

APPENDICES

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APPENDIX "A"

This checklist provides an opportunity for you to indicate whether you agree or disagree with the specifics of Judge Broderick's initial Order, which is being appealed by Pennsylvania.

Check whether you favor or oppose each of the service provisions of the 3/17/78 Court Order.

FAVOR

OPPOSE

SERVICE PROVISIONS OF 3/17/78 COURT ORDER

1. Suitable community living arrangements
2. Community services necessary for minimally adequate habilitation
3. Written individualized program plan
4. Annual review of individual plan
5. Opportunity for resident or friend to comment on individual plan
6. Monitoring to assure quantity and quality of services
7. Qualified community staff to manage preparation of individual plans
8. Continuing information to retarded people about Court Order
9. Continuing information to parents and family members about Court Order
10. Friend-advocates to assist in the protection of rights
11. No commitments or admissions to Pennhurst
12. Addressing any condition which threatens life, safety, or well-being
13. Interim operation of Pennhurst contributes to prompt provision of community services
14. Prevent physical or psychological abuse, neglect or mistreatment
15. Prompt investigation of each alleged incident of abuse, neglect, or mistreatment
16. Enforcement of DPW regulations on restraints and abuse
17. Limits on use of mechanical restraints
18. Limits on use of chemical restraints

FAVOR

OPPOSE

SERVICE PROVISIONS OF 3/17/78 COURT ORDER

19. Prohibition of seclusion except where there is clear and present danger
20. Attempts to prevent assaultive behavior by positive intervention
21. Absolute prohibition of abuse of residents by employees
22. Prohibition of excessive or unnecessary medication
23. Prohibition from using medication as punishment or for the convenience of the staff
24. Prohibition from using medication as a substitute for programming or in quantities that interfere with functioning
25. Allowing only appropriately trained staff to administer drugs
26. Training programs for staff who administer drugs
27. Prohibition from administering drugs on a P.R.N. basis
28. Monthly reviews by a physician of each residents medications
29. Program of medical and health related services
30. Detailed standards for the provision of adequate medical and health related services
31. Provision of individualized adaptive wheelchairs to each physically handicapped resident who needs them
32. Prohibition from feeding any resident in the supine position
33. Prohibition from denying programmed activities as punishment
34. Keep every residential building clean, odorless, and insect free at all times

SIMILARITY OF GOALS AND PRINCIPLES
IN SERVICES FOR RETARDED PERSONS
AS EXPRESSED BY:

FEDERAL JUDGE RAYMOND BRODERICK

IN THE MARCH 17, 1978 COURT ORDER

GOVERNOR RICHARD THORNBURGH

IN THE MAY 10, 1978 HUMAN SERVICES SPEECH

Minimally Adequate Habilitation

and Opportunity

...to provide such minimally adequate habilitation as will afford a reasonable opportunity for them to acquire and maintain such life skills as are necessary to enable them to cope as effectively as their capacities permit

...I knew the problems that handicapped people face. I also know their potential for growth, their potential for independence. ...I want to see a state that provides opportunity for the handicapped...to provide the education necessary, and to place people in jobs that will give them the chance to support themselves and contribute to their community.

Rights

...That the Rehabilitation Act of 1973, 29 U.S.C., Section 794 grants rights to the retarded residents of Pennhurst, which rights have been and are being violated.

...I want to see those unable to care for themselves cared for equitably. To do less is to divide people into first-class and second-class citizens...The vision for Pennsylvania...a state in which the rights of all are protected so that the future for each is secure.

Too often some of our citizens have been excluded from this vision.

BRODERICK:

THORNBURGH:

Suitable Living Arrangements
and Community Services

...to provide suitable community living arrangements...together with such community services as are necessary to provide them with minimally adequate habilitation...

...the difficulties that one individual encounters are shared by others: the need for adequate health care, the need for suitable living arrangements...

...we must assure educational opportunities to help people develop according to their abilities...The dream of finding a place in the mainstream of society and thus gaining dignity and independence will be shattered if we do not provide suitable work.

