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Today states finance and manage 530 institutions to care for the mentally disabled—300 for the mentally ill and 230 for the mentally retarded. These institutions were created, for the most part, through state appropriations, and states continue to manage them directly. Despite two decades of deinstitutionalization, state institutions still meet practical as well as humanitarian needs.

Yet state institutions themselves are a relatively new initiative. Prior to the creation of these institutions by state government, the disabled were cared for in special “homes” scattered across most counties. Every historical analysis of the nineteenth and early twentieth centuries indicates that much of the impetus for creating state institutions was based on a desire to improve conditions in local county homes, where the blind, elderly, mentally ill, mentally retarded, and those dying from infectious or chronic diseases were boarded together and supported with minimal funding that often ebbed and flowed with the local economy.

Once established, state institutions grew inexorably, driving the census of state hospitals for the mentally ill to a peak of 559,000 in 1955 and the census of state schools for the mentally retarded to a peak of 195,000 in 1970. What produced this growth? First, the industrial revolution required new complex human skills and knowl-
life for its residents, Institutional living came at a price. The institution could never replicate, even with unlimited resources, the kind of life to which most Americans aspired. And this quality of life, of course, was the standard to which the institution was held when it became the target for deinstitutibnalization. The standard was as idealistic and generous as Americans can be; but it reflected little clear understanding of the human problems that county homes and then state Institutions were created to address.

Mental illness and civil liberties

Until this time, there were few doubts raised about the responsibility assumed by state government in the care of the mentally disabled. The state's decision to create institutions for the disabled was widely seen as providing them asylum and sometimes successful treatment. This was good government, and seen by many as reflecting a caring society. Since the alternative in many cases was death itself, few questioned the *pareshape patriae* authority of state government. It seemed quite reasonable for state government to substitute its decisions for those of individuals who, without this parenting function, would likely not survive.

Two major events occurred in the 1960s and unfolded during the 1970s which changed the primary role of state institutions in mental health care. First, Congress enacted a number of statutes, beginning with the Mental Retardation Facilities and Community Mental Health Centers Construction Act, that shifted the focus of mental health care from state Institutions to local communities. With these new laws, control of the mental health system flowed out of the hands of institutional superintendents, who like most state commissioners were physicians, and into the hands of social workers, psychologists, and other community-based professionals who it was thought were better suited to carry out comprehensive care. Second, individual rights of the mentally ill and mentally retarded came under careful scrutiny by federal courts. Under this judicial review, the liberty clause of the Fourteenth Amendment to the Constitution was for the first time interpreted as one protecting the mentally disabled from state decision making. In case after case, the federal courts was for the first time interpreted as one protecting the mentally disabled. The state's decision to create institutions for the disabled was widely seen as providing them asylum and sometimes successful treatment. This was good government, and seen by many as reflecting a caring society. Since the alternative in many cases was death itself, few questioned the *pareshape patriae* authority of state government. It seemed quite reasonable for state government to substitute its decisions for those of individuals who, without this parenting function, would likely not survive.

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One of the first and most important legal attacks on a state’s parens patriae power came in 1972 when a federal court, in Lessard v. Schmidt, held that decisions made by a psychiatrist on behalf of someone presumed incapable of making them himself during an involuntary admission to a psychiatric center may not be made apart from a court-supervised "adversarial hearing" that protected the patient’s liberty interests. The court found a state statute unconstitutional because it permitted involuntary commitment merely on the testimony of a psychiatrist that a patient was mentally disabled and a proper subject for custody and treatment. The court also ruled that any future state commitment statute must be construed to require proof of "an extreme likelihood that if the person is not confined he will do immediate harm to himself or others." This new standard of dangerousness and the adversarial proceeding in which it was applied effectively destroyed the state’s "parenting" authority under the doctrine of parens patriae, at least as it would occur during a civil commitment.

In a single decision, this federal court reshaped the relationship between the mentally disabled and the state. Future decisions, at least those concerning involuntary commitment, would not be based on the "best interests of the patient" as determined by a mental health professional, but would be tested against an objective standard based on proof of danger capable of withstanding cross-examination.

