



PENNHURST CENTER

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Action for Community Services
Leslie J. Fenton, Editor
Office of the Special Master
649 South Henderson Road
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Dear Ms. Fenton,

I must question your interpretive editing of the Lemanowicz, Feinstein, Conroy paper "Institution and Community: A Comparison of Populations", which ran in the November issue of ACTION. I feel that you misrepresented the total findings of that study by selectively printing only a very small portion of the results. While I realize that your newsletter is designed to foster public acceptance of the movement towards community-based services for the retarded, you do a disservice to your readers by minimizing the real problems that must be confronted if this change in service delivery is to be successful. All concerned professionals in the field want to see the community-based service system become a successful reality, but we can only impair the chance for success of that effort if we paint a false picture of what is needed to make it happen.

Specifically, you note that 24% of the CLA population is severely or profoundly retarded, while 82% of the institutional population is. By cutting short your quote on this, you alter the true finding, which is that there are "considerable differences in the distribution of level of mental retardation". In fact, if you look at just the profoundly retarded, Figure 2 (p.10) shows that only 4% of the CLA clients in Philadelphia function at the profound level, while 52% of the institutional population is profoundly retarded. In real numbers, of the 211 persons in the CLA program, only 9 are profoundly retarded. (Interestingly, this holds true state-wide. The Office of Mental Retardation, in its June, 1979 Draft Position Paper on Residential Services reported that 3% of the 2755 clients in CLAs are profoundly retarded, as opposed to 41% of the state center population.)

On the question of maladaptive behavior, the study itself has some weaknesses. The Behavior Development Survey (BDS) is susceptible to interpretive inconsistency by the reporter who completes it. The items grouped under the Maladaptive Behavior heading are quite global and lack precision. Based on personal experience, I know that behavior considered highly maladaptive by one person completing the BDS, may be dismissed entirely by another. Having seen those few clients who have returned from the community over the years, due to "behavior problems", it is obvious to me that the concept of what is or isn't problem behavior varies greatly between Pennhurst and the community. In fact, clients with histories of problematic behavior in the institution have traditionally been dropped from consideration for community placement by the Base Service Units and CLA providers. Of course, you could not be expected to take these problems with the BDS into account in your story. But you did misread the actual results of the survey. The higher sum score of the CLA clients showed that they had "the least behavior problems" (p.7) not the most as you state. A more accurate comparison between

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those people in CLAs and those in Pennhurst could be derived from Figure 18. This shows that 63.2% of the CLA clients fall on the High functioning/Low maladaptive arm of the matrix, while only 24.1% of the institution clients fit into that category.

Lastly, with regard to medical involvement, the survey again falls short of presenting a true picture of the populations in question. Short-term hospitalizations are not indicative of the presence or absence of conditions that require close medical monitoring. Neither is the frequency of chronic illnesses (Table 6) although that measurement shows that nearly ten times as many of the institutional clients report some chronic illness, primarily or secondarily, than do the CLA clients (427 to 45). The authors of the report might have done well to examine primary diagnoses or the etiology of the retardation. Neither of these are covered by the BDS. Question 3-(11) of the BDS does cover Medical Needs. The authors did not report the results of this measurement. They also failed to compare the number of institutional clients versus CLA clients who do not walk (Question 1-(45)) or who require wheelchairs (Question 3-(16)). It is simplistic to assume that the medical needs of the various people studied are similar, based solely on the fact that they spent time in a hospital in the same proportionate numbers.

I hope I have adequately presented my reasons for questioning your article. I also hope that you understand the motivation behind this letter. I am not trying to prove that "institutions are better" or that "these people can't live in the community". On the latter point, I testified during the Halderman trial that anyone could live in a community setting, no matter how severe their needs, given the availability of all the appropriate services and support systems. My fear is that if service providers and the general public do not know and accurately understand what is needed by our clients, then those services will not be ready for them as they move into the community. Painting the false picture that those people still in Pennhurst will need little more than what is currently available in the community does no one any good.

I have one other complaint, which is more of an emotional plea than a statistical query. In your Parent Involvement article you ran the quote, "This is the first time I've ever heard anyone say something positive about my child". I am sure that some parent could have said that, but I think your inclusion of the quote as representative of the Pennhurst experience is unfair. We place a strong emphasis on positive skills and client strengths in our program planning and have done so for years. Running that quote infers that Pennhurst is a totally repressive organism and that we deal solely in negativism and client degradation. You should be able to sell community services without resorting to such cheap shots at Pennhurst and the people who work here. After all, Pennhurst does not exist in a vacuum. It is reflective of what society decided was appropriate for the retarded at a point in time, just as the movement to community services reflects what society feels is right, today. Please try to stay away from such cheap shots in the future. They only serve to fragment and polarize the public and do nothing to further the cause of retarded people.

Sincerely,



J. Gregory Pirmann

Special Assistant to the Superintendent

JGP/sjm