

Deinstitutionalization: Do We Still Know How to Fail After All These Years?

My friend Tom Kohler dusted off and sent me an extra copy he found of a yellowing booklet called **Way Out**, published in 1979 by the great advocacy pioneer Lotte Moise from her family's print shop in Fort Bragg, California as part of her effort to influence the then raging debate over the institutionalization of people with disabilities. It included this little essay, written in 1977. At the time I was at work on efforts to make institutions unnecessary both for people with developmental disabilities and people who wound up spending a lot of their lives in psychiatric facilities. Accordingly, this essay considers how to fail with both populations.

Because making and distributing pdf files is pretty easy, I thought to republish it, 35 years later, both as a matter of slight historical interest and to offer a chance to think about which of the mechanisms for failure recommended 35 years ago still have legs and what new strategies for organizing misery that Wormwood and I should consider recommending if we got the job today. I have slightly adjusted the language so as not to distract readers with references to "handicap" and "mental retardation". I leave it to you to replace the buzz words of that day with contemporary hyphenated shibboleths. Choose among: "person-centered"; "self-directed"; "evidence-based" and "outcome-oriented" or any combination, as it pleases you.

Though the work of replacing institutions remains unfinished, especially counting all of the people in nursing homes and the variety of privately operated facilities and "campuses" that mimic the essence of institutional segregation and control with nicer buildings and trendier wardrobes for inmates and staff, the urgency that animated the 70's and the subsequent heat seems to have gone from the institution question except when die-hard advocates for segregation and control feel threatened by the possible closure of a facility and rise up to save it (almost always successfully and typically in the name of "choice").

Both Wormwood and I underestimated two developments: the great power of reproducing institutional conditions in community settings by entangling services in a truly fiendish net of bureaucratic mechanisms to enforce compliance with myriad process details; and, the irony of the US Supreme Court protecting the rights of institutionalized people by enshrining the medical judgement of institutional staff as keeper of the institution's door and endorsing the well-worn dodge of deliberate progress as the pace of institutional de-population.

I remain grateful to C.S.Lewis and Wormwood's diabolical mentor, Screwtape, for loan of the sensibility of the essay.

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A MULTICOMPONENT APPROACH TO ACHIEVING FAILURE IN DEINSTITUTIONALIZATION: A PLANNER'S GUIDE TO PREVENTION

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PRIMARY PREVENTION

In most places, efforts to decrease the dependency of people with disabilities and their families on institutional arrangements and to increase the adequacy of community services will fail as a matter of course. Primary prevention of deinstitutionalization can safely be entrusted to the dynamics of large-scale bureaucracy. The everyday process of government will typically ensure that the service workers and communities dependent on institutions for their livelihood, and the legislators who represent them, will not suffer unnecessary inconvenience. A recent report to the US Congress by the Government Accounting Office notes that no fewer than 135 federal programs have obligations to assist in the process and concludes that it will fail in the absence of their ability to coordinate their efforts and achieve their objectives in a unified manner. This alone should ensure the collapse of the initiative.

THE NEED FOR SECONDARY PREVENTION

However, the past few years have seen an alarming increase in the number of naïve souls who have taken the rhetoric of community service development seriously. Their attempts to move a commitment to institutional decline off the shiny pages of the annual report of the President's Committee on Mental Retardation and into community reality are symptomatic of a disease tentatively labeled the "Community Service Syndrome". In its earliest manifestations, CSS can often be managed most cost effectively at the secondary level by a set of strategies aimed at demoralizing the potential change agent:

