

PENNHURST STUDY

BRIEF REPORT #13

PROGRESS OF CLIENTS IN COMMUNITY
LIVING ARRANGEMENTS: CLASS MEMBERS
COMPARED TO OTHERS

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INTRODUCTION

The Halderman vs. Pennhurst suit was first filed in Federal District Court in May 1974. In an opinion filed on December 23, 1977 the Court found that the institution was unacceptable on Constitutional, state statutory and Federal statutory grounds. The judge suggested that the parties meet in an attempt to agree upon a court order which would be agreeable to all parties. The parties informed the Court that they had been unable to agree and would never be able to come to an agreement. As a result, an order of judgment was handed down by the Court on March 17, 1978 in favor of the plaintiffs and against the defendants.

As part of Judge Broderick's March 17th Order, the Office of the Special Master was formed. The Special Master was given "the power and duty to plan, organize, direct, supervise, and monitor the implementation of this and any further Orders of the Court." Included in this Order were provisions for the development of an Individual Habilitation Plan for each member of the plaintiff class. In addition the Court requested a plan for the development of mechanisms to monitor community services, to be sure that appropriate services were continuously being provided to members of the plaintiff class in the least restrictive environment possible.

One must then ask whether or not Judge Broderick's Order of March 17, as well as subsequent Orders, produced any visible changes in the lives of the clients in the plaintiff class. While change can be measured along several dimensions, we have chosen to look at developmental growth over a two year period in both adaptive and maladaptive behavior. The research question is: once they have been placed in CLAs, do Pennhurst Class members show developmental growth patterns that are different from those of other CLA clients?

METHODS

Subjects

The subjects for this study were 103 mentally retarded people living in Community Living Arrangements (CLAs) in Philadelphia. The total Philadelphia CLA population had 237 residents, 174 of which had two Behavior Development Surveys administered. The members of our sample were the first 103 people with two forms completed, and there was no reason to believe it was biased. Table 1 presents the demographic information on the sample used ($N=103$) and the population from which it was drawn ($N=237$).

TABLE 1

DEMOGRAPHICS ON CLA POPULATION AND SAMPLE

	Phila. CLA Population $N = 237$	Sample $N = 103$
LEVEL OF RETARDATION		
Mild	35%	33%
Moderate	35%	37%
Severe	24%	22%
Profound	6%	5%
Unknown	1%	3%
SEX		
Male	64%	63%
Female	36%	37%
AGE		
	Mean = 34	Mean = 39

Although the sample was not chosen randomly, the demographics are comparable to that of the total Philadelphia CLA population (particularly for sex and level of retardation), and the sample appears to be representative of the entire population.

The sample can be broken down into three groups which are of particular interest. They are:

- | | |
|-------------|--|
| CLASS | Pennhurst class members who were at Pennhurst Center but left after Judge Broderick's March 1978 Order (N=25). |
| NON-CLASS | Non-class members who were at Pennhurst Center but left before the March 1978 Order (N=36). |
| NEVER AT PC | This group was never at Pennhurst Center (N=42). |

Instrumentation

The Behavior Development Survey (BDS) is the instrument used to measure client functioning. It is actually a short version of the AAMD Adaptive Behavior Scale, developed by the UCLA Neuropsychiatric Research Group at Lanterman State Hospital, by selecting only the most reliable and valid items from the full scale. The BDS has separate sections on adaptive and maladaptive behavior, and uses change over time to measure developmental growth.

Procedures

The BDS was first administered in early 1979 to all residents of Philadelphia CLAs. In early 1981, approximately two years later, the BDS was re-administered. This report examines the changes found in the three groups for that period of time.

RESULTS

The three groups which form the sample are broken down by level of retardation in Table 2.

TABLE 2

LEVEL OF RETARDATION BY GROUP

LEVEL OF RETARDATION	CLASS	NON-CLASS	NEVER AT PC
	N = 25	N = 36	N = 42
Mild	16%	47%	28%
Moderate	40%	39%	33%
Severe	44%	11%	29%
Profound	0%	3%	10%

This table reveals that the CLASS and NEVER AT PC groups have a high proportion of severely/profoundly retarded residents while the NON-CLASS group is mostly mild /moderate. CLASS and NEVER AT PC groups also have very similar male/female distributions; the NON-CLASS members contain a very high proportion of males (81%). The CLASS, NON-CLASS and NEVER AT PC groups have mean ages of 43, 41, and 34, respectively. A one-way ANOVA reveals a significant age difference ($F = 5.8$, $p = .004$) between the NEVER AT PC group and the other two groups.

