U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

Third Year Comprehensive Report of the Pennhurst Longitudinal Study

1983

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This report was prepared under contracts #130-81-0021 and #130-81-00022 between the U.S. Department of Health and Human Services (HHS), Office of Social Services Policy (now the Office of Disability, Aging and Long-Term Care Policy) and Temple University. For additional information about the study, you may visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The DALTCP Project Officer was Ron Conley.

THIRD YEAR COMPREHENSIVE REPORT OF THE PENNHURST LONGITUDINAL STUDY

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The Temple and HSRI research team would also like to recognize the enormous contribution of the DHHS Project Officer, Mr. John J. McCann. The achievements of this study can in large part be credited to his conscientious management and commitment to the integrity of the research objectives.

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I. SUMMARY OF FINDINGS

This summary is intended to restate the major research questions being addressed in the Pennhurst Longitudinal Study and provide executives, decision-makers, and lay persons, in an extremely abbreviated form some tentative answers based on the analysis of the data collected to date. Such a report is necessary because the documents generated by the Pennhurst Study now extend into the thousands of pages. While these reports are of keen interest to the researcher, they are not as likely to be read by the layman. It is hoped that this report will be widely read, thus providing additional information to decision-makers weighing the pros and cons of deinstitutionalizing mentally retarded persons.

This document is the work of both parts of the Pennhurst Longitudinal Study team, Temple University and Human Services Research Institute, and was developed at the request of the Office of Human Development Services in the Region III Office of the U.S. Department of Health and Human Services. Temple is concerned with questions relating to the measurement of client, family, and community impacts, while HSRI is centering on documenting historical facts, and legal and policy issues, as they evolve, as well as cost issues.

The importance of the Pennhurst Longitudinal Study is derived from three main facts:

1. Policy makers do not possess nearly enough quantitative data to be confident that deinstitutionalization actually benefits mentally retarded clients and their families, despite the fact that nearly 60,000 mentally retarded citizens have been deinstitutionalized in the past decade. This study is adding to the quantitative information available to them.

2. The Constitutional foundations of Judge Broderick's decision of December 23, 1977, in Federal District Court have not yet been tested at the Circuit or Supreme Courts. If they are supported, the national impact would be tremendous. Already, the case has encouraged filing of suits in approximately 20 other states. This study is providing an analysis of Judge Broderick's decisions and assessing their impact in other states and on Federal policy options.

3. The relative cost of the two modes of care (large/institutional/segregated versus small/community-based/integrated) has never been clear to policy makers. Past studies have been severely flawed by non-equivalent clients and/or services in the two settings. This study is designed to collect some aggregated cost information in the short run, while designing and testing a new method of collecting comparable cost data for possible application in the future.

The summary that follows lists the research questions, gives the answer to each if data are available (preliminary data are noted where necessary), and references the project documents that are relevant to each question.

A. Questions Related to Measurement of Client, Family, and Community Impacts

1. Has the Court Order hastened or slowed the "normal" process of deinstitutionalization?

In the two years following the Court Order of March 17, 1978, we could find no evidence that the rate of Community Living Arrangement (CLA) placement had increased (96 placements in the 2 years before, and 81 in the 2 years following, the Court Order). However, more recent activities suggest a delayed but very large impact; 177 people were placed in 1982 alone. Moreover, evidence indicates that the placement of severely impaired clients has been far more rapid than would otherwise have occurred (over 80% of relocated clients are labeled severely or profoundly retarded).

2. Are deinstitutionalized clients better off?

(a) **In terms of independent functioning?**

Here the answer is definitely yes. Our measure of independent functioning/adaptive behavior was collected for all Pennhurst residents in 1978, and for all who had moved to CLAs in 1982. The scale ranges from 0 to 128. For the 157 clients for whom complete prepost data were available in mid-1982, the average gain was 9.2 points (from 59.0 to 68.2). This change was highly significant.

(b) **In terms of developmental growth, compared to matched clients remaining at Pennhurst?**

Yes; 70 of the earliest movers were compared to 70 matched stayers. The movers showed enhanced functioning in adaptive behavior once moved, while stayers showed no change. This study could not strictly be generalized to all remaining clients, but the evidence shows that the earliest movers are not greatly different from those remaining; hence we do have moderately strong grounds for generalization.