Individualized Programs

...to develop and to provide a written individualized program plan

...Our tendency to group people into homogeneous categories distorts the reality of the circumstances and potential of each individual...We must treat people as unique and individual...

Involvement of Individual or Friend

...to provide to each an individualized habilitation program...and the opportunity to each member of the plaintiff class and to his or her next friend to be heard theron.

...Further, I will insist on better communication between those serving and those being served. Our citizens should influence the decisions and policies that affect them.

BRODERICK:

THORNBURGH:

Quantity and Quality Assurance

...to assure that community living arrangements and other community services of the necessary quantity and quality are provided and maintained.

...We should make certain these institutions provide quality care and dignity to the individual and are adequately staffed by competent and compassionate professionals

...Our objective must be to insure that a variety of living arrangements are available in which responsible people can make choices as to which best suits their needs.

Bureaucratic Reform

...the implementation of this Order will be impossible without the appointment of a Special Master...with the power and duty to plan, organize, direct, supervise and monitor the implementation of this and any further orders of the court.

...Today this system is almost a non-system. We have a vast, impersonal bureaucracy that shuttles people from one agency to another for different services... I will insist that the highest levels of executive officers, including the Secretary of Public Welfare... stop the endless bickering over proposals and work together to clean up the bureaucratic mess and cut through the red tape that prolongs problems and prevents solutions.

Standards for Living Arrangements

...specifying the quantity and type of community living arrangements and other community services necessary for the habilitation of all plaintiffs in the least separate, most integrated, least restrictive community setting...

...we must assure that proper living arrangements are available to match each person's needs.

BRODERICK:

THORNBURGH:

Qualified Staff

...recruitment, hiring and training of a sufficient number of qualified community staff

...I would insure the many good human service employes have the leadership and skills they need to do their jobs and be responsive to the needs of the people they serve... and are staffed by competent and compassionate professionals...

Protection of Residents

...address...condition at Pennhurst which threatens the life, safety, or well-being of any resident...

...I will direct that all out efforts be made to secure safe and suitable living arrangements...

Normalization

...minimally adequate habilitation cannot be provided at Pennhurst because it does not provide an atmosphere conducive to normalization, which the experts all agree is vital to the minimally adequate habilitation of the retarded...

...I believe the best atmosphere is created in a loving home. And that is where we ought to concentrate--on enabling individuals to live in their own home and neighborhood. Where this isn't possible or desirable, then it is best for people to be able to live in a setting where they are part of a community in which they can participate.

Intention

...to make certain that each and every retarded resident who is moved from Pennhurst can be accommodated in a community facility which will provide minimally adequate habilitation.

...I want a state that is compassionate, concerned, and committed to making the lives of each citizen in our Commonwealth, lives filled with opportunity and hope, not disillusionment and despair.

THE STORY OF JOYCE Z.

The story of Joyce Z. reveals a person who has escaped the system. At age 9, Joyce drowned in a backyard swimming pool. Joyce was revived by first-aid from the brink of death. However, Joyce suffered severe brain damage, which caused her to be dependent in every way.

At age 13, Joyce's rehabilitative stay at Pittsburgh's Home for Crippled Children ended because she could make no more progress. Child welfare and MH/MR officials petitioned Juvenile Court for a commitment of Joyce to Western State School and Hospital, a state-run institution.

Ginny Thornburgh, armed with extensive knowledge about Western and other institutions, informed Judge Maurice Cohill that Joyce's health and safety could not be protected in the institution. Ginny added that the health and safety of the current residents would be less protected by this commitment and further overcrowding.

Ginny's testimony was corroborated by state officials who verified the overcrowding, under-staffing, and lack of programs.

Judge Cohill entered an opinion, which is now a basic legal precedent. Joyce was guaranteed a right to treatment by the 1966 MH/MR Act and the United States Constitution. He found that the institution was unable to provide that required care and treatment.

A foster home was suggested as an alternative to Joyce's institutionalization. The Judge ordered, over the protest of county officials, that a foster home be sought.

