committed to the institutional model. As a matter of ideology, many state and institutional officials believe in segregation. As a matter of economics, they strive to meet minimal standards of institutional care in order to obtain federal monies. As a matter of pragmatism, they wish to avoid scandal and exposés. "We can only have community programs," these officials state, "after we have good institutions." Thus, they may continue to pour resources into the institution endlessly even though this may drain away funds necessary for community services. Or they may alleviate institutional overcrowding and understaffing through the haphazard release of people into the community, as though small warehouses were better than large ones. In the context of an institutional system, then, resources for the community-based services, like minorities in the job market, are the last to be employed and the first to be cut.

*Dual systems of services.* Some states have turned to local governments or regions to develop community programs, while themselves maintaining a state institutional system (Goldman,

1975). Typically, these states offer to reimburse localities if they allot a certain proportion of their expenditures for community services. For example, a state may underwrite one-half to three-fourths of the net operating expenses of programs in the community. As currently established, such schemes are certain to fail. In times of fiscal austerity, which is almost always, localities will hesitate to pay even a part of the costs of services as long as the state will pay the full cost of institutionalization. Thus, even the mildly retarded will be labelled as "the state's problem," being "too retarded to live in the community," or "in need of specialized services only the institution can offer." Under a dual system of services, the local government's incentive to institutionalize people all too often offsets its incentive to serve those people in the community.

*Laissez-faire.* Finally, some states have adopted a laissez-faire system, based on the assumption that private agencies will develop a range of services if sufficient funds are allocated for that purpose. Yet a continuum of services cannot evolve through the voluntary actions of service providers. In the absence of proper planning and coordination, small agencies will flounder, because they lack the expertise to obtain funds and to establish programs; large agencies will operate mini-institutions, with little accountability; and services will be congregated in low-income areas of the community. Under a laissez-faire system, service providers also tend to engage in "creaming" (Miller, et al., 1970; Bogdan, 1976) and "bounty hunting" (Bogdan, 1976). That is, they serve those who are the easiest to serve and those who may not require services at all, rather than those with the most severe disabilities. In short, laissez-faire guarantees neither quality services, nor services for all who need them.

Unlike these deinstitutionalization models, the conversion model implies an orderly and planned transition from an institutional to a community-based system of services. As such, it requires administrative structures with fixed lines of responsibility to prevent bureaucratic buck-passing. In a later section of this paper, we describe the administrative precondition to conversion.

## THE INSTITUTIONS

We have seen how handicapism and school exclusion policies act as obstacles to conversion. Because of their disabilities, the institutionalized are discriminated against by society and ex-

cluded from typical school programs. They face further discrimination as well, for institutions foster the very behaviors which society and the schools find least acceptable.

In response to progressive ideologies, the custodial institutions of the past have gradually become "training schools" and "developmental centers." However, today's institutions, like yesterday's custodial asylums, foster dependence and incompetence among their residents (Blatt, 1970; Butterfield, 1967). At institutions, both new and old, residents' meals are selected, prepared, and served at specific times; the inmates' clothes are laundered; their routines and activities are planned by others (Biklen, 1973; Bogdan, et al., 1974). They are told what to do and when to do it. As a staff member at one institution we have studied put it:

"The staff has a lot of power here and they do use it. The staff tells them when to get up in the morning, when to go to bed at night, when to eat, when to brush their teeth . . . The residents are virtually completely dependent on the staff for everything."

In some instances, the brutal realities of institutional life have even more dramatic implications. For the sake of convenience, staff members feed residents, rather than teach them to feed themselves, or change the children's diapers, rather than toilet-train them (Bogdan, et al., 1974). Thus, residents are denied opportunities to develop the skills needed for adjustment to the community.