(c) **In terms of their own rate of developmental growth?**

This is a longitudinal question. Rephrased, it asks whether each client is growing and learning more rapidly in the community than he or she did while at Pennhurst. Four observations are required to answer the question (two at Pennhurst and two in the community). Sufficient data for preliminary conclusions will be available in Summer 1983, but final data will only be available at the end of the study in 1984.

(d) **In terms of family satisfaction with the settings?**

Among the earliest movers, 37 families reported that they were more satisfied with the CIA than they formerly were with Pennhurst. This was a preliminary finding, because we were forced to rely on memory of former satisfaction, which could be distorted.

When prepost data are examined, we find that the families of clients who have moved: (a) were initially more optimistic about community placement than the

average Pennhurst family; and (b) are now even more pleased with the community settings than they expected to be. This prepost finding is also preliminary because only 65. families have been surveyed.

(e) **In terms of family perception o f client happiness?**

Yes, families report that the greatest change they see, among 14 possible areas, is in the client's general happiness. The perceived change is in the positive direction, and significantly exceeds the expectations of the 65 families thus far Interviewed pre and post.

(f) **In terms of the quality of their living environments?**

In terms of Program Analysis of Service Systems, a measure of the degree of normalization, the answer thus far is yes; on the average, relocated clients have experienced a change from 28% of the highest possible score (at Pennhurst) to 71% of the highest possible score (in CLAs). In terms of the Resident Management Survey, a measure of individualized treatment practices, the answer is also yes; average scores changed from 76% to 92% of the highest possible.

(g) **In terms of the amount of services rendered?**

Considering both day program time and hours of supportive, developmentally-oriented and structured service (e.g., instruction in dressing self, in use of money, in communication, in physical therapy, etc.), the clients thus far relocated received an average of 6 hours of such service per day while at Pennhurst. For the same clients 2 years later in CLAs, the average was over 10 hours per day. In this deinstitutionalization, then, we must conclude that clients thus far placed are receiving more service than they did at the institution; the Issue of the relative **quality** of the services is best judged by relative outcomes, and this has also been tested in a preliminary way, and the results suggest better outcomes in CLAs.

(h) **Are clients deinstitutionalized under Court Order developing faster than others?**

Thus far, our study of 103 Philadelphia CLA clients strongly suggests that the answer is yes. All CIA clients improved behaviorally from 1979 to 1981, but only in the area of maladaptive behavior. The subset of CLA clients who were Class members improved in both the adaptive and the maladaptive areas.

3. Do clients at Pennhurst regress, as was claimed (and accepted) in Federal Court?

No, from 1978 to 1980, the average client gained a very slight amount in self-care skills. No changes were seen in community living skills, personal responsibility/motivation, or maladaptive behavior.

Factors that appeared to be related to client development **within** the institution (beyond the effect of client characteristics) were the amount of day programs, the degree of individualized treatment (as opposed to regimentation in groups) and the number of medications given daily (the more medication, the less growth). Whether or not a cottage was ICF/MR certified was not related to the developmental progress of clients in that cottage.

4. How do clients themselves feel about relocation, both before and after it occurs?

We have interviewed 56 of the 287 verbal Pennhurst clients while they were still at Pennhurst in 1981. Each will be reinterviewed after s/he moves to a CLA. Thus far, 9 clients in the sample who have moved and have been in the CLA over 6 months have been reinterviewed. 'Preliminary prepost analysis of the responses of those 9 clients shows that their satisfaction with nearly all aspects of their living situation has increased. More definite statements must await larger numbers of reinterviews.

5. How do families of Pennhurst clients feel about deinstitutionalization?

(a) **Before relocation?**

Over 70% said they would oppose relocation to a CLA.

(b) **What factors account for those family attitudes?**

The family's perception of their relative's level of medical needs was the strongest predictor of attitudes toward deinstitutionlibation. This was followed b race, resident age, and family educational level.