County officials interviewed and rejected all 27 families who responded to the ads for Joyce's foster home. One of the families rejected included a nurse who cared for Joyce at the Home for Crippled Children, and her husband, who was a minister.

Not only had the family raised two grown daughters, but the wife was familiar with Joyce's needs and the necessary daily medical procedures to keep Joyce going. These "rejected" candidates for foster parents were further qualified by their unusual dedication and energy.

The Judge found the family to be acceptable. The family found the \$4.75 (\$2.75/day plus \$2.00 allowance) per diem unacceptable. The wife intended to quit her \$10,000 a year job to care for Joyce which she felt would be a very demanding responsibility.

Judge Cohill was informed that the cost of care in that state institution was \$35/day. Cohill ordered the family to be paid \$35/day. (Today, five years later, the per diem cost in the institution is \$101/day. The foster family still receives \$35/day.) The following update demonstrates how Joyce's abilities are flourishing while saving taxpayers \$24,000 annually.

Joyce Z. Update - July 1979:

A check on Joyce in July, 1979, reveals significant developmental progress and a loving home. Joyce's foster mother told of progress in all areas including: self-feeding, swallowing regular food, mobility, walking, toilet training, head and trunk control, lower medication doses, response to commands, verbal ability, attention span, and ability to relate to other people. You name it and Joyce has progressed.

According to the foster mother, Joyce now feeds herself almost independently, a major growth in five years. Joyce can take 10 steps independently and walks well with one hand assistance from another person. Joyce's wheelchair, her only means of mobility five years ago, isn't used now.

Joyce had no head or trunk control in 1974. She has it now.

Medication to control seizures made Joyce groggy. The dose has been successfully and drastically dropped.

Joyce now holds her urine and coughs to let her foster parents know she has to go to the bathroom. Joyce wet herself constantly when she first entered the foster family.

Best of all the improvements in her life, Joyce avoided entering the impersonal institutional life and instead belongs to a loving and dedicated family. The tender, loving care provided to Joyce is not replaceable and not found in institutions.

APPENDIX "D"

WILLIAM W. SCRANTON - GOVERNOR - (1965)

"Mentally retarded children and adults have for too long been denied maximum opportunity for fullest development of their potential . . . The citizens of our Commonwealth must now be made fully aware of the nature and scope of mental retardation so that local communities can provide the multiple needed services."

RAYMOND P. SHAFFER - GOVERNOR - (1970)

"This Administration has publicly announced its commitment to cut through bureaucracy, red tape, heartbreak, and despair with a revolutionary approach, including reducing resident populations at existing institutions for the mentally retarded, placing residential services in the communities where they belong and coordinating these services with the full range of community services."

MILTON J. SHAPP - GOVERNOR - (1977)

"All of these programs, and services make it possible for retarded persons of all ages to live, to work, to learn, and to be part of the community. It is this goal that we will continue to strive toward for every retarded citizen in Pennsylvania."

APPENDIX "E"

APPENDIX OF STATE DOCUMENTS WHICH SHOW THE COMPATIBILITY
OF D.P.W. POLICIES AND ACTIVITIES WITH THE COURT ORDER

1. Management Objectives
2. Program Objectives
3. Social Service Goals - 79-80 State Plan
4. The Department's Budget 79-80
5. Governor Elect Thornburgh's Study Team Report - 1979
6. Mrs. O'Bannon's Speech at Senate Confirmation Hearing
7. The MH/MR Act
8. The MH/MR Act Appendix IV 5200 Regulations
9. Title 5200 Regulations MH/MR - Service Content of Program
10. The Residential Services Position Paper
11. The Pennhurst Internal Reform and Dispersal Plan
12. The Admissions and Discharge Policy
13. The Community Living Arrangements Implementation Packet
14. Program and Budget Guidelines for Special Living Arrangements for Retarded
15. D.P.W. Position Paper on Deinstitutionalization - 1978
16. The D.P. W. Transition Document 1978
17. D.P.W. Abuse Policy
18. The Bolton Report
19. Case Management Position Paper
20. Adult Day Care Regulations
21. Family Resource Services Program Regulations
22. Vocational Rehabilitation Facilities - Regulations
23. The Vocational Services Position Paper

APPENDIX "F"

IN THE WORDS OF DPW OFFICIALS:

The Governor of Pennsylvania and the Department of Public Welfare are committed to developing and expanding opportunities in the community so that every mentally retarded person in this state can live, work, earn, and enjoy the benefits of living as normally as possible in the community.