Although Lessard and similar decisions in other circuits did not affect all institutional residents, these cases entirely changed the role of the state institution. By using criminal law standards and an adversarial rather than a paternalistic approach to decision making during a commitment hearing, and by focusing on the loss of liberty experienced by a mentally disabled individual living in a state institution instead of on the capacity of this individual to exercise liberty, the courts overnight redefined state asylums as prisons. As the Lessard court said, and as many courts echoed in the following years: "The power of the state to deprive a person of the fundamental liberty to go unimpeded about his or her affairs must rest on a consideration that society has compelling interest in such deprivation."

Targeting institutions

Lessard applied only to the disabled who resisted admission to mental institutions. A far broader attack on state institutions, however, was launched by civil liberties lawyers. The strategy adopted in state after state followed a rather similar pattern: 1) Select a state institution that is obviously overcrowded; 2) Identify several parents or relatives of residents who are critics of the institution, then gain their support as future witnesses in federal court and obtain permission to use their relative as an example of a victim of state decision making; 3) Identify disgruntled (or recently fired) state employees who will also testify about institutional conditions; 4) Contact the press about the impending suit; 5) Sue the state in federal court for violating the constitutional rights of residents because of the quality of institutional care based on the facts testified to by these parents and employees; 6) Convince a judge to permit a class action suit by all residents living at the institution so that relief given to the named parties will be extended to every resident; 7) Begin discovery of all state records related to the institution and seek court permission to visit the institution at will; 8) Take photographs of the most awful conditions to be found or to be created by working-but-disgruntled employees; 9) Demand documents that are impossible for the state to produce; 10) Conduct motion sessions before a federal judge during which the state is accused of not dealing in good faith and of attempting to hide the horrible conditions it has created; 11) Report these events to the press.

This strategy of the civil liberties lawyers was used successfully at Willowbrook State School—the lead case in forced deinstitutionalization—and adopted in many other states because it created political pressure so great that the state eagerly entered a consent decree rather than litigating these issues. This decree, essentially a settlement agreement, was usually written by civil liberties lawyers, and generally called for two state actions subsequently enforced in court: rapid reduction of the census and the creation of extensive new community programs. Fearing that the governor would be perceived as callous if he rejected improvements for the mentally disabled, the state was initially manipulated into signing a consent decree and then forced into compliance with this agreement when it became a court order. Later the state discovered that the consent decree’s terms, Incorporating the ideal standards written by civil liberties lawyers, could not be met. Thus each state, whether under the same governor or a new one, found itself in constant contempt of court. Because few judges like to reverse or modify their own orders, there is constant litigation testing the state’s performance action against the consent decree’s ideal standards. And, of course, during this litigation the civil liberties lawyers hold the high ground, advancing the interests of the disabled, while the state agency that officially cares for the disabled appears to oppose better care.

Although hardly any state escaped a class action suit based on
some variation of this strategy by civil liberties lawyers, not all entered consent decrees; in fact today no state with good legal advice will sign a consent decree. Nor are the consent decree terms of later suits as idealistic as the earlier ones. Yet after a decade and a half, many consent decrees are still in place despite being bettered by constant litigation and aging very poorly.

These years of judicial review at the state level have more recently yielded some unsympathetic decisions by the Supreme Court. And, experience gained through the actual application of liberty to the disabled through the creation of community-based care now teaches us that few state institutions will ever be closed, because such closings have profound unintended consequences.

A few institutions have been or will be closed in the near future as a result of the efforts of civil liberties lawyers and modern mental health workers. But these closures must be seen as an exception rather than the rule for two reasons: First, statewide mental health systems have found that they could consolidate institutional care by placing higher functioning individuals (who did benefit from the increased opportunity for liberty) in community care. Second, some of the institutions affected by consent decrees now cost so much—for example, 50 percent more per resident ($75,000) in New York State targeted institutions than in nontargeted ones ($50,000)—that states may be forced to close these institutions for financial reasons alone and distribute resources and residents more evenly throughout the remaining state institutions.

Unintended harm

Indeed, the great push for deinstitutionalization has reached its natural end. But what has it accomplished? There is no doubt that institutional care has improved in the nation’s state institutions during the last decade and a half. And there is no doubt that the credit for this improvement rests to some degree with the civil liberties lawyers who mounted this vast effort. But something went wrong along the way. Careful analysis reveals that there has been too much harm done to too many individuals.