(c) **Are families' perceptions of medical needs accurate?**

We cannot say with certainty if they were accurate, but they certainly disagreed with the perceptions of Pennhurst medical staff and records. Families perceived **much** more urgent needs for medical care than were reported by the staff themselves.

(d) **How do family attitudes change after relocation occurs?**

Thus far we have conducted prepost interviews with 65 families of relocated clients. (This is the first prepost study in the field.) These 65 families were initially about neutral toward the idea of deinstitutionalization. After placement of their relatives in CLAs, they were significantly more positive. Moreover, their initial expectations about CLA placement have been exceeded in nearly all areas. However, the primary remaining issue, that of the permanence of this new way of serving their relatives, continues to be a deep concern, and one which decreased only slightly after relocation.

6. What are the attitudes and reactions of neighbors of the new group homes?

(a) **Before they open?**

We were limited to asking general attitudinal questions to avoid sensitizing the neighbors, nearly all of whom (8 sites, 362 respondents) were unaware of plans for a group home in their neighborhood. About 16% said they would be "bothered" to varying degrees by a group of 2 to 5 mildly retarded neighbors; 31% would be bothered by severely retarded neighbors. Also, 21% thought mildly retarded neighbors would negatively affect property values, while the figure was 31% for severely retarded neighbors. Figures for "bother" were 8% for physically disabled, 32% for mentally ill, and 38% for a different race.

(b) **What factors account for these attitudes?**

Respondent age, race, and sex were significant predictors; the younger, the more positive; nonwhites were more positive; and males were more positive. After these variables were accounted for, knowledge about retardation and contact with retarded persons in the neighborhood (but not anywhere else) were also significant: more knowledge, more positive; and more contact in the neighborhood, more positive. This last item would seem to have definite policy implications.

(c) **After they open?**

About 6 months after each group home opened, and again at about 18 months, the same respondents contacted in the baseline survey (6 months pre-opening) were reinterviewed. At 6 months, only about 28% were aware of the group home, and at 18 months the figure was about 33%. For those who were aware of the group home, general attitude toward retarded persons became slightly but significantly less positive 6 months post-opening; but at 18 months, they had changed significantly again, returning to the more positive baseline level. The results suggest that negative reactions of neighbors to group homes may be, as many have speculated, a phenomenon that fades with time and familiarity with the new neighbors.

7. In terms of movement, what has happened to the 1155 clients who were living at Pennhurst on the date of the Court Order?

As of October 1982, 289 clients had been placed in CLAs in the Southeastern 5 counties of Pennsylvania, and 80 had been placed in ClAs elsewhere in the state. Since 1978, 59 had died at Pennhurst and 3 had died after moving to a CLA; 11 had returned to their families (6 in state and 5 out of state); only 8 had been transferred to other institutions. A total of 705 clients remained at Pennhurst. (These numbers from the Temple tracking system differ somewhat from other agencies' estimates because of different criteria for when a client is considered to be “officially” placed.)

8. Has the Court Order influenced the types of_clients selected for relocation (i.e., are more severely retarded clients being placed)?

Yes, the Pennhurst deinstitutionalization appears unique in the **lack** of "creaming," that is, taking the highest functioning clients first. The clients that have been placed thus far are **not very different** from those who still await placement.

Behavioral differences **can** be detected statistically, but the differences are very small. The stayers have, however, been at Pennhurst about 5 years longer than movers, and are correspondingly older. This age difference may be due to Judge Broderick's order that children receive highest priority for placement.

The majority of people thus far deinstitutionalized are severely or profoundly retarded (70.2%). Our findings to date are therefore **not** restricted to mildly retarded clients.

9. What are the relative costs of community-based and institutional service delivery?

In a small but relatively well controlled cost-effectiveness study in 1982, Temple tracked nearly all public funds expended for 2 matched groups of clients (age, years

institutionalized, adaptive behavior score, IQ). We also measured developmental progress of, and services rendered to, the 2 groups. There were 4 conclusions from this preliminary study:

- Clients placed in CLAs increased in adaptive behavior, while clients remaining at the institution did not;
- Clients placed in CLAs were receiving greater total amounts of direct, structured, developmentally oriented services than their matched peers at the institution;
- The public dollar amount expended for clients in the CLAs was less than that in the institution (institutional mean, $47,000/year, median $47,000; CLA mean $42,000, median $36,000).
- The state share of the public cost was far greater for the clients in CLAs (89%) as opposed to clients at the institution (45%).

