

Quality Review Panel
People First v. Clover Bottom, et al.

Supplemental Report on Community Placement

Clover Bottom Developmental Center

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Submitted by:

QUALITY REVIEW PANEL

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The following report is submitted to the Court as a supplement to the Quality Review Panel's report on its annual system review of the Clover Bottom Developmental Center, dated April 22, 2008. Primarily this additional report is an amplification of the Panel's findings regarding transition and community placement activities at Clover Bottom (p.8-11)* and an elaboration on how the defendants' application of certain Settlement Agreement provisions has operated to deprive numerous plaintiff class members of their right to community placement.

Background

As the preamble and guiding principles (section II of the Agreement) make clear, a primary purpose of the Court-ordered settlement is to assist and enable class members in all appropriate cases to emerge from segregated congregate facilities and to enjoy the benefits and opportunities of life in the community:

A. Each citizen must be provided services in the least separate, most integrated setting appropriate to meet his or her individual needs....

C. Tennessee's programs and services must be designed to provide all citizens the reasonable opportunity to grow, develop, exercise independence, and to live full and productive lives.

D. Tennessee recognizes the need to provide services to each citizen in his or her home communities and to provide a broad array of living environments and services, including homes adapted to individual needs, health care and therapy, work at regular, meaningful, and compensated employment, opportunities to develop relationships with family, friends, neighbors, co-workers, helpers and support staff and community organizations, and participation in community activities.

* As our April 22 report suggests, the factors affecting transition and community placement are significantly different at the quasi-forensic Harold Jordan Center included in the Clover Bottom review, as opposed to CBDC itself. This report therefore applies to the "main" Clover Bottom facility.

These provisions of section II are not intended to be independently enforceable, but as the preamble says (p. 2), they are meant to “aid in the interpretation of the operative provisions of the Agreement,” which all support the goal of community placement. Section IV (A) of the Agreement requires a comprehensive evaluation of each class member by that person’s interdisciplinary team, including a determination of suitability for community placement. If an individual residing in an institutional setting is not recommended for the community, an independent evaluation for such placement is required to be conducted by a qualified outside professional, and this recommendation becomes part of the basis for the person’s plan (section IV (A)(1)). The defendants are then required to develop appropriate community programs for all institutionalized class members who have been recommended for such placement (section V (B)(2)). This evaluation, planning, and placement process was to be completed four years after judicial approval of the Settlement Agreement, i.e., by July 3, 2001 or at the latest November 23, 2003 (Schedule of Implementation, p. 72).

Class members and their families or guardians (among others) are required to be included in the individual evaluation and planning process (sections IV (A)(2) and V (A)(1) of the Agreement), and their input must be encouraged and respected by the other members of the interdisciplinary team (section V (A)(3)). But families, guardians, and conservators do not have a right to veto interdisciplinary team determinations or to maintain the individual in an institution even when the decision has been made that community placement is appropriate. No such right is mentioned in the Agreement, and in fact the Court has held that it was unlikely to exist (opinion of July 3, 1997 at p.16).

What families and conservators do have, in addition to a right to participate in all decision-making, is the right to be informed of and to exercise their statutory freedom of choice with respect to participation in the Medicaid waiver, as opposed to being served in an intermediate care facility for mentally retarded individuals (also funded by Medicaid). (See section V (A)(4) of the Agreement and section 1915(c)(2)(C) of the Social Security Act). Simply put, the individual or his or her legal representative is entitled to choose between services in an ICF/MR or in a program funded under the

Medicaid home and community-based waiver. As was understood in this litigation at the time the Settlement Agreement was approved, however, the Medicaid law and regulations do not create a right to insist upon placement in a particular ICF/MR (or waiver) facility, including the Clover Bottom Developmental Center, if the facility decides through its interdisciplinary team process or otherwise that an alternative setting is appropriate. (See the letter dated August 9, 1996 from the former Health Care Financing Administration to the Tennessee Attorney General's office, attached as Exhibit 1).

Problems with Freedom of Choice

The point of this report, though, is not to re-argue the correctness of the above interpretations but rather to show how the legal provisions involved have been used to minimize the likelihood of CBDC residents' becoming members of the larger society. As noted in the Panel's 2008 Clover Bottom report (p. 8), 126 individuals were living at the facility at the time of the review (February 4-8), all but five of whom had been recommended for community placement by their interdisciplinary teams. Yet only eight of the 121 class members recommended for alternative settings were actively involved in the transition process, while for ten more that process was in a suspended status. No community placement activity was occurring or anticipated for anyone in addition to these 18 individuals.