First of all, institutional residents, whose disability often prevents them from exercising genuine decisions regarding where they live, have been shuttled during this period by the tens of thousands from institution to institution and from institution to community. But has this mass exodus toward greater liberty actually increased meaningful decision making for the mentally ill and mentally retarded? Or has it, to the contrary, made the disabled the real victims of deinstitutionalization?

When clients of state schools and patients in state hospitals personally requested a discharge during this mass exodus, a move out of the institution may have been warranted. However, where patients and clients were coached by staff or simply could not, because of their disability, express any preference at all about where to live, a rather different set of circumstances arose. Not only was the exercise of decision making by proxy—the very act abhorred by civil liberties advocates—necessary prior to community placement, but at that very moment institutional residents became faceless statistics on the plaintiffs institutional rundown charts. The decision to transfer was often driven not by the long-term needs of the disabled individual but rather by the monthly target of new residents who would be introduced to increased liberty.

Two treatment philosophies, in effect, were in conflict: Was it in the resident’s best interest to remain in a protected environment with familiar surroundings, with people he recognized and, more important, with people who knew and cared for this individual, sometimes for decades, despite their admitted problems with institutions? Or should this resident, because of his interest in liberty, be transferred to a new, often unknown environment with new, inexperienced staff working for a newly formed private organization whose funds were unstable and whose managers were often untrained? The reasonable decision would have been to choose the new treatment philosophy only with great caution. But the other variable—the interest in liberty—weighted the decision with more idealism than reason.

What happened to the mentally disabled when they were torn from a social environment that was familiar and predictable to them and thrust into another that was new and unstable seems less of a tragedy when compared to what happened to the families of the disabled. As disabled individuals were transferred to the community, their families were suddenly forced into conflict with the state government and with other families. Overnight, parents were introduced to enormous uncertainty about the most important family event in their lives: the deep personal burden of bringing into the world and raising a disabled child. Each family found itself facing an agonizing decision, sometimes fighting other parents who were carrying the same enormous burden. Although they were frequently given a voice in developing treatment goals for their children—which effectively meant participating in the decision to choose a community placement—parents had no authority to veto this decision short of taking their child, who was more often than not an adult, home and assuming primary care responsibility.
Parents who objected to this strategy because they did not trust the new promises about community care were portrayed by civil liberties and modern mental health workers as being selfish. They were accused of resisting the "best interest" of their child and of expressing their own personal fears that their child, if he failed in the community, would be sent home. In contrast, parents who became advocates for forced deinstitutionalization were encouraged to form nonprofit organizations which received financing from the state to start up new community programs. It is fair to say that today the most vocal parents advocating deinstitutionalization are those who manage community programs or have some financial stake in their continued growth. Obviously a court or executive order stopping admissions to institutions creates a huge waiting list of exhausted (and traumatized) parents who can be recruited with promises of quicker placement for their children. And, of course, advocates exploited this opportunity.

The effects of playing one group of parents against another was and continues to be emotionally devastating for those caught in this warfare. Parents who become involved in discharge decisions are either put through a new emotional wringer when expressing doubts about the new approach to mental health care or are offered the dual reward of renewed hope for their child and of state financing for a business undertaking, which are inextricably linked for purposes of advocacy.

Parents choosing community programs are then subjected to the threat of annual budget cuts by state government. These threats in turn require their aggressive advocacy with state representatives to protect the financing of private community programs. In the case of parents connected to targeted institutions, the threat of budget cuts also requires expression of their children's success whether true or not before the court In order to bring judicial sanctions against cuts in community programs. In other words, the fragility of community programs during a period of limited state government funding creates a constant crisis for these parents. Inevitably, where this sort of advocacy emerges and where the stakes are both emotional and financial, the factual issues about deinstitutionalization become distorted. The harm to parents as a whole is inordinately severe, not just because a second injury arises from parent fighting parent but because the deinstitutionalization movement has left parents no room to find a middle ground.