The mass "warehousing" of people afflicted with this handicap, in isolated institutions providing only custodial care and little hope for return to their home or community, is no longer an acceptable alternative.

In asking his question, it never occurred to him that cruel and inhumane are adjectives which can well be applied to long-term institutionalization itself. For what can be more dehumanizing than shutting a person up in a world which is limited to a few buildings, or even a few hundred acres of land.

It is not only the physical confinement which is inhumane, but the barriers to the development of skills and abilities which results from long term institutionalization and dependency. For far too long, society and even the so-called professional experts believed that mentally disabled people needed to be isolated from the community. Every person has the rights to live as normally as possible within our communities.

Most people, when they think of group homes, think of the highest functioning retarded living in those homes and the lower functioning needing institutional care. Experience has shown that this is not the case, and even the severely and profoundly retarded can have their residential services provided locally.

The ever-increasing costs of an institutional program, which every year serves fewer people, limits our ability to adequately finance the community-based program which already serves five times more people and each

IN THE WORDS OF DPW OFFICIALS (con't) -2-

year serves more. It is a major objective of the Department to break this cycle, where the increasing demand of the state hospital system consumes the resources needed to develop a quality community program. . .

Only through sound planning and a rational allocation of resources can the cycle be broken. To facilitate this, I ask that you seriously consider combining the institutional MH/MR and the community MH/MR appropriations.

COMPARISON OF THE COMMONWEALTH'S EXPERTS' REPORT
("THE PENNHURST PAPERS") AND ASSERTIONS BY
COMMONWEALTH ATTORNEYS TO COURT OF APPEALS

Justice Department:

But, at bottom, the Eighth Amendment finding cannot be sustained in light of the abundant evidence of the many beneficial programs and services offered to residents. (P. 39)

Department's Experts:

Shortage of program staff is evident . . . (P.37)

Although the team visited at various times (early morning, weekdays, weekends and evening) there was little programmatic training by resident life staff observed. (P. 37)

Lack of sufficient programming. (P. 37)

Programs are developed and implemented at the convenience of staff rather than best interest of residents.(P.40)

Clients needing programming worse are denied it. (P. 40)

They do not know how to carry out programs--they are non-stimulating and they are care and custody rather than growth and human potential oriented. (P. 77)

The treatment sample revealed a serious lack of programs and activities for most residents. (P. 77)

The visual scene encountered everywhere--residents idly sitting, milling, sleeping or behaving in tension-reducing and bizarre manner designed to compensate for the lack of a meaningful social existence. (P. 77)

Particularly irresponsible, is the total lack of weekend activity and the total lack of indoor and outdoor exercise. (P. 77)

A custodial attitude prevails. (P. 142)

(Residents) were receiving zero activity daily. (P. 150)

About 80% of the staff time is taken up in custodial care. (P. 197)

As one enters the cottage, residents are seen milling around, sitting and sleeping on floors, in the hall or the day room. No programming was ever observed. (P. 229)

Once a resident awakens, he or she generally spends the remainder of the day either sitting or laying on the floor or furniture or roaming around the cottage. (P. 239)

Pennhurst remains an overcrowded, understaffed institution removed from society with inadequate programming. (P. 5)

An example of such a human warehouse is Pennhurst. (P. 293)

Justice Department:

The rationality of Pennhurst and like facilities is plainly obvious--there are presently no suitable alternatives which provide all of the necessary support and health services which are not provided at Pennhurst (P. 24-25).