The last finding was traceable to the fact that the Federal government, under the ICF/MR program, paid over half of the total institutional costs, while CLAs were not part of the ICF/MR program.

B. Questions Centering on Historical Facts and Legal and Policy Issues

1. In what ways has federal policy influenced implementation of the Pennhurst decree?

The ICF/MR program provided the centerpiece for resource development in the third year of the study. Specifically, the availability of funding for community-based ICF/MR facilities was the key to compliance with the district court judge's implementation order for 1981-1982, which mandated the creation of community programs for 400 persons. In fact, without Title XIX funds -- both from the community ICF/MR program and from a surplus in the institutional accounts -- it is doubtful that even half of the placements could have been made with state funds alone.

The state's plan involved both the conversion of existing community living arrangements to ICF/MRs and the development of new programs. In the state's budget for 1982-1983, the number of ICF/MRs in the community was limited to a total of 500 beds statewide -- a ceiling that caught many providers by surprise. A combination of shrinking state resources, coupled with a threatened cap on Medicaid is responsible for the limitaLion on ICF/MK development.

The cap on ICF/HR beds, and a more recent cap on reimbursements, means that further movement of Pennhurst residents will have to be accomplished with state funds and/or use of the Medicaid community services waiver provisions. As this project year concluded, the state was considering the latter alternative.

2. What implications does the Pennhurst decree have for other states?

After three years of analysis, the following lessons can be shared with other states:

- Deinstitutionalization of more severely handicapped mentally retarded persons can be accomplished, but should be accompanied by a

comprehensive structure that includes case management, individualized planning, monitoring, and family involvement.

- The presence of the forum provided by the Hearing Master has provided an outlet for the varying views of parents and other relatives of class members. Though family preferences have not been uniformly supported by the rulings of the hearing Master, the process itself provides one of the few opportunities most parents have had to air their concerns.
- Institutions, such as Pennhurst State Center, which are involved in community-oriented (rather than institutional improvement) litigation, may be indirectly benefited by the public exposure that the suit continues to generate.
- Litigation directed at the advancement of one class of individuals inevitably generates resentment among those who are excluded; as a correlary, litigation that focuses on one care alternative over another (i.e., institutional vs. community) inevitably polarizes the constituency surrounding the mental retardation program.

3. To what extent has the Master's Office been successful in carrying out its mission in the Pennhurst case? What are the obstacles? What tangible results can be pointed to?

By the end of the third project year, the operations of the Office of the Special Master (OSM) had been significantly cut back and the Commonwealth was in the process of assuming many of OSM's functions. Further, the federal district court judge in the case had issued an order requesting that the Special Master prepare a plan for the ultimate phase-out of the Office by the end of 1982. In issuing the order, the judge stressed that this was not to be construed as a lessening of the court's vigilance, but rather the logical culmination of the work of OSM.

In carrying out its duties during the year, OSM faced several obstacles including:

- For a period of three months, staff of OSM were forced to volunteer their services since the Commonwealth was not paying the judge's payment vouchers.
- The uncertainty of the future of OSM had an impact on the morale of the Office.
- Continuing chilliness in relations with the Commonwealth hampered communications.

Tangible results of OSM activities included:

- An agreement regarding the transfer of monitoring and Individual Habilitation Plan functions to a Special Management Unit (SMU) operated by the Commonwealth was forged.
- OSM conducted spot checks on the monitoring and IHP activities of the SMU during the transition stage.
- OSM provided periodic reports to the court regarding the adequacy of SMU procedures, and made recommendations regarding improvement.
- The Hearing Master has taken on two controversial issues -- tile condirions of the state's private licensed facilities for mentally retarded persons, and the proposed cap on reimbursements for community-based ICF/MRs. In the first case, OSM is preparing a report. In the second instance, there was no final outcome by the end of the project year.