Workers in state institutions were also deeply affected by forced institutional rundown. Many became involved in these cases to protect institutional based jobs from being cut by executive order. Iron-ically, public employees working in state institutions fill what might be the most demanding government job. Yet they were confronted with the sudden elimination of tens of thousands of jobs, many held by people who had given decades of public service.

The remaining work force (and it is now clear that, with the exception of a few targeted institutions, a large but demoralized work force will remain for years to come at all state institutions) has been unable to focus on patient care as Its first priority. Workers have been fighting deinstitutionalization for years, not only to justify their jobs, but because they believe in the kind of care they provide and feel that the sacrifice required to do the job well cannot be created in an unstable private sector. Direct care workers have been fighting both the press and state executives, who blame them for the conditions previously found in state institutions.

Yet society must still entrust to these workers the direct care of society's most disabled: Those who cannot be transferred to community care and must remain in state institutions. Civil liberties lawyers misunderstand the human dynamics that make for quality care In any setting. Effective workers must carry out their hands-on work in an environment that respects and supports them.

With a policy that attacks workers in state institutions, the state has turned upon itself In self-destruction. In the last decade, it has probably wasted more resources by creating a demoralized work force than it appropriated through new federal and state funding. In fact, the entire lives of some disabled Individuals have now been dominated by worker turmoil. And if the new community programs under contract with state government fail because of poor management and an unstable work force, which appears Increasingly to be the case, then the state Is left alone with no acceptable alternative to care for the mentally disabled. The best workers are being or have already been driven out of the state institutions.

Quality care in any residential setting rests, first of all, on the human relationships between direct-care staff and residents. The prototype for this, of course, Is the relationship between parent and child. The prototype, however, is Impossible to replicate between strangers, even with generous funding. Love and caring are not easy to buy and become even more difficult to create for disabled adults who cannot care for themselves and who show little or no real improvement over their lifetime. The workers who do this hands-on work, if they are to show caring, must be valued by state leaders. They must be able to work in a stable environment with a known group of residents about whom they can develop some knowledge and, It is to be hoped, some personal attachment.
To devalue workers and to destabilize the institutional work environment is to break the fragile bond between worker and resident. It is not easy to do the work of caring for severely disabled individuals. As one New York State official told a judge when chastised for not meeting a target of increased numbers of state workers, it is not easy to find people willing to change diapers on grown men. The assault on state workers was more than an economic loss for those who lost jobs; it was also an unintended assault on the residents who remained in every institution. Yet the image of harm caused by state workers is now deeply embedded in the public’s mind as well as reflected in state policy. This image could not be more wrong. It violates the property interest workers have in their jobs; it destroys the years of experience many workers have gained from different institutional jobs; it harms the quality of care in institutions by destroying the real caring that does occur there, and with all of this it wastes public resources.

Losing control

The inability of state governments to manage their resources is another far-reaching effect of forced deinstitutionalization. States lost control over the single largest item in their budgets—care for the mentally disabled. Annual expenditures are now made on an irrational basis, often shaped simultaneously by courts and advocacy groups with huge financial stakes in allocation decisions. The publicly financed but privately delivered system is the tail that daily wags the dog because in many states it is now larger than the public sector.

Further, the federal pot of gold so forcefully sought by state government under Medicaid, Medicare, SSI, and SSDI distorted the decisions that were made for the mentally disabled. Vast new expenditures medicalized and professionalized services that should have been more informal, long-term care services. Then, because of federal cutbacks, these programs were stripped of professional staff. Even before penalties from some federal programs (a $56 million grant for Medicaid-supported Intermediate Care Facility/Mental Retardation programs was disallowed in 1984 because the state of New York failed to carry out the provisions in a five-year plan to run down and close its state institutions) major private providers simply went bankrupt.

The state created small community residences in a private sector that promised to provide better care at lower costs, but many of these community facilities seem to have a rather short half-life. The rapid turnover of staff, poor management, and costs that now appear equal to or greater than institutional care (one study done by this author determined that a state institution bed in Manhattan cost $50,000 a year, while the equivalent bed in a community facility cost $130,000 a year), raise questions as to the future of community residences.

Under permanent crisis conditions, state policymakers are simply unable to ask tough questions about the stability and viability of these private agencies over the next decade. Problems are largely hidden from view (unlike in large institutions where there are lots of eyes) and, except in rare circumstances, the state is unable to penetrate into private agencies to observe the day-to-day quality of life experience there.