Department's Experts:

It is the contention of this review panel that as long as Pennhurst continues to exist in any form, the service delivery structures for retarded citizens in Southeast Pennsylvania will be less than adequate. (P. 301)

The institution, in the opinion of this review panel, has no role, ultimately, and has an interim role, at best, a responsibility for facilitating its own demise. (P. 291)

Justice Department:

The crucial failing of the Court's Eighth Amendment analysis is its failure to identify even one incident of punishment.

Department's Experts:

Restraints and seclusion are used for punishment.

Justice Department:

In fact, the client security officer testified that in his seven years at Pennhurst he had witnessed only one incident of patient abuse. (P. 35)

Department's Experts:

While physical abuse was not observed, personal and psychological neglect abound and resident-to-resident injury was found to be common. (P. 77)

While there, more than one resident showed off an injury sustained the day before, and which had required a number of stitches. (P. 96)

Several pools of urine were on the floor and, of the three aides on duty, one was busily and conscientiously attending to a resident who had slipped on urine, causing a rather lengthy gash on his skull. At the time of arrival, 20 minutes had passed, and the physician who had been called had not arrived. Two aides were on break. (P. 143)

A profoundly retarded woman who had blinded herself through years of gouging her eyes (P. 146)

Serious psychological neglect and abuse of the residents, and a serious apathy toward resident-to-resident injuries (P. 155)

In December, 1976 an aide was fired from the Unit following a case in which he had physically abused a resident by "branding" the resident on this unit, . . . dismissal in 1976 for forms of abuse, mostly involving punching, shoving, tripping, or hitting (P. 198).

HIGHLIGHTS OF COMMONWEALTH'S EXPERTS' REPORT ON PENNHURST
FEBRUARY 1977 (THE PENNHURST PAPERS)

The authors, Alexander Hersh, S. Kenneth Thurman, and Valaida Walker, were commissioned by Department of Public Welfare to answer four questions raised by the Department of Justice. The questions concerned: What is the role of the institution? Is an institution an appropriate setting? Is Pennhurst an adequate facility? Can Pennhurst be made an adequate facility?

Their answers came in a 306 page report which found:

"The institution . . . has no role, ultimately, and has an interim role, at best, a responsibility for its own demise."

"Pennhurst is not an appropriate educational and treatment setting."

"Pennhurst, however, is not alone. No institution is an appropriate form of educational or treatment setting."

"Pennhurst is not an adequate facility." ". . . as long as Pennhurst continues to exist in any form, the service delivery structures for retarded citizens in Southeast Pennsylvania will be less than adequate."

The report, An Analysis of Pennhurst Center: Its relationship to Mental Retardation Services in the Southeastern Pennsylvania Region (February 1977, Confidential--for Authorized Eyes Only), is both well written and thorough.

The authors recommend:

- I. The closing of Pennhurst by moving all residents into the community by January 1, 1982
 - A. No admissions
 - B. Implement D.G.S. Project (Act 256)
 - C. Counties accomodate 20% of Pennhurst residents per year
 - D. Arrange for residents from outside Southeast Pennsylvania

II. The development of legislation to provide a mechanism which places funding with the client and puts the responsibility for service clearly with the counties.

A. Draft legislation by July 1, 1979

B. Introduce into General Assembly by January 1, 1980

III. Development of a plan to make use of existing Pennhurst physical facility

A. No additional appropriations for physical renovations

B. Turn over modular units to Chester County MH/MR by July 1, 1979

C. By January 1, 1980, submit an alternate use for Pennhurst

In summary the authors found Pennhurst to be "overcrowded, understaffed, institution removed from society with inadequate programming". They found Pennhurst to be "a human warehouse" whose "continued existence was intolerable".

The experts found Pennhurst was based on an antiquated model; providing no opportunities for programs to the clients who live there; isolated from the community at large; breaking up families, providing a tenuous psychological environment, dehumanizing residents, providing no privacy, placing residents in physical danger.

I suppose the "Pennhurst Papers" are secret and suppressed because they refute the Pennsylvania Justice Department's alleged facts and arguments which were made after the report. I guess the Commonwealth's "Pennhurst Papers" have been hidden because they closely parallel the findings and conclusions of Judge Broderick's opinion and order.