The reason for this discrepancy lay in the way the facility was administering the above mentioned freedom-of-choice requirement. Under the current system, conservators for Clover Bottom residents are asked to execute a choice form every year, and if the ICF/MR option is chosen, no effort is made to pursue community placement regardless of the interdisciplinary team's recommendations.

During its 2008 review, the Panel tried to look more closely at how these life-altering choices are made. Pursuant to a request made before the review, information was provided to the Panel as to 128 then-current choice forms completed on behalf of 128 Clover Bottom residents. On 18 of these forms the conservators had requested

Medicaid waiver services, and in these cases the person had been referred to the DMRS regional transition office to begin the process of placement. The remaining 110 forms indicated a choice for ICF/MR services, in which cases no such referral had been made, even though all but five individuals had been recommended for community placement.

In order to understand the thoughts and feelings behind these numbers the Panel was able during the review week to contact conservators for ten of the 18 individuals (55%) for whom waiver services were selected and for 35 of the 110 (32%) for whom an ICF/MR was chosen.* Interviews were also conducted with eight qualified mental retardation professionals (in effect, case managers) at Clover Bottom who were responsible for determining the conservators' choices on an annual basis and providing whatever explanation was offered as to the two types of Medicaid services.

As described, and as the Panel has observed, the way the process works is that conservators for Clover Bottom residents are mailed freedom-of-choice forms to be completed annually (see the form and cover letter attached as Exhibit 2). The forms are returned by mail or in person, and CBDC examines them to determine what option has been chosen. Follow-up telephone calls are made to secure return of the forms, but it does not appear that much back-and-forth or face-to-face discussion occurs as to the content or meaning of the choices offered.

It is not clear in any event how much guidance could be offered. Six of the eight QMRP's interviewed by the Panel were knowledgeable about ICF/MR services (including models other than Clover Bottom), but there was a general lack of familiarity with community programs available under the Medicaid waiver. The QMRP's agreed that the language on the freedom-of-choice form was confusing for parents and guardians and most likely affected their decisions (i.e., they chose or intended to choose the ICF/MR option with which they were familiar, which was Clover Bottom).

* A single Comcare corporate representative was the conservator for eight of the ten in the former category but only six of the 35 in the latter group.

Notably, of the conservators interviewed who had selected ICF/MR services, only three said they understood the language used in these forms.

According to information obtained from the conservators who had chosen Medicaid waiver services, eight of their wards were currently in some phase of transition to the community. However, in the other two cases it was reported that the transition process was at a standstill because it was thought that communication was lacking between the regional office and prospective community providers.

Probably the Panel's most important finding, though, was that none of the conservators interviewed who chose ICF/MR services meant to signify any such option other than the Clover Bottom Developmental Center. All of them, when they marked their choice for ICF/MR, intended to ensure or thought they were ensuring that their ward or family member would remain in that facility. Either because it was not explained to them or because they (or possibly their QMRP's) did not understand, they were not aware that if the individual they represented had been recommended for community placement (as most had at the time), their choice actually meant they were selecting ICF/MR services in the community. Indeed, all but two or three of these conservators seemed unaware that such other options existed or could be established under the ICF/MR program.

Lack of Informed Choices: Consequences

Many possible consequences may flow from the failure to offer an informed choice to conservators for Clover Bottom residents. First, if they had known their choice of ICF/MR might mean something other than Clover Bottom, they might not have selected that option or might have decided that the choices were equally attractive (or unattractive). Second, they might have been interested in a community-based ICF/MR placement if they had known such programs existed, but the forms do not differentiate between Clover Bottom and other ICF/MR's and the choice is treated by the system as a preference for Clover Bottom. Thus, as the Panel has been told many times, there is no attempt to locate suitable vacancies in community-based ICF/MR's when the ICF/MR

box is checked, and as far as we have been told, there is no current effort to develop community-based ICF/MR homes in Middle Tennessee for persons whose conservators might be interested if they knew about them.*