Institutions also tend to accentuate the behaviors they claim to treat (Blatt, 1970). As a response to boredom or lack of stimulation, many residents develop habits such as head-banging, rocking, and self-abuse. In the absence of proper exercise, their limbs may atrophy and wither away (deGrandpré, 1973). Because they have never known privacy, residential inmates urinate, defecate, or masturbate in public. Since they have had to fight for social-psychological rewards at the institution, residents and former residents attempt to ingratiate themselves with strangers by such inappropriate remarks as "I love you," or "You're my friend." Ironically, institutional staff members often cite such behaviors as the reason why "the community will never accept this kind of person." So they breathe life into handicapism and provide school officials with rationales for exclusion and segregation.

Institutionalization itself is therefore a major barrier to the integration of the formerly institutionalized into society. In deinstitutionalizing the residents of state schools and centers, we

must take the institution out of the people, as well as the people out of the institution.

### *Relevance for Teachers*

The transition from institution to community is a complex process. Deinstitutionalization has failed because its proponents have ignored this reality. Such factors as societal discrimination; funding mechanisms and construction costs; school exclusion; professionalism; bureaucratic structures; and institutional dependence have acted as barriers to the movement of individuals from the institution.

We have discussed a different way of thinking about deinstitutionalization: in the context of the larger society, and in terms of specific elements of the conversion system. We must now articulate the relevance of conversion to teachers and to schools.

1. Teachers cannot control the course of deinstitutionalization. The process of bringing children from institutions back into the community involves many groups, and interests other than those connected with the schools. For example, in a handicapist society, a teacher cannot pretend to overcome prejudice toward children with disabilities by using a new curriculum that emphasizes positive attitudes toward the disabled.

2. However, if the teacher wishes to do more than add a new curriculum or subtract an old one, his actions can surely influence society's treatment of disabled children. How?

3. The answer is found in the term itself: conversion means societal efforts to eradicate handicapist attitudes and practices. Obviously, teachers, as members of a larger society, can play a role in such efforts. Conversion means rechannelling funds to support community placements for the handicapped. This process will ultimately provide resources for the schools. Conversion means retraining institutional staffs and community personnel. Teachers can play major roles in such programs. Conversion means creating noncategorical systems of educational treatment. Such policies will eventually affect the design, the appearance, and the functioning of all school classrooms and curricula. Conversion means changing attitudes of school administrators toward acceptance of zero reject policies. Conversion means planning community services, of which education is a major component. Conversion means the appointment of professional and consumer advocates for community programming. Last, conversion means developing classroom strategies that focus on promoting integration of disabled

children into regular school programs. This implies efforts to increase awareness, understanding, and acceptance of disabled students by non-disabled students and, obviously, acceptance by teachers, principals, and other school officials.

Teachers and their colleagues can promote new understanding and positive values about individuals with special needs. They can learn, and teach others to learn, to recognize handi-capist assumptions and to work to eliminate them. If conversion is to succeed, the schools must change. For the schools to change, and for children to change, teachers must change.

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## Appendix

When President Ford signed into law the Education for all Handicapped Children Act of 1975, he intensified our need to know, fairly precisely, the incidence and the prevalence of children with special needs. Without such knowledge, there could be no funding, and even more important, it would be impossible to plan effectively for the resources we do have. Without such knowledge, conversion could fail.

A substantial portion of the new federal money (authorized at \$387 million for fiscal year 1977-1978 and escalating to an authorization of \$3.1 billion by 1982) will flow through local school districts and through state-operated programs. Among its many provisions, the act requires, for funding eligibility, the identification of specific children.

While labels have always been important in contributing to the definition of a person and, thus, to how that person is regarded and indeed regards himself, in recent years some labels have been anchored to various funding schemes. This is seen as a serious problem by those who believe that many so-called handicaps are neither diseases nor conditions which presuppose certain characteristics and predictable occurrences. Nonetheless, we have one committee reporting that there are six million mentally retarded individuals in the United States (an application of the 3% estimate), while other committees report or claim a 1% estimate, or a 2% estimate, or more, or less. Of course, some discrepancies and confusion attend all attempts to define, discuss, or enumerate anything in any significant manner metaphorical; incidence and prevalence data are not grounded in objectively based disease entities. One example is the definition of homosexuality, changed by vote of the Board of Trustees of the American Psychiatric Association in December of 1973, whereby it was decided that homosexuality should not be

designated a "psychiatric disorder" and, instead, should be labelled a "sexual orientation disturbance" (Blatt, 1976). A second example is the 1973 revision of the American Association on Mental Deficiency's definition of mental retardation.

