

4519 Sequoia Drive
Harrisburg, Pennsylvania 17109
July 27, 1979

The Honorable Dick Thornburgh
Governor
Commonwealth of Pennsylvania
Main Capitol Building
Harrisburg, Pennsylvania 17120

Dear Dick:

There are four reasons why you should stop appealing, and in fact, should vigorously implement the March 17, 1978, court order in the Pennhurst Case.

Reason I: The court order is consistent with the "Thornburgh position".

I assume you will disagree with no particular part of this order regarding retarded persons. Testing this assumption, I extracted the key service provisions from Judge Broderick's order and formed a checklist to see where you, at this point, agree with the court order. (See Appendix A)

I would be surprised if you dissented from any of the specific principles of the order.

In fact, a comparison between your major statement on human services and Judge Broderick's order demonstrates an almost identical vision for the lives of Pennsylvania's retarded citizens.

Although the contexts of the two statements differ there is a resounding similarity. The means to accomplish goals as well as the goals themselves are identical! (The Comparison of the two statements is made in Appendix B.)

On this matter, there is an abundance of evidence indicating clearly that the Judge and the Governor are in philosophic harmony.

For the same purpose, your wife has worked diligently over ten years to obtain the same action from the same parties that Judge Broderick now seeks. The bulk of Ginny's work does not need to be recalled here. But, the parts that were vital to the development of this case are terribly relevant.

For it was Ginny, and a small band of her fellow parent-volunteers who observed, uncovered and cried for reform of the inhumane treatment of persons in private and state institutions throughout this State. Ginny's message, and that of the other parents, was that care of retarded citizens in this State was shamefully inadequate and that major changes were essential.

The former State Administration responded immediately with appropriate short term measures. In his Pennhurst ruling, Judge Broderick promises to make that change, cried for by those advocates, unequivocal and lasting.

I see links between the Pennhurst case and the Thornburgh household. It was in the Thornburgh dining room, on Devon Road, that the need for the Right to Treatment law suit was discussed and strategies to begin it were developed. At another time in the Thornburgh living room, next to that dining room, Ginny and her fellow advocates insisted that PARC's state leadership initiate the class action suit. State PARC's indispensable involvement in Pennhurst is history. Steu Brown, former PARC President, informed me that you (maybe from the Thornburgh kitchen) suggested that PARC seek the U.S. Justice Department's intervention and assisted Steu by directing him to Mr. Stanley Pottinger.

Later, Ginny, as ACC-PARC President, sent four-hundred pages documenting inhumane conditions to the United States Justice Department, in the hope that Justice would enter Halderman V. Pennhurst and extend the impact statewide.

Importantly, the connection continues. One of the Federal Court's legal findings was that the 1966 Mental Health and Mental Retardation Act establishes the Right to Adequate Habilitation. The court in its opinion

(pages 65 to 67) cites Joyce Z., the first case where this law was so interpreted. The Federal Court was secure in leaning on Joyce Z. since more than forty cases referenced Joyce Z. and also found the Right to Adequate Habilitation. The case of Joyce Z. (summarized and commented on in Appendix C) would never have ever begun, nor concluded with Judge Maurice Cohill's precedent setting opinion, without Ginny's active participation.

And so, the Federal court order is consistent with the very concerns and objectives which brought the Thornburghs into public life.

Reason II: The order is consistent with state policy

For more than fifteen years standing, Governors of Pennsylvania, Scranton, Shafer and Shapp proclaimed as state policy the very essence of Judge Broderick's order. Retarded citizens should be provided opportunities in the community to develop to their maximum potential.

The Governors' statements (Appendix D) should be of no surprise, for this mandate is repeatedly stated in official state documents. A brief search found this direction expressed in state laws, regulations, guidelines, budgets, plans, goals, objectives, position papers, policies, press releases, speeches, testimony, study team reviews and consultant reports. (See Appendix E)

Often the direction was set most clearly by the Secretary of the Department.

"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." (Former Secretary Wohlgemuth)

"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." (Former Secretary Beal's November 1976 Speech to five hundred parents at an Allegheny PARC meeting in Pittsburgh.)

Since state policy has been so clearly pronounced by state leaders (see also Appendix F) and so often promulgated in official documents, it is shocking to see the states attorneys, in part, ignore, and worse--reverse the state's position in their arguments to the Court of Appeals.

In my opinion, the brief, unless changed at your direction or not submitted as part of a larger decision to stop appealing, will mislead the higher courts.