Another important way in which the current process frustrates true freedom of choice is in the lack of information provided to conservators about community programs funded under the Medicaid waiver. Most parents and guardians of Clover Bottom residents have years of experience with that facility, but not necessarily any exposure to or knowledge about alternatives available under the home and community-based waiver program. There was no evidence that such information about community programs was routinely provided to conservators in connection with the freedom-of-choice process, and it did not appear that the QMRP's who administer that process were in any position to provide this type of input. Thus the process in effect "steered" class members' conservators toward choosing or intending to choose the only option most of them were familiar with.** In addition, as noted in the Panel's Clover Bottom report (p.11), transition profiles for Clover Bottom residents who have been recommended for placement are not disseminated to community providers, even on an anonymous basis, without the conservator's permission – with the result that the ICF/MR – vs. – waiver choice is usually made without any direct contact or sharing of information between the class members' representatives and one or more waiver-funded programs that might be viable options. The conservator is left with the choice (or presumed choice) between a program he or she has long been involved with, for better or worse, and one that has no name, shape, or form.***

* Steps are reportedly being taken to develop State-operated, community-based ICF/MR homes in East and West Tennessee, but not in the Middle region which is home to most Clover Bottom residents. A certificate of need has been approved for a 32-bed expansion of a currently 40-bed private institution operated by MurCi Homes in Antioch, but that program, whatever its merits, is not a community placement.

** No one denies that Tennessee's community-based mental retardation programs suffer from numerous problems, as the Panel's annual system reviews have consistently noted; but so does Clover Bottom, as indicated by this year's and previous reviews. Actually the Panel's most recent review of class members' programs in Middle Tennessee showed a considerable degree of improvement (see report dated October 9, 2007). On the other hand, the defendants' continuing measures to reduce the cost of community programs to an arbitrarily determined level, and to focus Medicaid waiver services on a rigid definition of "medical necessity" rather than the more expansive and humane purposes of the Settlement Agreement, are negative factors that cannot be avoided in considering transitions to the community (see the Panel's supplemental report to the Court dated March 1, 2008). These unilateral actions on the part of the defendants threaten to increase the risks and diminish the potential benefits of community placement for all class members everywhere.

*** The sequence in which these events occur further detaches the conservator's choice from the Settlement Agreement's person-centered planning process and from any practical reality. Instead of determining the conservator's choice between ICF/MR and waiver services in isolation, thus removing the issue from meaningful interdisciplinary input or consideration, the sequence set forth in the Settlement Agreement should be followed. First, an IDT determination should be made as to the individual's suitability for community placement, and if the team decides not to recommend such placement an independent professional review must be conducted (section IV (A)(1)). If the outcome is a recommendation for community placement, a transition planning process (with family and guardian participation) should be undertaken with a view to implementation of that recommendation (sections V (A)(1)-(3), (6), (11)). After a recommendation for placement has been made and the transition process has begun, then the conservator should be given a choice between ICF/MR and waiver services that will meet (cont'd)

Finally, more information should be provided to conservators as to the long-term consequences of choosing ICF/MR services for their wards if this option does or can mean the person remains at CBDC. It is almost certain that the defendants will not keep Clover Bottom open indefinitely to serve 100 or fewer individuals at a cost of \$1,000 or more per person per day. Individuals remaining at Clover Bottom if and when the facility is closed (and their representatives) might be faced with placements not of their choosing, possibly including nursing homes (currently prohibited by section V (A)(5) without the parties' and Panel's approval), private institutions such as MurCi Homes, or as Governor Bredesen suggested in his 2008-09 budget hearing with Deputy Commissioner Norris, the far-away Greene Valley Developmental Center. If such future possibilities were explained to conservators, choosing a waiver-funded community placement closer to home (while such choices are still available) might be seen as a more prudent option.

Sudden Increase in Non-Placement Recommendations

While community placements for class members recommended for transition are being frustrated as set forth above, the number of Clover Bottom residents who are not being recommended for community placement by their interdisciplinary teams has recently gone through the ceiling. For almost the first ten years of the Settlement Agreement's existence, from July 3, 1997 to May 29, 2007, every class member at CBDC was consistently recommended for placement by his or her interdisciplinary team. On May 30, 2007 the first non-placement recommendation was received by the Panel, and as indicated above the number of such recommendations had risen to five as of February, 2008. As of the date of this supplemental report, however, the number of Clover Bottom residents who have not been recommended for community placement has ballooned to 42,* leaving just 84 who have been so recommended whereas three-plus months ago there were 121.

