CLOSING INSTITUTIONS: LESSONS LEARNED?

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I like coming to the YAI conference, not only to meet old friends and make new ones, but also because it offers the chance to think aloud with thoughtful people about issues that affect people with disabilities. I am not a clinician, and my job largely consists of observing what is going on, listening to people in the field, and trying to understand practice sufficiently to influence the direction of public policy.

Today, I'd like to think aloud with you about closing mental retardation institutions, about the lessons I think we have learned and how they affect or should affect the role that each of us play in the development and execution of a policy to close institutions.

Since the dark days of Willowbrook, both New York and the rest of the country have come to learn that no one really belongs in an institution. We have developed in this state and in this nation a body of experience that teaches that people with all forms and natures and severity of disabilities can be supported and assisted to live in the community, and that they generally benefit from such an option.

The lessons have been powerful, the evidence persuasive and a growing band of converts now believes that institutions are obsolete or rapidly becoming so. A movement which began with a small group of parents, professionals and advocates challenging the conventional wisdom and practice has become the conventional wisdom and practice, embraced by the major professional organizations, parent groups, advocacy programs, and officials in the legislative, executive and judicial branches of government. And it sounds as if the story should have a happy ending, with this broad alliance opening the doors of institutions and restoring freedom to their inhabitants,

But wait. There are warning signs of trouble ahead. The familiar tension between conscience and convenience, about which David Rothman has written, is raising its ugly head.

The experiences which form our conscience teach us that many of the same things that we value in our own lives are of value in the lives of people with disabilities: where we choose to live and with whom; how we choose to spend our waking hours; the opportunity to form personal relationships with others of our choice, and so on. We have seen these experiences at work in many parts of the country as imaginative parents and professionals worked with people with disabilities to create personal support systems to enable them to live their lives as they choose. It has not always been easy but we know how to do it and we know that the effort has enriched the lives of all involved.

We have also learned that it's not always convenient and it's usually not fast. And convenience, as we know, is a powerful force. The 19th century reformers who closed the poor houses and alms houses and replaced them with the institution later learned that the demands of convenience soon overwhelmed the needs of inhabitants and allowed wretched abuses to proliferate.

Today's reform of closing institutions is also caught in the same dichotomy between conscience and convenience, and likewise risks overlooking the needs and desires of inhabitants in the rush to execute the emerging public policy. There is added risk from the growing financial troubles sweeping the state and nation.

States across the country are wrestling with staggering budget deficits. In New York, it's $6 billion, or approximately 10% of the budget. In California, it's $12 billion, or 23% of the budget. In Connecticut, it's over 30% of the budget. In this climate, it is tempting to embrace closing institutions as good fiscal policy. Perhaps we've all done too good a job of selling the cost-effectiveness of community-based care and sold legislators and fiscal officials primarily on that value. We've done less well in teaching and selling the underlying values of choice, integration and independence, which make community-based ' services a good policy option.

The unfortunate lesson that fiscal policy makers seem to have learned is to close institutions and close them quickly, and to look for economies of scale in the development of large community residences of standard size and even larger day programs. The policy to close institutions risks being driven by perceived fiscal imperatives alone, and while the objectives may look the same and sound the same, they have rather different consequences for the people being affected. As in many areas of life, how one defines the task is critical.

If the task is simply to close an increasingly expensive institution or to avoid fixing up an old building, any means that accomplishes that goal may be suitable. We've had some of that type of development, with large prototype houses quickly erected in clusters to replace dilapidated institutional buildings.

The results are invariably and unquestionably an improvement over what they replace. But once the task of quickly building these 12-bed houses was mastered, the demands of convenience readily adopted the lesson that if these prototypes could be replicated, the whole process of institutional closure could be accelerated. Learning how to perform an emergency task began to shape what policy ought to be.

In short order, the demands of convenience and efficiency produced a public policy that has resulted in a proliferation of 12-bed residences all over the state, to the virtual exclusion of other residential options. We seem to be approaching a policy much like Henry Ford's in producing the Model T: "Any color you want, as long as it's black."

I have no professional or clinical training in mental retardation, but it seems to defy common sense that all of the hundreds of people now living in institutions and the hundreds and thousands now living at home, who may one day require a residential placement, all need and want a 12-bed residence!

"One size fits all" is a poor policy for selling pantyhose. Does it work any better in determining the housing needs of people with mental retardation? What happened to the individualization that we all fought to have required by law — remember the "I" in IHP, IEP, IWRP? Did we replace it with a "U" for uniform? What happened to normalization? The recent census data indicates that the average household in America has 2.6 people. What is it about being mentally retarded that makes adults want to live in groups of 12? How do clinical professionals justify such recommendations?