Since the Behavior Development Survey has been administered twice for every member of the sample, an examination of the data can show what progress the three groups have made over time. Adding together all the pertinent items on the forms, we have computed adaptive and maladaptive behavior sum scores, which represent overall functioning levels in each area. The overall change scores for the entire sample were 0.42 points gained in adaptive behavior

sum (NS) and 1.67 points gained in maladaptive behavior sum ($T = 4.50$, $p = .000$). These figures are very similar to those found for the entire population (increase of 0.53 points in adaptive behavior and 1.57 points in maladaptive behavior).

Table 3 shows the sum score changes found for the three groups.

TABLE 3

SUM SCORE CHANGES BY GROUP

Adaptive Behavior

	N	\bar{X}_1	\bar{X}_2	Change
CLASS	24	87.42	93.29	+5.88
NON-CLASS	36	100.69	99.28	-1.42
NEVER AT PC	41	89.10	87.93	-1.17
OVERALL	101	92.83	93.25	+0.42

Maladaptive Behavior

	N	\bar{X}_1	\bar{X}_2	Change
CLASS	25	18.36	20.12	+1.76
NON-CLASS	36	18.64	19.72	+1.08
NEVER AT PC	42	17.52	19.64	+2.11
OVERALL	103	18.19	19.79	+1.67

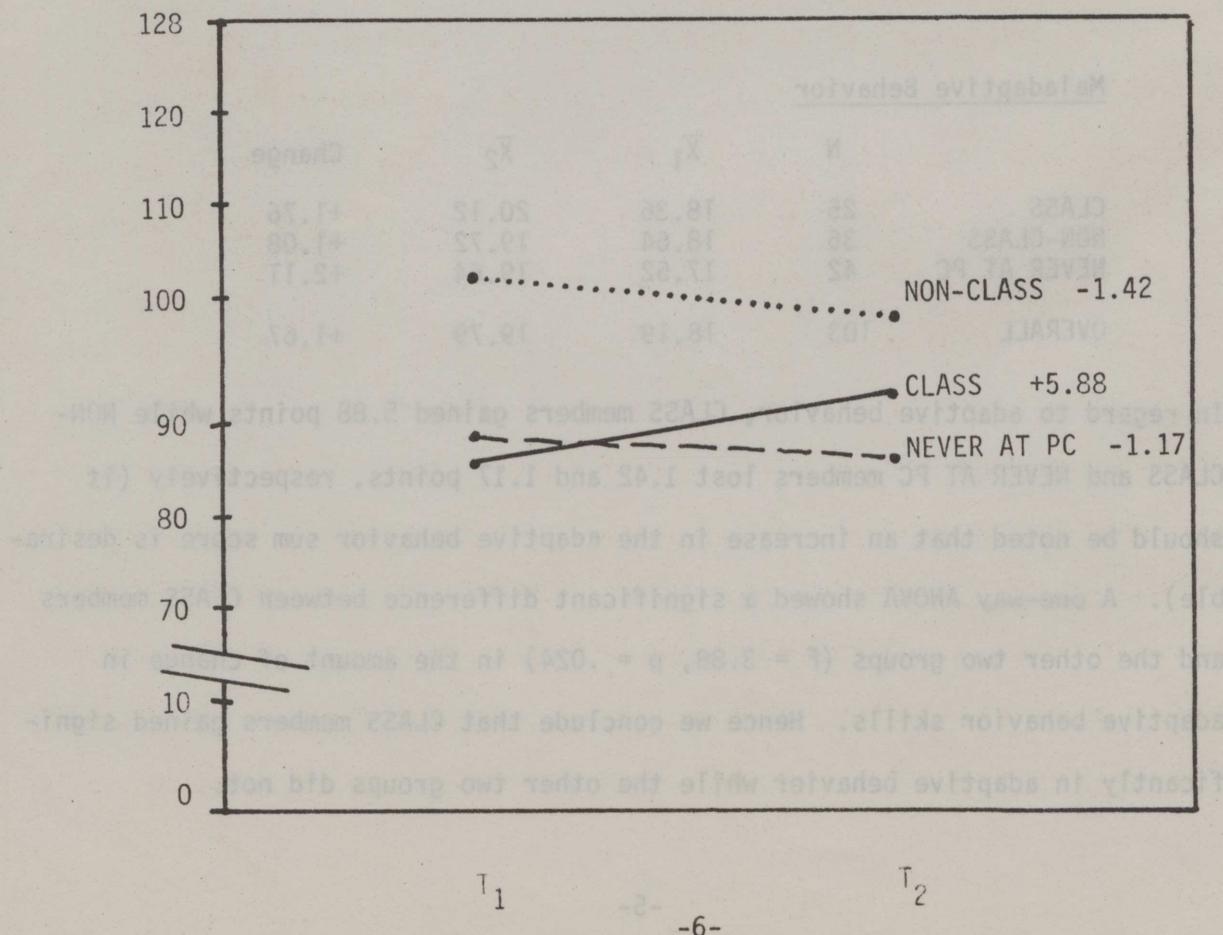
In regard to adaptive behavior, CLASS members gained 5.88 points while NON-CLASS and NEVER AT PC members lost 1.42 and 1.17 points, respectively (it should be noted that an increase in the adaptive behavior sum score is desirable). A one-way ANOVA showed a significant difference between CLASS members and the other two groups ($F = 3.88$, $p = .024$) in the amount of change in adaptive behavior skills. Hence we conclude that CLASS members gained significantly in adaptive behavior while the other two groups did not.

