

THE "CONTINUUM" AND THE NEED FOR CAUTION

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It's been said that every good idea contains the seed of its own perversion. One of the most potent seeds of perversion in the field of human services is our imprecise use of otherwise progressive sounding terms. The language of human services may be, in fact, one of the major handicapping conditions imposed on the recipients of public assistance.

Take the term "deinstitutionalization" as an example. If by "institutionalization" we mean forced residence in very large, self-contained facilities—"forced" either by court action or scarcity of choices to the contrary—then it is true that many people across the nation have been "deinstitutionalized" over the last decade or so. However, many of these "deinstitutionalized people" now live in small regional institutions, nursing homes, and no-exit group homes. If, on the other hand, we understand institutionalization to mean any human service model that tends to isolate, confine, and congregate people who are devalued by the community-at-large, then we must confront the reality that the last decade has witnessed a great deal of

trans-institutionalization, not de-institutionalization. Thus, depending on our understanding of the word institutionalization, we can either be proud of our professional-political effort over the last ten years, or we can feel a sense of failure and shame. Perhaps our language—our choice of slogans—handicaps our vision of the future. Perhaps if we had chosen to name the policy one of "de-confinement" or (better yet) "community presence and participation" our assessment of the results might be more accurate, if not more worthy of pride.



Tony Bracho and Charlie Galloway

The increasingly fashionable term "continuum of services" worries a number of us in the same way that the term "deinstitutionalization" should have worried us ten years ago. Whether we're talking about education, vocational training, leisure, living arrangements, or all of the above, it would be wise to pause here and now in the political process of policy shaping to locate potential seeds of perversion in this otherwise good idea called a continuum of services. Let me describe briefly what some of us feel are potential drawbacks to the slogan.

- The concept of a "continuum of services" translates too quickly into a continuum of existing facility and program types, ordered from most to least segregative. Once that translation is rooted, it follows that for every point on the continuum, there must be a group of people who—because of their shared characteristics—"fit" that facility or program type. (We will identify, for example, group home-type clients and state institution-type clients).
- Once located along the service continuum, one will be required to *learn* his or her way out of that point and into the next, less segregative, facility or program. (You will hear increasing discussion of behavioral "exit criteria" for movement along the continuum).
- Finally, the prognosis for full participation as a valued member of the community will be determined by his or her present location along the service continuum. (For years, we've been told through the federal wage and hour Saws that work activity center-type clients cannot be expected to be economically productive in any consequential sense. We've been told wrong, incidentally.)

If these seeds of perversion take root, we will have succeeded in constructing yet another elaborate, bureaucratic machine for trapping people in a handicapping world—one now called a "continuum of services."

Let's break stride for a moment and consider just a few of many real lives which dramatize the rather sweeping cautions offered above.

A while back I met a young woman whom I could describe to you in a number of ways. Michelle recently moved into her own apartment and is "on her own" for the first time. She has experienced the fun of selecting her own furniture and the freedom of being a bit impulsive—like buying a parakeet she liked during a casual visit to a pet store. She has close friends her own age, and she worries about her future. Like many young people her own age, she is just awakening to her own rights and her own personal sense of citizenship. Michelle also has a little difficulty telling time—she only recently was taught the basics. She has trouble remembering some information, such as her address and phone number. But Michelle is being allowed to take the risks that will promote her growth as a participant in her community. She is being assisted in the process of acquiring the skills of self-reliance in a living arrangement which expects it of her and which gives her a sense of self-value. Michelle was not forced to march through a "continuum" of decreasingly segregative living arrangements in order to reach her goal of having a "place of her own."