Numerous questions are raised:

Did the Commonwealth really mean to defend the institution or argue for its continued existence? Isn't this a reversal of state testimony at trial, that the state defendants also wanted Pennhurst closed? And doesn't this position directly contradict the Commonwealth's own experts, who concluded that Pennhurst is "providing an inadequate and inhumane, dehumanizing type of environment" and that Pennhurst's existence is "intolerable"?

Did the Commonwealth's lawyers believe that the level of services to Pennhurst residents was defensible? When our attorneys defended the level of service to the residents, had they read Pennsylvania's own experts' opinions, stating that there was: "a serious lack of programs and activities for most residents", "a custodial attitude still prevails", and Pennhurst is "a human warehouse"?

Were Commonwealth attorneys truthful when they argued that there was no punishment, implied that there was no abuse, and down played the detrimental effects of excessive drugging? Had our attorneys read the experts' report, written for them, concluding that the residents were in danger, that abuse occurred, that punishment happened and that Pennhurst was unsafe?

Could our attorneys have been knowledgeable about state policy and still opposed (1) the resident or representative being involved in the planning for their own future, (2) the enforcement of departmental regulations against

abuse, (3) the provision of friend/advocates to assist in the protection of rights, etc.?

The factual misrepresentations and reversals of state policy by Commonwealth lawyers are improper, at least, and, I believe, unethical. Department officials have not in recent years tried to justify Pennhurst's dreadful past or current conditions. Our attorneys are the first to defend this inhumanity!!

You should correct these mistakes and mis-statements.

The attorneys' brief to the higher court is routinely refuted (Appendix G) by, among other authorities, the Commonwealth's own top secret report. This report, An Analysis of Pennhurst Center: Its relationship to Mental Retardation Services in the Southeastern Pennsylvania Region (February 1977, Confidential -- for authorized eyes only), was written by experts hired by the Department of Public Welfare to answer questions raised to the experts by the Department of Justice. I think of it as "The Pennhurst Papers".

The 306 page report, plus appendices, was authored by Alexander Hersh, D.W.W., Associate Professor, University of Pennsylvania; S. Kenneth Thurman, Ed.D., Assistant Professor, Temple University; and Valaida Walker, former DPW Commissioner for Mental Retardation in the Southeastern Region.

Highlights of the "Pennhurst Papers" are extracted in Appendix H. The gist of the Papers is:

"the institution ... has no role, ultimately, and has an interim role, at best, a responsibility for facilitating its own demise." "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 authors support their findings by a couple hundred pages of ward by ward observations of inhumane conditions, care, and inadequate programming.

The Commonwealth's experts' and Judge Broderick's findings are strikingly similar. The Commonwealth's "Pennhurst Papers" call for the closing of Pennhurst by moving all residents into the community by January 1, 1982, exceeding Judge Broderick's deadline by one day.

The closing dates symbolize how close the court and the Commonwealth are on the entire matter. No wonder that Ginny asked during a DPW briefing, "If the Commonwealth and the plaintiffs are in agreement on all the basic principles and differ only on timing, then why can't we sit down and resolve the differences?"

In fact, Judge Broderick commented on the closeness both in his opinion and also his order (March 17, 1978 Memorandum, Page 3).

"As was pointed out in this court's opinion, the Commonwealth defendants agreed that the retarded should be removed from Pennhurst and readily admitted that the only reason that the litigation was necessary was because they wished to accomplish the closing of Pennhurst as a residence for the retarded, pursuant to their own schedule which was vague and indefinite."

Broderick expected a change in the Commonwealth's approach to the case when you became Governor. Raymond Broderick had a dream of court and Commonwealth cooperation. It must be hard for him to comprehend. Why, he asks, does this new Governor, a strong and responsible leader, who has compatible visions, resist, appeal, or seek a stay on every order?

Reason III: Implementing this order will bring improvements at no additional cost

State mental retardation officials agree that it will cost no more than presently being expended to provide services in small community settings rather than large rural settings.

Although much more detailed analysis needs to be done, a preliminary work-up (see Appendix I) by DPW show the cost in the community is less.

Today, we spend \$40,000 a year to keep a person at Pennhurst. One has to continually question whether an absolutely appropriate program for even

the person with greater than average needs should cost \$40,000, the average cost!

This is a problem which is not being adequately addressed. Frank Beal recognized the problem:

"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 every year serves more. It is a major objective of the Department to break this cycle ..." (See chart Appendix J)

This year your administration requested \$27 million more for institutions, which will serve fewer people, and \$20 million more for community programs, which will serve more people. The cycle is yet to be broken.