Figure 1 presents a graph of adaptive behavior sum change for the three groups. It shows that the CLASS and NEVER AT PC groups started at approximately the same adaptive behavior level; however, the CLASS members gained points while the NEVER AT PC groups did not change significantly. The NON-CLASS members started at a much higher level than the other two groups, but failed to show a significant change.

No difference was found among the three groups in maladaptive behavior; all three groups improved. An increase in maladaptive behavior sum score is the desired result, since it indicates a decrease in maladaptive behavior. The one-way ANOVA on maladaptive behavior sum change failed to show a significant difference among the three groups ($F = .759$, $p = .471$). Hence we conclude that all three groups improved about equally in reducing problem behavior.

FIGURE 1

ADAPTIVE BEHAVIOR SUM OVER TIME



DISCUSSION

As the results indicate, there are differences in characteristics among the three groups (CLASS, NON-CLASS, and NEVER AT PC). When one looks at the three groups with regard to the level of retardation, it is apparent that the NON-CLASS members have the highest proportion of mildly and moderately impaired individuals, while the other two groups have a larger percentage of severely and profoundly impaired clients. This can best be explained by a process called "creaming." Early in the deinstitutionalization movement those individuals selected for community placement were those who would be most likely to succeed. Therefore the highest functioning clients left first; they were "creamed." This process has not been used for class members. According to the orders of the court, the only group given priority in the placement process is children. Beyond that group there seem to be no consistent criteria for selection for placement in the community.

Upon examining adaptive behavior growth for the three groups, significant differences have been found. Both the NON-CLASS members and NEVER AT PC groups lost slightly in adaptive behavior, in marked contrast to the 5.88 gain in adaptive behavior for CLASS members. All groups improved significantly, and the same amount, in the maladaptive behavior area.

While most provider agencies maintain Individual Program Plans for each client, CLASS members, as ordered by the Court, must have Individual Habilitation Plans which must be approved by the Office of the Special Master. The Individual Habilitation Plan contains nine areas (Health, Sensory/Motor Skills, Communication Skills, Activities of Daily Living Skills, Vocational/Education Skills, Social Interactions, Self-concept/Coping Skills, Leisure/Recreational/Religious Activities, and Other Special Concerns). The Master's Office has requested that there be one goal in each area. In addition, goals

must be written in a behavioral objective format, must have a timeline, and must list a person responsible for monitoring and supervision of each goal.

The Office of the Special Master periodically monitors clients' programs to ensure that services are being provided as prescribed in the IHP. The responsibility for coordination of services is that of the Pennhurst Case Managers.

Thus the clients covered by the Pennhurst court order enjoy several protections not available to others, among which are strict written plan requirements, regular monitoring, and specially assigned Case Managers.

While this study has not established that the cause of greater developmental growth among CLASS members is the court protections, the data certainly suggest that class members have been doing better. The average CLA client improves in the maladaptive behavior area, but not in adaptive behavior; CLA clients who are CLASS members improve in both areas. We regard this as the first evidence that the quality of written plans, systematic monitoring, and good case management do make a difference.