

WILLOWBROOK, THE COMMUNITY CHALLENGE & THE ROLE OF LEADERSHIP

By

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On May 2, 2000, I attended a ceremony marking the 25 anniversary of the signing of the Willowbrook Consent Judgment by New York Governor Hugh L. Carey. I could scarcely recognize the spacious and well-kept grounds of the College of Staten Island of the City University of New York as the former Willowbrook State School for the Mentally Retarded. I distinctly recall visiting the former institution when I served as an Assistant Counsel to Governor Carey and wanted to learn first-hand about the case I had inherited from a previous Administration.

Then, the evidence of prolonged neglect was everywhere -litter-strewn grounds, overgrown and weedy lawns, buildings with crumbling facades, torn window screens, rotting door frames and peeling paint first hit the eye. But the squalid conditions I saw when I first walked into the buildings-conditions in which human beings lived and died - have been indelibly seared in my brain. Gritty floors that crunched underfoot, walls smeared with feces, a suffocating stench of human wastes, and an unrelenting cacophony of screams, wails, moans and grunts. Herds of naked people in barren rooms, some rocking, others pacing aimlessly or gesticulating wildly, still others huddled in the corners. The staff were most easily identified as the only clothed people in the room.

Governor Carey's signing of the Consent Judgment was an acknowledgement by government of its obligations not only to protect a class of people long forgotten behind the walls of institutions, but also to affirmatively create opportunities for them to return to society, to become a part of the community and to lead more normal lives. As importantly, his decision to extend the benefits of the Consent Decree to non-class members within the State diminished, but did not eliminate, the problem of a two-class system that has plagued many states. In succeeding years, Governors Mario M. Cuomo and George E. Pataki maintained this course.

As with other similar cases, implementing these policy decisions was neither smooth nor simple. In hindsight, it is easy to recognize how vastly the parties underestimated the difficulty of transforming an entrenched bureaucracy and a culture of low expectations into a responsive system of services and supports; how they failed to anticipate that other actors, not covered by the Consent Decree, could frustrate implementation; how wildly optimistic some of the deadlines for action were; and so on.

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But the larger reality is that the Willowbrook Consent Judgment did succeed in getting people out of that and other institutions, and into community living environments, where they unquestionably have better lives and more opportunities for normal living.

In his remarks at the ceremony, Governor Carey, who is widely credited with rescuing New York City and myriad public authorities from threatened bankruptcy, nevertheless rated his actions in signing the Willowbrook Consent Decree and improving the care of people with mental retardation as the most significant of his public contributions. He also had the vision to recognize the need for permanent, independent oversight of the institutional and community service system for people with mental disabilities as bulwark against the type of insidious neglect that makes Willowbrooks possible, and allows them to exist on the fringes of public consciousness. He proposed and signed into law a bill creating the New York State Commission on Quality of Care for the Mentally Disabled and charged it with being the eyes and ears and the conscience of the community in watching over the mental hygiene system in New York.

Decisions like these, and the consistency of purpose exhibited by all three Governors over a quarter of a century, are an essential part of the reason why the Willowbrook litigation in New York ended successfully (albeit later than the parties initially anticipated), while other similar cases, begun about the same time in other states, still limp along inconclusively.

NEW CHALLENGES

Marking a milestone like this 25th anniversary is also an opportunity to look at the road ahead. While there are still cases being litigated over conditions in institutions in several states, the vast majority of persons with developmental disabilities are being served in the community and there is now a clear preference for such community-based services. But there seem to be fires raging and alarm bells ringing in the community.

In the past year alone, there have been series of news stories in major media about the significant problems in community-based services in several states. The *Washington Post* won a Pulitzer Prize for its exposure of the continuing and serious problems affecting the lives, health and safety of mentally retarded persons in our nation's capital, placed in the community in the wake of the closure of Forest Haven under federal court order. Other similar stories have been published by the *Atlanta Journal Constitution* about community services in Georgia. The NBC program, *Dateline*, recently exposed abusive conditions in group homes in California. The American Prospect magazine published an article "Neglect For Sale" depicting abuse and neglect in group homes run by proprietary corporations in several states.¹ The Health Care Finance Administration continues to cite state after state for deficiencies in their Quality Assurance systems in monitoring services in the community. And these developments only hint at a larger problem lurking in the shadows.

¹ Eyal Press & Jennifer Washburn, *Neglect for Sale*, THE AMERICAN PROSPECT, vol. 11, No. 12 (May 8, 2000).

GOVERNMENTAL RESPONSIBILITY

Just as the conditions in Willowbrook and other institutions were a visible manifestation of an abdication by government of its responsibility to be a competent service provider, the emerging problems in the community signal an equally profound failure of government to fulfill its responsibility to be a competent funder and regulator.