Prior to 1959, there was more or less general agreement that the incidence of mental retardation is approximately 3%. That is, mental retardation was assumed to be normally distributed in the population and it was further agreed that the psychometric "cutoff" would be 75 I.Q. or 1½ standard deviations away from the mean. In 1959, the Association's Terminology and Classification Committee, chaired by Rick Heber, redefined mental retardation and, included in the revised definition, there was the statement that subaverage intellectual performance refers to a psychometric score which is greater than one standard deviation below the population mean on tests of general intelligence (Heber, 1959). With that change in definition, 16% of a typical population would be, psychometrically at least, eligible to be designated as "mentally retarded."

In 1973, a subsequent committee of the Association, now chaired by Herbert Grossman, again revised the definition to include as mentally retarded only those who are "significantly" subaverage in intellectual functioning, where "significantly" means performance which is two or more standard deviations from the mean or average of the tests (Grossman, 1973). With the figurative, and possibly literal, stroke of Herbert Grossman's pen, a committee sitting around a conference table reduced enormously the potential incidence of mental retardation, never having to see or dose or deal with a client, only having to say that, hereinafter, mental retardation is such and such, rather than this or that. We cannot redefine measles, or cancer, or pregnancy with such external procedures. It is obvious; mental retardation and emotional disturbance, and even such seemingly objective conditions as blindness and deafness, are less objective disease entities than they are administrative terms; and they are metaphors more than anything else (Blatt, 1976).

The Grossman Committee is back at work and very shortly will be issuing a revised definition, again increasing the psychometric cutoff. Unfortunately, added to the metaphorical nature of labels associated with special education, is the unpleasant fact that careful epidemiologic research cannot be conducted without a great deal of effort and resources and, consequently, there are relatively few such reports in our literature. Therefore, in spite of the influence preparative

labels have on the treatment of the handicapped, and in spite of the ever-increasing chaining of resources to identified clients, incidence and prevalence estimates vary so remarkably and change so frequently to fit certain pragmatic needs that they are relatively unhelpful, if not altogether untrustworthy.

However, there have been several attempts to estimate the occurrence of various handicaps in our schools and in other program areas. We believe some general statements can be made, based on our own research (Finn & Blatt, in Blatt, 1973) and the work of others. Table I summarizes estimates drawn from several of these studies (Blatt, 1976).

It should be noted that, with the exception of our own preschool estimates, reports here are for age groups 5 through 19. Second, none of these estimates accounts for what is now termed minimum learning disability. Third, multiple handicaps are not included as a category in three estimates and, with the exception of mental retardation, severity of handicap is not considered. What Table I does illustrate is the significant range of such estimates. The relatively recent Rand study provides additional documentation in support of this contention (Kakalik, 1973).

Because there is an important difference between, for example, psychometric mental retardation (at the present time, approximately 2% of the total population) and known mental retardation (approximately 1% of the total population), and because other disability areas show similar discrepancies, we believe it is both reasonable and in the best interests of clients to use incidence and prevalence estimates that are based on available studies of known cases in the various categories. As we recently concluded, and as Table 2 shows: from our own demographic studies of mental retardation, our evaluation of the epidemiologic literature in the field, and from a careful analysis of the data obtained from both our Head Start questionnaire survey and our observational studies of selected Head Start programs, we estimate that 1% of the total population (incidence) needs special services because of their mental retardation, another 1% requires it because of behavioral disturbances, and another 1% because of moderate and severe sensory and/or physical disorders. We would not include the so-called speech-impaired in such designations; nor would we include the so-called learning disabled. We believe it is not in the best interests of either the children or the programs to label children with mild disabilities, who could otherwise be adequately dealt with in ordinary