The responsibility for effective management of these programs is delegated to the executive branch by each state legislature. Today, there is growing concern that too much executive authority has been taken away from state government by federal judicial review. However, state executive authority, a prerequisite for effective management, has not only been directly reduced by judicial review, it has also been indirectly weakened by the court’s preference for the private sector, which has grown enormously as a result of litigation. Thus, state government must also be considered one of the victims of forced deinstitutionalization.

Finally, local government has been severely affected by deinstitutionalization. Indeed, the burden flowing from this policy may be one of the most serious unresolved problems facing cities across the nation. Beyond the increased financial demands placed on local governments by discharged institutional residents, local governments have struggled to solve problems of where to place the homeless. Indeed, the burden flowing from this policy may be one of the most serious unresolved problems facing cities across the nation. Beyond the increased financial demands placed on local governments by discharged institutional residents, local governments have struggled to solve problems of where to place the homeless. According to Robert Hayes, the attorney for the Coalition for the Homeless, twenty thousand individuals reject these shelters every day and instead choose warm vents, tattered cardboard partitions, and a dirty blanket roll for their night of rest in the city’s public places. Less visible to New York City residents, another group of several thousand adults, some of whom are also disabled, and their children live in “hotels” supported by local government. The number of homeless individuals in New York City alone is estimated to be over thirty-six thousand with 30 to 60 percent of them mentally disabled. The responsibility in practice for the care of these individuals
now rests with local government. Yet local officials believe that responsibility should be lodged in the state, which failed to follow up many of the former residents when they were transferred from state institutions to the community. They argue that many of the homeless would now be in more controlled environments had not states been forced to reduce the numbers in their institutions in such an uncompromising and hurried way. In the minds of most officials in New York City, there is no doubt about the cause and effect relationship between the one hundred thousand beds that were emptied within New York State's forty institutions during the last two decades and the people now living on the city's streets.

This is only part of the burden on local government. Children living at state institutions when class action suits were initiated and children on the waiting list when admissions were closed became the responsibility of public schools. Thus, the responsibility of local government now includes the provision of residential care as well as day programs for these individuals.

Local education boards did not (and still do not) have the specialized professionals required by these disabled children, especially in the smaller school districts. Further, when these children turn twenty-one, local government no longer has either financial or legal responsibility for them, thus triggering another hasty move for disabled individuals, one totally unrelated to individual needs.

Liberty al a price

Powerful social forces converged to make deinstitutionalization attractive. The romantic idea of community, bursting forth in the 1960s, created a vision that affected our judgment. And the desire to "teach the retarded" and "cure the mentally ill" is so deeply embedded in our psyche that hope generated by community programs took on a life of its own. And the rapid economic expansion from the mid-1980s to the mid-1970s did create a new political infrastructure (community-based professionals and private local delivery systems) that came to dominate public decision making. Finally, the marriage between conservatives at the state level who thought money would be saved in the long run by closing institutions, and liberals who hoped to improve services by closing state institutions continued until deficit spending threatened to bankrupt both state and federal government.

We must now ask what values are still advanced by further reducing the numbers in state institutions, whether by state policy or judicial order. Does the idea of liberty, when thrust into the lives of the mentally disabled, yield benefits that outweigh the harm caused by the destruction of the state's parent patriae authority, the demise of its institutions, and the harm to its residents, to their families, to workers, and to the ability of state and local governments to manage its human service organizations?

To answer this question we must distinguish the liberty interests that are advanced for the mentally ill from those liberty interests advanced for the mentally retarded. The interest advanced for the mentally ill is their freedom to make decisions about their lives, whereas the interest advanced for the mentally retarded is principally their freedom from physical restraint. But what kind of liberty do the mentally ill and retarded actually gain? Ideally liberty frees individuals from control or restraint by government. With increased liberty disabled individuals are empowered to make unrestricted decisions and to act as they see fit. However, in practice many mentally disabled people only partially exercise—if at all—the rights that fall under this liberty.