If newly appropriated dollars are still poured into the institutions, it must be nearly impossible to switch previously appropriated dollars from the institutions. Much work will need to be done with the Legislature, the bureaucracy, the unions, and the Feds. But it will not cost more! It very well may, as Broderick believes, cost less.

He may be right if Joyce Z. is any example. Joyce Z. was about to enter an institution at a cost of \$35 a day. Judge Maurice Cohill ordered a foster family to be paid a similar rate, which is still being paid today. In contrast, the cost in the institution, five years later has tripled to \$101 per day. Predictably, Joyce's abilities are flourishing, an event which would not have occurred in the institution, at a \$24,000 annual savings per year to Pennsylvania's taxpayers.

The plaintiffs have done some preliminary fiscal comparisons of the costs to serve the plaintiff class in the community or at the institution. The Commonwealth has yet to estimate the costs in the community or attempt such a comparison. The plaintiffs project significantly better care and training at less cost to the taxpayer.

The challenge is not how to raise more revenue; it is how to use current revenues in an effective and cost efficient way.

It is incredible that such basic fiscal planning has not been undertaken by the Department. The Department doesn't seem to care about using the tax dollar more efficiently. Nor does the Department have the ability to plan fiscally, programmatically, politically for the conversion from the institution to the community model.

The DPW performance on this issue diverges greatly from your Inaugural pledge to the people, "We promise a frugality - that insists on a dollars worth of service for every tax dollar spent." (\$40,000 per Pennhurst resident per year!)

Reason IV: Implementing the court order is the right action to take

A. The Special Master is needed to make the system work.

The Commonwealth, the Court, and the plaintiffs agree on what is best for the residents of Pennhurst. The court is merely pushing the Commonwealth to do what it all along has wanted to do but was unable to do.

There is evidence that the court's power is needed to make the system advance. One good example is case management, a necessity for individual planning and monitoring. The court has ordered and is overseeing changes in the case management system. The changes are those proposed by the Department.

It is generally conceded that the current case management system does not work well and that state law, which places this function on county governments, is being ignored. The Department recognized both of these facts and developed position papers to correct these problems.

After the Special Master adopted the Department's position and got the court to order this change, county officials finally began to comply with the law.

The Special Master and the court did what the Commonwealth had been unable to do since 1973 when it was proposed to affix a single point of responsibility for securing services.

Other needed changes are following. Individually adaptive wheelchairs are being provided. Individual habilitation plans are being written. Federal funding is being sought. Monitoring mechanisms to assure quality are being developed. Comprehensive planning is occurring. Suitable living arrangements are being planned.

Each of these activities, and others supervised by the Special Master, are mandated by state statute. For years, the Department and the county programs had not fulfilled these legislated responsibilities. Because of the court's and Special Master's clout, these crucial activities now happen.

The MH/MR Act also requires citizen participation in decision-making at all levels of the system. Repeatedly, the state has charged that the Judge and the Master are accountable to no one. Ironically, the court officials may be more accountable than Department officials to the public's views.

When the Special Master attempted to propose the plan to move children with only a court hearing and no public hearing, there was a massive outcry. Five lengthy court hearings were required to hear all the testimony. Scores of letters were written. Dozens of reporters covered the events. Many people expressed their views in a demonstration.

In contrast, the Department sets major policy on a daily basis, without even the interested parties aware that the issue is being discussed. The public's views, contrary to the Act, are almost never heard.

On July 3rd, 1979, Secretary Helen O'Bannon, acknowledged the need for the Special Master's office to exist. She recognized that the Master could cause desired changes, which the Department had been unable to bring about. Two weeks later, the Secretary instructed that a motion be filed to

put the Special Master out of business.

Perhaps Helen does not understand that the Department's failures are long-standing. She will learn that these are not momentary lapses. The Department has a disgraceful history of brutalizing retarded residents by failing to follow state law. The Federal court moved only to fill the void, caused by the Department's inaction.

Having abandoned its Pennhurst Dispersal Plan on March 20, 1979, the Department does not now have a plan to move Pennhurst residents to community programs. When the plan existed, the Department had only very limited objectives, which were never achieved.

The Federal court and Special Master are critically needed to make the system work!

B. Judge Broderick's legal findings are just

Earlier, I challenged the facts in the Commonwealth's brief to the Court of Appeals. Now, I question the broad legal assertions.

Pennsylvania contended that no legal rights were violated. Is it possible that Pennhurst's life-threatening, health-weakening, regression-causing environment is "legal"?