Ed Roberts requires full assistance in order to eat. In a chapter of a book devoted to the facets of mealtimes for people with severe disabilities,* Ed described a period in his youth during which his therapists and teachers put him through a strenuous program to teach him to eat his meals independently. They thought it was important for his future. Ed wrote that he eventually decided that the process of feeding himself was too exhausting and time-consuming; he had better things to learn and do

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*in R. Perske, A. Clifton, B.M. McLean, and J. Stein (Eds.), *Mealtimes for severely and profoundly handicapped persons*. Baltimore: University Park Press, 1977

with the limited energy he has at his disposal. If Ed's decision hadn't prevailed then, he would not have much time today to function in his capacity as chief of California's Department of Rehabilitation. If Ed had been trapped in a continuum of services that required skills of independent eating as a criterion for exit into the real world, he might have learned, but he would be totally unknown to any of those who struggle with him now toward a better quality of life for people with severe disabilities. That loss would have been shared by all of us.

Tony Bracho is a young friend who has major physical disabilities. He is a client of his local regional center. Tony also is a senior in high school and is doing quite well in regular classes with the help of an assistant who tends to the physical demands of his school tasks. College is clearly in Tony's near future. Although he is in no sense "ill," Tony has to live in a skilled nursing facility with more than fifty other people. He doesn't like his current living arrangement. He wants his own place along with the customized living support he needs. And he wants it now.

Until an exciting new program became available to Tony and others in his region with similar predicaments, Tony felt trapped in the continuum and the "exit criteria" it imposed. Tony knows quite well that he will never be totally independent—as if anyone can be—but he was being told a year ago that he must be trained in independent living skills *before* he would be helped to find and live in his own place.

Having completed the first phase of a sequence of independent living training, Tony's chances of leapfrogging several steps in the "continuum"—of receiving the further self-reliance training and support he needs in "a place of his own"—have greatly improved. About a year ago, his prospects for the future didn't seem so bright. It was then that he shared with me a particular poem he had written; and he gave me permission to share it here with you.

The Past has scarred me
The Present has wounded me
The Future might kill me

These words are not those of a young man who was melancholy and feeling sorry for himself. Rather, they are the words of one who

recognized (and still does) the reality of the traps around him and what they could do to him. In spite of a sense of his predicament, Tony is far from defeated. As he put it to me a year ago, "The trap is on me, but not closed yet." Tony's advantage is that he can comprehend his own vulnerability to human service traps; others are not so fortunate.

We have enormous instructional and engineering competence at our disposal. The fundamental issue at the heart of the "continuum of services" topic is not one of technology, however—the propelling issue, really, is how we frame our first human service design question. As a starting point, we can choose to ask one of two questions:

- We can ask, "How do we design alternatives to institutions for people with severe disabilities?"
- Or we can ask, "How much do we have to compromise on the most natural and valued living, educational, and vocational arrangements to increase or maintain this person's opportunity and ability to be a fully participating member of our community?"

If we ask the first question, we will work toward the construction of a continuum of *alternatives* to the places in which the rest of us would least like to live, learn, and work. And we'll rest easy in the knowledge that things are not as bad as they could be, or were. If we ask the second question, on the other hand, we will see our services and places as a continuum of *compromises* on the best that is possible. We will more likely then judge our service accomplishments with a proper degree of humility and act with a greater urgency to work toward reducing the existing degrees of compromise.

I'd like to wind up with a story I heard a while back about a federal land management agency that was troubled by an overpopulation of wild donkeys on one of its land preserves. The agency came up with a plan to solve the problem—the solution was described in bureaucratic shorthand as "a direct reduction in number." At the obligatory public hearing prior to implementing the plan, a man stood up in the audience and asked the hearing officer, "Is what you mean by 'direct reduction in number' that you're gonna kill the donkeys?" There was a pause. "Well, yes," the hearing officer replied, "I guess, if

you put it that way, that is what we mean." The point, of course, is that there are several ways to achieve a "direct reduction" in the number of wild donkeys—killing them on the spot is only one of the possibilities.

Especially if you are not one yourself, please be cautious when you listen to the advice and plans of us well-intentioned human service professionals. It's helpful to remember something John McKnight said so well: "The basic function of modernized professionalism is to legitimize human beings whose capacity is to see their neighbors as half-empty." Be cautious enough to ask us what we value, what we assume, and—most importantly—what we "mean" by attractive slogans such as "the continuum of services." Keep in mind that we've all spent a lot of time in school. As a result, we have a way with words.