What is the meaning of this Increased liberty if the retarded individual must be fed, clothed, directed in movement, and toileted by others whether living in a two-hundred-bed institution or a four-bed apartment? What is the meaning of this liberty if the mentally ill individual's "decisions" are merely an innate instinct to eat when starving or to find shelter when freezing, rather than the ability to Increase personal self-control or self-care?

For the severely and moderately disabled, where substituted decisions continue In all daily living activities despite the change in residence, the benefits, if any, are minimal. Where the critical decisions about life—such as where to live and work, when to eat, and what to wear—cannot be exercised because the individual is too dis-integrated, there is in practice little benefit from liberty.

The tragedy of deinstitutionalization stems not from the idea of liberty itself but from its extreme application to all disabled individuals irrespective of their disability. What remains to be determined is exactly where the scales are in balance, that is, where the benefits of liberty to the mildly disabled are sufficient to balance the harm caused by deinstitutionalization.

When the Supreme Court decided Youngberg v. Romeo in 1982, it settled many questions about the constitutional rights of the mentally disabled. The Court held that the state has a duty to provide adequate food, shelter, clothing, and medical care to the residents of its state institutions. Furthermore, the state has a duty to provide reasonable safety, freedom from undue bodily restraint, and mini-
mally adequate training—apparently at the level of self-care skills exercised when residents entered an institution—when they are unable to exercise free movement and safe conduct for themselves. However, the most far-reaching aspect of Romeo was not its definition of a basic level of care (because most state institutions in the 1980s already met this standard), but rather the process by which disputes about the adequacy of care in future cases will be decided. The state and the decisions of its professionals about minimally adequate training are now presumed to establish the standard of care. After Romeo, the question of liberty no longer offers grounds for an adversarial review of professional decision making as long as it falls within "acceptable professional conduct" as defined by the state.

The states are gradually resuming the right to make decisions under the power of *parens patriae*. While Romeo was being decided by the Supreme Court, a New York district court ruled for the plaintiffs after a twenty-eight-day trial during which the state had unsuccessfully attempted to modify provisions of the Willowbrook consent decree, one of those that had not aged well. But on appeal, the Second Circuit reversed the district court's decision and remanded the case back on the question of whether the views expressed by the state's experts as to this modification in the consent decree constituted professionally acceptable choices or, in the words of Romeo (which had now been decided), were "such a substantial departure from accepted professional judgement, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment." After Romeo, a federal judge was no longer free to choose between the different views of the plaintiff's expert witnesses and those offered by the defendant-state. Instead, a presumption had been extended to the state's professional judgment (that of substitute "parent" for the severely disabled), and unless this decision was a substantial departure from accepted professional judgment, it stood unmodified by interests in liberty.

A second but probably more significant decision based on Romeo occurred in 1984, when the Second Circuit decided *Society for Good Will to Retarded Children v. Cuomo*. In this case the Second Circuit vacated a district court's order because it had entered too far as a federal court into the domain of state government decision making. The district court had ordered that 400 of the 1,221 residents living at the Suffolk Development Center(SDC) in New York be placed in community residences, ruling that institutional residents have a legal right to live in a setting that was least restrictive of their liberties.

The Second Circuit reversed this decision because: "we may not look to whether the trial testimony established the superiority of a least restrictive environment in general or of community placement in particular. Instead we may rule only on whether a decision to keep residents at SDC is a rational decision based on professional judgment." A second reason for vacating the district court's order was also based on Romeo. The Second Circuit found that SDC residents were "not unduly restrained by residing at a state institution."

Romeo has stopped forced institutional rundown and greatly reduced adversarial decision making. No state is now likely to enter a new consent decree requiring institutional rundown; a state's hand as a potential defendant in a threatened federal court action is enormously strengthened by the return of the doctrine of professional paternalism and *parens patriae*. Furthermore, as the SDC reversal points out, even where a federal court chooses to require the highest levels of minimally adequate care, its orders will be directed to institutional improvement, not institutional replacement.

There is now an opportunity for states to regain control of executive decision making and to reduce the amount of litigation. Such control could not be more timely as each state attempts to respond in a humane way to the enormous new difficulties arising from decreased funds, and most importantly, attempts to redress the consequences of forced deinstitutionalization.