Broderick recognized in his Opinion (page 57),

"No constitutional mandate has been called to our attention which would require a state to provide habilitation for its retarded citizens. However, whenever a state accepts retarded individuals into its facilities, it cannot create or maintain those facilities in a manner which deprives those individuals of the basic necessities of life. In the case of the retarded, this constitutes an obligation to provide them with minimally adequate habilitation."

The Commonwealth disputes this. In its view, institutionalized citizens can be deprived of the basic necessities of life; no minimal level of habilitation must be provided. Pennhurst's history reflects this policy and its inhumane consequences.

Broderick found it is discriminatory and unlawful under the Constitution and federal statute to unnecessarily separate and provide less than minimally adequate services. The Commonwealth opposed this finding.

Individuals at Pennhurst should not be separated simply because they are retarded; nor should these individuals be denied services solely because they are segregated.

In spite of its attorneys' views, Pennsylvania has already demonstrated that retarded persons of all ability levels can benefit from community services. They need not be segregated!

On May 10, 1978, you said it so well:

"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."

Segregation of retarded people into separate and inadequate settings is not tolerable.

Broderick held that residents of state institutions have both an eighth and fourteenth amendment Right To Be Free From Harm. You know the misery caused by injury, death, abuse, and neglect in our state institutions. You need to know that the Commonwealth argued that Pennhurst's citizens are not entitled to be free from harm. Historically, they have not been free from harm. If the Pennsylvania Justice Department prevails, they will never be free from harm!

Broderick wrote:

"it is abundantly clear that the Mental Health and Mental Retardation Act, 50 P.S. Section 4201 et seq., grants to the retarded in Pennsylvania the statutory right to minimally adequate habilitation."

It was abundantly clear to Judge Maurice Cohill in Joyce Z.. It was abundantly clear to dozens of other Pennsylvania Judges. It was abundantly clear even to Pennsylvania Justice Department attorneys, who did not appeal Joyce Z.. It was not clear to the Commonwealth's attorneys who combat this

finding in Pennhurst.

However, in the first such case to be argued at the Pennsylvania Supreme Court, in Re: Joseph Schmidt, the Justice Department contends that the 1966 MH/MR Act guarantees a right to:

"adequate habilitation services that such individual requires"

and that the Court has the duty to order:

"the County MH/MR program to develop a more appropriate, less restrictive, community based residential placement."

Why does the state oppose the statute-based Right to Habilitation in Pennhurst, while completely supporting the finding in other cases? The contradiction is inexplicable!

During a briefing, Ginny asked why the Commonwealth appealed to the Third Circuit Court. The (acting) Deputy Secretary answered, "for legal and technical reasons". She added, "The program office did not recommend appealing".

Pennhurst has produced the predicament for some Commonwealth officials, who believe that the ruling is right for retarded people but not legally sound. A byproduct is the succession of legal arguments which do not represent our program's goals.

I suppose this is how some attorneys work. A good attorney might not be embarrassed to make these arguments; but, a good person would be ashamed.

Conclusion: The Thornburgh opportunity to contribute

Forever, the service delivery system for retarded citizens will need improvements. Your election drastically raised expectations of real advances.

Ironically, Raymond Broderick, raised expectations in a similar way during his campaign for Governor in 1970. To his credit, Broderick advocated long ago (see Appendix K) the very same ideals, now embodied in his Pennhurst ruling. Mr. Broderick is attempting to do something significant and lasting

for Pennsylvania's retarded citizens. Dick, now it is your turn!

You have an opportunity to avoid suffering for thousands. You could prevent the revisiting of "snake pits" and "hell holes" of the recent past. You could cleanly stop "warehousing" of human beings. You can give hope to fellow parents, who are concerned about their son/daughter's future, when they can no longer care for them.

You can lead the nation by setting an example of how to serve retarded citizens. Pennsylvania was the first state to operate institutions; it can be the first state to end this unnecessary segregation.

These are opportunities which are not likely to reoccur for decades. They certainly will not reoccur during your term of office.

I urge you to reexamine the Commonwealth's opposition to the Pennhurst ruling and its historical relationship to incarceration or services for retarded people. I will help in any possible way.

Only attitudes within the government prevent an incredibly constructive use of the Pennhurst ruling. In six months, not one Office of Mental Retardation official has remarked positively about this nationally hailed decision. The staff agree with the orders (like the case management reform) but fight them totally.

In a way, I'm reminded of the Vietnam War. We know the "enemy". We strike at the "enemy". But, we have a tough time remembering or explaining why we are mixed in this conflict.

Stop appealing and start vigorously implementing the Pennhurst decision! The order is both cost efficient and consistent with Thornburgh and Commonwealth policy. And it is just and needed.

Sincerely,


Robert Nelkin