1. Make a few derisive remarks about ivory tower theorizing and the (unspecified) hard realities of the "real world".
2. Invoke a scare image of people with disabilities. Allusion to the overwhelming complexity of the medical needs of those institutionalized will do for some, but many who have uncritically swallowed a so-called "developmental" view of people with disabilities will require more dehumanizing images of profound dependency ("crib cases" or "vegetables" will often do nicely) or menace and dangerousness. Guilt aroused in the tender minded by these images can be managed by promoting a view of the institution as a high technology, professional-intensive wealth of the "most appropriate" resources. Referring vaguely to "recruitment patterns" and "economies of scale" will usually deal with the resistance expressed by those who wonder why these services cannot be provided as well outside institution walls.
3. Invoke a negative image of the families of people who are institutionalized as rejecting, irrational, demanding, disordered, or dirty, and a counter image of the institution as a place of acceptance and concern.
4. Invoke a negative image of the home communities of institutionalized people as rejecting and dangerous to their safety or happiness with the institution portrayed as a haven or asylum.
5. Invoke an image of families and communities as helpless victims of people with disabilities who must be rescued by an institution which can contain and "treat" them.
6. Disarm the occasional resistance expressed by those who point to model programs by pointing out the obvious differences, both in context ("It might work in Nebraska, but it won't work here.") and in clients ("Our severely handicapped people are more severely handicapped than their severely handicapped people.")

Note that each of these strategies is founded on a bit of truth. For example, the prevailing culture does indeed contain powerful forces that tend toward the rejection of people with disabilities. There are some people with disabilities who are, at least at some point in their lives, profoundly dependent. There are some few people

with disabilities who commit violent and occasionally inexplicable crimes. What is absolutely essential to the early management of CSS is that under no circumstances should the person at risk of becoming a change agent be allowed to frame these issues as a problem to be analyzed. It is tantamount to malpractice to permit the person at risk to begin to speculate on alternative explanations and approaches to these problems. Inability to be diverted from this pursuit - say persistent attempts to think about a community-based intensive medical support service - is pathognomonic of an advanced state of CSS, which will probably not respond to secondary intervention.

CHRONIC SEVERE COMMUNITY SERVICE SYNDROME: TERTIARY PREVENTION

Those in a chronic, severe state of CSS will have the bad taste to promote their notions in a fashion that may find support among some powerful segments of the community. No degree of verbal intervention appears to be effective and no biochemical agent is available. Tertiary prevention of deinstitutionalization efforts, therefore, must focus on supportive environmental manipulation with the goal of controlling the outbreak of epidemic CSS. Contemporary civil libertarian values will not support a strategy of physically isolating these believers in community services as the dis-ease carriers they are. Therefore, their quarantine must be achieved in a systematic, and comprehensive multi-modal thrust.

The object of effort at this advanced level of CSS is to take control of the environment in order to ensure long term collapse of efforts to reduce institutional dependency. Several major strategies to achieve this are outlined below.

1. A preliminary strategy, always appropriate and occasionally sufficient is simply to maximize confusion of language by incorporating as many of the words used by the chronic CSS sufferer into discussion, planning, and operation. "Not only do we agree with you, in fact, we are already doing what you seek," is the message to broadcast. Talk frequently of a "comprehensive continuum of care" (which, of course, visualizes the institution as the haven of last resort). Sprinkling planning documents calling for greatly expanded institutional budgets with references to normalization will help, as will holding conferences with such titles as "Normalizing the Institutional Environment Through Creative Fingerprinting". Labeling a locked ward on the grounds of a state hospital a "Community Support Unit" is a nice touch, though it won't hold a candle to the practice of counting all of the people with disabilities moved from state institutions into nursing homes as having been "deinstitutionalized". Under these conditions, clear thought becomes next to impossible.
2. It is also useful to keep the terms of discussion under close control. Seek to keep the focus on a negative goal - the very term "Deinstitutionalization" is ideal for this - the reduction of institutional size. This makes it possible for a diligent effort at secondary prevention to clearly establish in everyone mind that we will always need an institution. This allows declining population curves to be preferred as markers of success and occasion for celebration. Allowing chronic CSS sufferers to publicly ruminate on a positive image of community services and on issues of service quality is always to be avoided as deeply dangerous.
3. Whenever possible, dump as many people as possible out of institutions into the street without any support beyond psychoactive drugs and a minimal housing allowance. The maximum number of ex-institution residents possible should be encouraged to saturate the smallest possible geographic area. And, for these purposes, mixing the types of institutions people were dumped from is very adaptive. For instance, mix large numbers of people with schizophrenia with a substantial number of people with disabilities, and as many ex-prison inmates as are available in an urban area characterized by grossly substandard housing,