TABLE I  
*Prevalence Estimates of Various Types of Handicapped Children*

Handicap	Prevalence Estimates by Percent				
	1 <sup>a</sup>	2 <sup>b</sup>	3 <sup>c</sup>	4 <sup>d</sup>	5 <sup>e</sup>
Educable Mentally Retarded	.5	2.0	2.3	1.30	1.30
Trainable Mentally Retarded				.24	.24
Hearing Impaired	1.1	1.5	.575	.10	.575
Visually Handicapped	.6	.2	.1	.05	.1
Speech Impaired	3.4	2.0	3.5	3.60	3.5
Physically Handicapped	1.0	1.5	.5	.21	.5
Brain Injury & Learning Disabled	1.7	N.E.	1.0	1.12	1.0
Emotionally Handicapped	1.0	2.0	2.0	2.0	2.0
Multiply Handicapped	N.E.	N.E.	N.E.	.07	.07
TOTALS	9.3	9.2	9.975	8.69	9.285

<sup>a</sup> Estimates based on a Syracuse University-Systems Research Incorporated Head Start questionnaire; T.M.R. and E.M.R. combined; no estimate (N.E.) on "Multiply Handicapped."

<sup>b</sup> Estimates by Mackie, R. P., & Dunn, L. M., *College University Programs for the Preparation of Teachers of Exceptional Children*.

<sup>c</sup> Estimates prepared for *Estimates of Current Manpower Needs in Education for the Handicapped, 1968-69*.

<sup>d</sup> Estimates used by Rossmiller, R. A., Hale, J. A., & Frohreich, L. E., *Educational Programs for Exceptional Children: Resource Configurations and Costs*.

<sup>e</sup> Conservative estimates used by *The Fleischman Report on the Quality, Cost, and Financing of Elementary and Secondary Education in New York State*.

classes, as "handicapped," "retarded," "speech-impaired," etc. We believe it is in the interest of both the children who have been heretofore so labelled, and those others who are now denied a normal interaction with them, to reserve the categories of handicap only for those who have such severe and moderate needs where they will not be able to be served adequately in ordinary classes under ordinary conditions. For that group with such special needs, we estimate that there is no more than a 3% incidence across populations and age categories and, possibly, a 4%, and no more than 5%, prevalence during the pre-school and school years. Therefore, mild speech impairments, as mild retardation or disturbance, could not be considered a handicap requiring special attention in the traditional sense. Those children with mild disabilities should be served within the context of regular school settings. Those with severe or moderate speech impairments will be found to have general language disabilities and, more probably than not, learning, behavioral, sensory, or physical disorders (Blatt, 1976 pp. 144-146).

While the experts in the field of special education have argued that 3%, or as much 5%, of the population is "psychometrically mentally

TABLE 2

*Estimated Needs for Special Community and Residential Services for Children and Adults in a Model Region of 50,000 Population*