(cont'd) the class member's needs in a community setting (sections (A)(4), (9)). The entire process should be informed as soon as feasible by the prospective providers' responses to transition profiles.

* Two persons who were not recommended for placement are now deceased, and one has been transferred to a nursing home (see below). This transfer was made by defendants without the approval of the Panel or the other parties, in violation of section V (A)(5) of the Agreement, though ultimately it may have been approvable.

Certainly it seems peculiar that the percentage of Clover Bottom residents not recommended for community placement has gone from 0% to 32% in little more than a year, and from 4% to 32% between March 12 and the present. Also highly unusual is the fact that most of these changes in placement status were embodied in addenda to class members' individual support plans rather than in the course of annual ISP updates as might be expected. It appears that this wave of changes is due to the teams' being directed to reconsider their placement recommendations, in part with a view to the new beds being developed at the aforementioned private institution (MurCi Homes). Whatever the explanation, it cannot be denied that the defendants' ultimate community placement commitment has been very substantially reduced. The conservators, parents, and attorneys for these individuals would do well to start investigating what the State has in store for them, particularly if and when it is decided to shut down the Clover Bottom operation.

Pursuant to section IV (A)(1) of the Settlement Agreement, independent professional reviews must still be conducted with regard to the appropriateness of community placement for the 39 remaining individuals who were not recommended for same. The independent reviewers may or may not reverse some of these non-placement recommendations, but there is no reason for confidence that their determinations will be followed as required. At Greene Valley Developmental Center, the same reviewers have reversed 32 of 69 non-placement recommendations, but so far none of the affected individuals has moved to the community although we are informed that one is about to.

But even the first completed review at Clover Bottom, upholding Mary P.'s unsuitability for community placement, has a larger story to tell. Ms. P. is a 73-year-old woman who was admitted to Clover Bottom in 1971 and stayed there for more than 36 years until she was transferred to a nursing home in McMinnville in April, 2008. Because of Ms. P.'s dementia, behavior issues, and increasing need for medical and nursing care, the independent professional reviewer concluded in October, 2007 that it was just too late for Ms. P. to move from Clover Bottom to the community.

But according to the reviewer's report, Ms. P.'s niece, who became her conservator after her mother and brother died, had wanted Ms. P. to be closer to her home and family. As late as November, 2006, the interdisciplinary team recommended Ms. P. for transition to the community, and the conservator agreed with the plan being made so that her aunt could come home. In May, 2007, however, the team met again and changed its mind. Perhaps the team was right. But what happened in the previous ten years when the Settlement Agreement was in effect, when the family was evidently receptive to the notion of a placement in the community? The report does not say whether the problem was confusion about freedom-of-choice forms, a lack of communication, just plain inertia, or some other cause altogether, but for whatever reason the opportunity never came. Now at last Ms. P. is close to home and surrounded daily by family and friends – but she nearly had to die in order to effectuate what the system could not or would not provide.

Conclusion

Instead of consistently supporting and encouraging appropriate community placements of class members in line with the guiding principles of the Settlement Agreement, the defendants have, at times, accorded parents and guardians de facto veto power over class members' right to live in the community. They have distorted and confused the process for choosing between ICF/MR and waiver programs, used it to negate the interdisciplinary team process, and failed to provide families and guardians with full information about their community options. Now, somehow, they have brought about a situation where long-standing recommendations for community placement have been reversed en masse. As a result, as many as 105 and probably more of the remaining residents of Clover Bottom Developmental Center stand to be deprived forever of the opportunity to experience community living.*

* Ironically, the few who will be lucky enough to move to the community, and the hundreds more who have previously left the institutions, are now in danger of seeing their lives and programs reduced to the level of "medical necessity," far from what they were promised in the Agreement (see section V (A)(1)).

As the Court is aware, the defendants have refused to respond to recommendations made by the Panel and are unlikely to reply to our recent Clover Bottom review or this supplemental report. Thus there is little point to our making additional detailed recommendations, especially because so many of these matters have been covered in our previous reports, and because our basic adjuration to the defendants is simply that they fulfill the commitments they made in the Settlement Agreement.

Dated: June 10, 2008

Respectfully submitted,
QUALITY REVIEW PANEL

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