The first aspect of this failure is entrusting the welfare of vulnerable people to providers without adequate scrutiny of the character and competence of those receiving the franchise to provide service and get government money. Would McDonalds give out franchises as casually when all that is at stake is the quality of french fries? While much attention has been focused on profit-making corporations, the problem is not limited to proprietary companies. There are, unfortunately, examples of non-profit agencies that are also focused on self-interest rather than the public interest. In my work at New York State Commission on Quality of Care for the Mentally Disabled I saw enough of these providers slipping through the gaps in the regulatory oversight to be a cause for serious concern. We were able to investigate and catch them, and through a lot of effort with federal prosecutors, several are in jail. But what happens in states without such independent oversight? Where are the local prosecutors in responding to these crimes? Part of the problem is that the criminal laws are rarely enforced when the victims are mentally disabled -crimes are either not reported or, if reported, are not investigated vigilantly, and if investigated, are not prosecuted vigorously. Penal laws rely significantly on deterrence to promote law-abiding behavior, but if there is no visible enforcement, there is no deterrence.

As states implement the Medicaid Home and Community Based Waiver and policies on self-determination, we are expanding rapidly to non-traditional providers where there is even less scrutiny of competence and fiscal accountability.

We need to be much more cautious in handing out these franchises to serve people with disabilities, whether we call them operating certificates, licenses or contracts. Some states like New York chose not to open up the service delivery system to multi-state, profit-making corporations. In some states, these are becoming *de facto* monopolies, with all the adverse effects for choice that entails. In the tension between profit and care, the inevitable real loser will be the vulnerable consumer. Deregulated and downsized government agencies will prove no match for well-financed and politically connected providers. There are already examples of efforts at governmental regulation of these companies being strangled by the political and legal manpower these companies are able to marshal, financed with public funds.

The greatest promise for community based services and supports lies in local, consumer and parent-based non-profit service companies, where decision-making is close to the point of service delivery and there is accountability to a board of directors that is keenly concerned with the core mission of the agency, and engaged enough to keep informed about how that mission is being carried out.

EDUCATION & TRAINING

Second is the general lack of investment in staff training and education. Paradoxically, this problem is particularly acute in a good economy because the employees being hired for frontline jobs often have marginal skills, including literacy and language proficiency. Their deficits make it hard to train them effectively. In the absence of adequate training and education, the tragedies being reported are entirely foreseeable. We need a serious national effort to create minimum competencies for these positions and to pay commensurately for them. We need to develop career ladders to retain competent workers as caregivers rather than continuing to tolerate an endless revolving door of minimum wage workers as the mainstay of this multi-billion dollar human service enterprise.

Third, in the haste to embrace the philosophy of deregulation and downsizing, there has been a tendency towards mindless privatizing of traditional governmental functions. While there is a valid rationale for privatizing service provision, it makes little sense to also delegate all the monitoring and oversight responsibilities to private providers, without adequate consideration of the hazards of conflicts of interest which might leave people at-risk, services vulnerable and government in the dark.

Fourth, the Medicaid waiver is an engine for reform and offers access to public money and freedom from regulation. But its chief virtue is also its principle vice. The complete absence of standards and regulations continues to expose vulnerable people to unreasonable risks. We have to be more careful to ensure that the Medicaid waiver does not aid and abet a waiver of responsibility.

Increased emphasis on choice, self-determination and person centered planning are all steps in the right direction. But, as Will Rogers noted, even if you are on the right track, if you just sit there, you will get run over. The "just sitting there" part of this is not providing thorough training for people engaged in person centered planning to fully understand all that is involved in informed decision-making. Without this, people with significant cognitive impairments and limited life experiences are left to express choices when they cannot anticipate the foreseeable consequences. I have seen too many of them come to harm through expressed choices, while staff stood by and watched.

I fear that we are heading down the path that resulted in the nursing home scandals of the 70s, and we need to hear the alarms and smell the smoke. The growing awareness of the problems in community services is leading to calls from some quarters for a return to institutionalization, as if the solution to governmental neglect is to incarcerate the victims. I also hear attempts to minimize these problems as representing a very small part of a generally good community service system. If we tolerated airlines flying safely 99% of the time, the toll in daily human carnage would be shocking. With several hundred thousand people with developmental disabilities receiving services and supports from a broad array of providers, is performing well 99% of the time and exposing thousands of people to daily abuse and neglect an acceptable standard of performance?

The real challenge is to create a durable culture of caring to protect and nurture people with developmental disabilities as they learn and develop their decision-making capacities; and to support them as they reach for the fruits of full citizenship. Bureaucrats and providers, families and advocates, co-workers and friends, frontline staff and monitors, must embrace this culture if it is to preserve the promise of the reforms on which we embarked 25 years ago. A cornerstone of this culture must be a vigilant and effective governmental role supporting a stable workforce, and in monitoring and ensuring accountability for performance by those to whom it entrusts this responsibility.