I have had the opportunity to visit many of these residences and meet the residents and staff. I have been struck by two consistent comments I have heard front those who live and work there, and from some families: (1) they are generally better, more pleasant and comfortable than the institutions they replace; and (2) they are too large to provide the individualization and personal attention needed. My own observation could readily confirm the validity of the first opinion but I wondered why staff who formerly worked in large and crowded institutional wards would now complain about the size of community residences that were smaller than the wards they replaced.

I have slowly come to understand that the staff's own expectations for the level of personalization needed has been changing with the move to the community, and their presence in the community often serves to accentuate how separate they are <u>from</u> it.

> The huge modern houses with wide driveways, parking lots and large garbage dumpsters don't fit in very well.
>
> The vans they use to transport the residents, usually in groups, mark them as effectively as the agency names that once were emblazoned in bold letters on their sides.
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> The staff's own interaction with neighbors and the community is almost as limited as that of the residents.

It has occurred to me that, although many of us fought for the removal of stigmatizing signs in front of community residences and on their vehicles, the proliferation of these large prototypes of community residences in neighborhoods across the state is making them as distinctive and unmistakable as if they had a trademark orange roof or golden arches.

The lessons of the limitations of this type of community development are being taught daily, but those who are learning on the front lines have little influence on the course of public policy. I have been impressed by the almost invariable opinion of staff who have lived and worked in these facilities that their residents could live more independently and more as individuals in smaller settings. Their opinions are confirmed by level of care studies that consistently conclude that a sizable proportion of the residents of these large residences require less restrictive living environments. And, ironically, at the same time as so much of this development of large residences is occurring, other imaginative "pilot projects" are being developed to demonstrate yet again that people with complex disabilities can live normal lives if only we make the effort to let them have that choice. While these "pilots" are completed and evaluated with fiscal crumbs from the table, the bulk of the available funds will continue to support the development of 12 bed residences at an accelerated pace to facilitate the closure of institutions. Why must each closing institution repeat the process that others, who have already gone through it, have concluded was a mistake? What gives us the right to ignore the lessons others have learned at the high cost of opportunities lost for a generation of people with disabilities?

All too often policy decisions are made without a full appreciation that closing institutions is not an end in itself.

The streets of every city in America are testimony to the barrenness of that policy. Closing institutions is good policy only if it opens the door to real possibilities of a normal life, with genuine choices and opportunities. It must offer more than a chance to ride the same van to be segregated with different people in different places.

But it won't as long as we permit each institution targeted for closure to studiously refuse to learn and apply the lessons experience has taught and is teaching us. If the convenience of the moment allows us to discard the accumulated wisdom which led to laws requiring individualization, choice, normalization, we will act in haste and perhaps meet the deadlines of the moment, but spend the lifetimes of our clients repenting what we have done.

In a very real way, the challenge and opportunity of closing institutions forces us to confront the question: for whose benefit are we doing this?

If we believe we are acting in the interests of the residents of the institution, don't reason and common sense suggest that we be solicitous of their needs and preferences and plan the development of services around the individual? When I spoke here last year, I asked you to think about how the evolution of community services would be different if people with disabilities were directly allocated the money that now goes to providers on their behalf. How many people receiving 30, 40 or 50 thousand dollars per year would choose to buy a bed in an ICF and live with 10 or 12 other adults and a staff they have no voice in choosing?

When planning proceeds from the top down, with predetermined models of service identified uniformly and before individual needs and choice are considered, it is equally apparent that closing institutions is designed primarily to protect interests other than those of the residents.

The point of this discussion is not to criticize people who believe they are planning the closure of institutions with fiscal guns pointed at their heads. Rather, it is to raise the question about the ethical obligations of all of us who understand both the challenges and the opportunities to be advocates for making choices available to the people we serve. It is a question of considerable importance because whether there is choice and how it is exercised often depends heavily upon the advocacy of staff who are closest to the resident, and upon the values clinical and administrative leaders in provider agencies bring to their jobs. What is our obligation to apply the lessons we have learned as consumers, parents, providers, professionals, advocates, and government officials in influencing the course of public policy?

Do we silently acquiesce to the investment of public funds in the development of programs and services that may limit rather than enhance options for people with disabilities for the next 25-30 years? Are we obliged to do only that which is convenient and which we know how to do? If we don't make our voices heard, who will? And when?

I hope you will think about these questions and act on the conclusions you reach. William Sloan Coffin's words about fighting evil are relevant here in thinking about what we ought to do about a bad public policy. We must fight evil for two reasons, he said. To change it. And to prevent it from changing us.

Thank you.