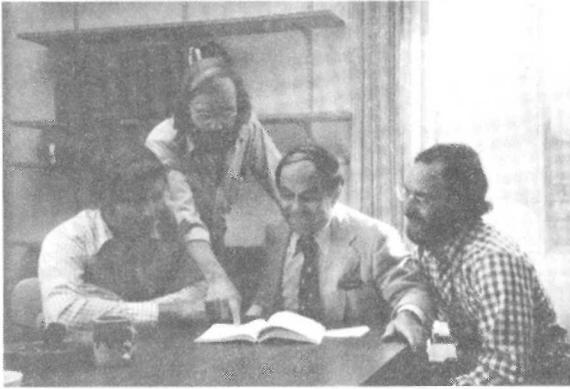
Category	Percent of Total Population in Categories	Estimated Number in Categories
<i>Major categories</i>		
1. Percent of total population needing special services due to mental retardation	1% of total population: .75% EMR; .20% TMR; .05% SMR	5,000
2. Percent of total population needing special services due to behavior disturbances	1% of total population: .50% severely ED or SM; .50% moderately or mildly ED or SM	5,000
3. Percent of total population needing special services due to moderate and severe sensory and/or physical disorders	1% of total population: .03% blind; .08% deaf; .14% severely sensory and/or PH; remainder partially disabled	5,000
<i>Sub-categories</i>		
1. Mental retardation		
a. Individuals in need of special programs in public school at any one time	1% of total school population (125,000)	1,250
b. Individuals in need of only minimum services other than special programs during school years	50% of entire mentally retarded population	2,500
c. Individuals in need of residential placement, at any one time, with alternative programs available	.1% of total population	500
d. Individuals requiring other services:		
Nursery and preschool programs	5% of known mentally retarded population	250
Day care programs	5% of known mentally retarded population	250
Sheltered workshop activities, vocational training, adult day activities	10% of known mentally retarded population	500
2. Behavioral disturbances		
a. Individuals in need of special programs in public school at any one time	1% of total school population (125,000)	1,250
b. Individuals in need of only minimum services other than special programs during school years	50% of entire emotionally disturbed population	2,500
c. Individuals in need of residential placement, at any one time, with alternative programs available	.1% of total population	500
d. Individuals requiring other services:		
Nursery and preschool programs	5% of known emotionally disturbed population	250
Day care programs	5% of known emotionally disturbed population	250
Sheltered workshop activities, vocational training, adult day activities	10% of known emotionally disturbed population	500
3. Sensory and/or physical disorders		
a. Individuals in need of special programs in public school at any one time	1% of total school population (125,000)	1,250
b. Individuals in need of only minimum services other than special programs during school years	50% of entire sensory and physically handicapped	2,550
c. Individuals in need of residential placement, at any one time, with alternative programs available	.1% of total population	500
d. Individuals requiring other services:		
Nursery and preschool programs	5% of known sensory and physically handicapped population	250
Day care programs	5% of known sensory and physically handicapped population	250
Sheltered workshop activities, vocational training, adult day activities	10% of known sensory and physically handicapped population.	500

retarded," our own studies indicate that a 1% estimate is more valuable for program planning and development. Similarly, estimates as high as 20% to 50% in the relatively new category called "learning disabilities" are provocative, but do not appear to be helpful for those planning or implementing programs. The studies that have been completed suggest that there are substantial differences between what we might call "administrative disability" and "objective disability." We believe it is reasonable to base our estimates on whatever studies of known cases are available (administrative disability). That advice might lead to a general conclusion that not more than 3% of a representative population will be moderately, severely, or multiply handicapped.

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Robert Bogdan, Steven Taylor,  
Burton Blatt, Douglas Biklen

ROBERT BOGDAN is Associate Professor of Special Education and Sociology at Syracuse University. He has published books on research methods and mental illness. His articles have appeared in such diverse journals as: *The American Psychologist*, *Phi Delta Kappan*, *Social Work*, *Orthopsychiatry*, *Journal of Health and Social Behavior*, *Educational Technology*, and *The American Behavior Scientist*.

STEVEN TAYLOR is a staff member of the Center on Human Policy, Syracuse University, and is currently working on his Ph.D. in Sociology. He has done extensive research on institutions and the effects of institutionalization. He has authored and co-authored a number of publications, including *Introduction to Qualitative Research Methods* (with Robert Bogdan).

DOUGLAS BIKLEN is Director of the Center on Human Policy and Associate Professor of Special Education and Rehabilitation at Syracuse University. He is author of the book *Let Our Children Go: An Organizing Manual for Parents and Advocates* and has written numerous other articles on advocacy, the legal rights of children with disabilities, institutional life, and the politics of behavior modification.



BURTON BLATT is Centennial Professor and Dean, School of Education, Syracuse University. He is author of approximately 150 books, monographs, and papers, among these *The Preparation of Teachers: An Unstudied Problem in Education* (with Seymour Sarason and Kenneth Davidson), *The Intellectually Disfranchised*, *The Educability of Intelligence* (with Frank Garfunkel), *Christmas in Purgatory* (with Fred Kaplan), *Exodus from Pandemonium*, *Souls in Extremis*, and *Revolt of the Idiots*.