already dangerous streets, and a native population which includes the greatest number possible of homeless people with severe alcohol and drug problems. The more of this that can be done, the better. In particular, the proactive planner will dump as many people as possible before CSS sufferers can learn the meaning of Strategy One above. Make it seem as though there is a great rush to move as many people as soon as possible. If anyone questions this blame it on the CSS sufferers. This will develop into a situation which will serve to discredit the efforts of chronic CSS sufferers and create so many problems in an unpopular area of the territory as to make solution, in fact, impossible. This ensures a long term demand for institutional services.

4. More structured efforts at creating community support can be disabled by neglecting a relatively few simple activities:
 - a. Fail to attend to local political processes. For instance, alienate zoning boards and avoid a systematic, long term approach to developing community supports.
 - b. Fail to predict or provide for the needs of the people who are moved out for income support and instrumental help such as medical and dental services, assistance with income management, guardianship, etc. When combined with maximum dumping, this will pay great dividends in allies from among the leaders of county governments who absorb the indirect costs of an increase in dependent people.
 - c. Define mental health or developmental services narrowly so as to exclude, for example, the provision of work opportunities for adults. This will increase the amount of unstructured time available for some people who have been dumped to congregate in bus stations, public libraries, and around playgrounds. Doing this in the name of “normalization” and “maximum utilization of generic resources” wins a prize for innovativeness.
 - d. Leave the choice of who leaves institutions and when up to the institution’s power structure. This will provide the opportunity to saturate what community programs do exist with people who have the most chance of validating the image of people with disabilities as unable to survive without the institution. Note that this strategy should be implemented early, but not exercised until there is a threat of success.
 - e. Neglect any systematized approach to quality assurance, especially eschew outside evaluation and attention either to outcome or quality of life. If some form of evaluation is unavoidable, create elaborate, expensive information systems which only track movement and be sure that reports are unintelligible and too late for decision making.
 - f. Neglect simple rules of implementation. For example, don’t make a plan for how money flows to pay for community services until community service providers are already in the red. This will only confound the crucial early stages of implementation. It will also contribute to an image of community service developers as irresponsible.
 - g. Neglect area differences by insisting that every area implement the same type of services within the same time frame. Tie this to a funding mechanism that minimizes the number of decisions that can be made at the local level. This will help put local community service developers at odds with local citizens and local government officials.
5. Do as much as possible to sow dissension among potential supporters of the notion of community services. It is especially important to diffuse the potential threat posed by voluntary, consumer based associations. Three tactics suggest themselves here:

- a. Ensure that as many service providers as possible join voluntary associations and gain control of their decision making process. They re often easier to talk to than people who share fewer socialization experiences with the planners, and can, if need be in extreme cases, be threatened.
 - b. Maximize attention to the real problem posed by grossly substandard living arrangements available to institutionalized people. This exaggerates dissension by engaging those who are concerned about institutionalized people in a conflict with those who want to develop alternatives. When each group sees the other as the enemy, their impact dwindles. Avoid at all costs any thinking about a long term, sequential plan.
 - c. When designing community services, be sure to offer services to some former institution residents that are not available to people with disabilities who have not been institutionalized. It will not take much of an inequity to create a good measure of anger and frustration that the skillful proactive planner can blame on chronic CSS sufferers.
6. Create a funding structure that maximizes profit for operating institutional services.
- a. Make public institutional services eligible for federal funds on the condition of increased capital investment of state funds in the institutions. These funds will make if possible to increase the economic dependency of an area on its institutional industries.
 - b. Make it profitable to operate proprietary institutions according to a formula that maximizes profits when the greatest possible number of people are congregated.

Taken collectively, these strategies represent a comprehensive, multi-component approach to the prevention of what otherwise could become a serious social problem.