In summary, the operations of OSM and the Hearing Master were made more difficult given the lengthy payment hiatus. During this time, the Hearing Master process took on increasingly more drama while the Office of the Special Master became less acid less of a presence. It still remains to be seen whether the procedures developed by OSM will be perpetuated if the litigation is overturned.

4. Has the Pennhurst litigation enhanced the development of community facilities and the deinstitutionalization of Pennhurst residents?

The following observations can be made:

- Given the increase in the rate of placements that has accompanied the district court judge's implementation order covering the last two fiscal years, it would appear that aggressive court action has hastened placements not only out of Pennhurst but in the community as well.
- Pressure to meet Title XIX standards in the institution appears to be a close second to litigation in hastening institutional phase-downs. As part of the state's general plan for ICF/HR compliance, one small institution for the mentally retarded has been closed and another mental retardation unit is close behind.
- The litigation has stimulated the development of a sophisticated monitoring system for class members placed in community facilities a system that should certainly enhance the quality of life and care for such individuals.
- Providers continue to accept severely handicapped clients into their programs and there is less and less discussion of the lack of community capacity to care for such individuals.
- Community development has not been accomplished without problems including militant community resistance among neighbors in Philadelphia, escalating costs, inadequate reimbursement levels, and so forth.

5. To what extent does the adversarial nature of the litigation enhance or constrain reform-oriented goals?

In the past year, the adversarial character ofthe **Pennhurst** case has continued and no settlement has been achieved despite two attempts to reach agreement. The continuing conflict and the polarization that such conflict creates is in part responsible for a legislative investigation of community programs in the state. Pressure from parents dissatisfied with the direction of the litigation led to the investigation and may eventually lead to a change in the entitlement character of the state mental retardation law.

In Pennsylvania and in the four comparison states visited during the past year (Maine, Michigan, Minnesota, and Massachusetts), litigation has certainly focused on reform issues. Most of those interviewed would agree that these issues would not have received appropriate attention had it not been for the litigation. However, use of the adversarial process to work out plans for implementation and the continual adjustments and readjustments that must be made to accommodate fiscal, political, and programmatic pressures, is tedious and sometimes leads to a distorted result.

6. Given the experience in Pennsylvania and in other states facing broad-based litigation in the field of mental disabilities, what is likely to be the future of such litigation?

- Reformers may begin to target suits on specific and discrete system problems in order to garner publicity and attention to the issue, while simultaneously implementing extra-judicial strategies such as lobbying.
- Litigators, given the uncertain state of case law, may be more likely to pursue rights based on highly definite legal rules rather than on more open-ended provisions. This preference may lead to statutory litigation in which the plaintiffs' priority may be the remedy rather than an abstract legal principle.
- The choice to litigate textual or statutory entitlements as opposed to the more debatable claims growing out of constitutional interpretation, may lead to more suits being brought in state courts. Since the protections in many major federal programs have been diluted over the past few ears, state laws will become a primary and central source of direction for the mental disabilities system. It may also be that litigators will use state courts to pursue more open-ended entitlements based on state constitutions.
- Judges may be more likely to balance remedies against both the financial climate in a state generally, and potential effects that a diversion of resources may have on other vulnerable populations.

C. Questions of Public Costs

1. What is the average cost per client year? What does it cost on average to provide services to people in the study population at Pennhurst Center and in the community?

(Temple analysis; see Summary section A.9. above.)

2. Given a particular type of client (e.g., profoundlyretarded, mildly retarded, etc.), which type of residential program (e.g., supervised apartment, grouphome, small ICF/MR, institutional living area) shows the lowest cost per unit of service (e.g., cost per hour of developmental service, cost per hour of staff time face-to-face with clients)?

No answer available at this time.*

3. Given a particular type of client (e.g., profoundly retarded, mildly retarded, etc.), which type of day program (e.g., pre-vocational, work activity center, etc.) shows the lowest cost per unit of service (e.g., cost per hour of staff time spent face-to-face with clients)?

No answer available at this time.*

4. To what extent are the differences found in program costs a function of organizational factors such as program size, staffing levels, occupancy races, salary and benefit scales, cost of space and so forth?

No answer available at this time.*

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* Answers to the above questions will be available at the conclusion of Year 4 of the project.