

P.H. file

Report of Visit  
Pennhurst Center  
Spring City, Pennsylvania  
June 28-29, 1980

I. Introduction

At the request of the Office of the Special Master, Federal District Court, Pennhurst Center was visited by James D. Clements, M.D., and John W. Cooleedge, M.D., on June 28-29, 1980, for purposes of gaining an overview of medical and related services, with particular emphasis upon the institution's recent mortality experience.

The practice of medicine is both an art and a science. In a closed institutional environment it is imperfect at best due to the kaleidoscopic influences, both physical and mental, affecting clients' well-being. Observations of behavior or lack of behavior, so important in determining peoples' states of health, are difficult to collect consistently due to the multiple authority figures who in effect govern the lives of institutionalized retarded people -- a multiplicity brought on by staff turnover, reassessments, shift changes, overcrowding, etc. Even when data collection is consistent, its interpretation may be confounded by this fragmentation of authority figures, or by failure to consider physical (often medically-correctable) discomfort as a cause of severe misbehavior in those unable to verbalize their pain. It is therefore mandatory that the large, variable, and sometimes discordant group of individuals, both direct-care and professional, unify and meld their efforts on behalf of the people whom they control: precise observations succinctly recorded, carefully individualized assessments of needs, and skilled treatment techniques must be drawn together into genuine interdisciplinary practice. This principle surely applies most firmly to institutional medical practice: because of physicians' unique authority bestowed by law and custom

to order that institutionalized persons be treated in some particular way, they have the highest possible moral and legal duty to practice according to this standard. At Pennhurst, we find that for a wide variety of reasons this duty is often not fulfilled.

## II. Observations

Due to the limited time available for this visit, observations were necessarily selective rather than comprehensive. Prior to our visits we examined in detail portions of records supplied to us for over forty Pennhurst clients who had expired during the period March 1978 through June 1980: this review included death summaries prepared by physicians, and where available, autopsy reports. Some of these were designated for more detailed record review during our visit. In addition, in order to gain a perspective on current patterns of care records of several living clients were also examined on site, and observations made of these clients' living environment and general condition. Comments about a number of these clients will be offered below.

Records of deceased and living clients shared certain characteristics. We found gaps, sometimes of several months; in decedents' charts these gaps were often just prior to the terminal event. Progress notes were fragmented and multidisciplinary, creating hazardous situations: for example, one "discipline" staff member would note that the resident appeared ill while on the same day, on the same record, another would state that the resident was doing well. In many instances, in the records of deceased residents, it became obvious that signs of problems were present long enough before the

terminal event, that if heeded and acted upon could prevent death or mitigate the threat of serious accident or disease.

Item: resident J S , who died in January 1979 after strangling on a sock, was known to have passed a sock in his stool several days earlier; late the previous month he was known to have ingested yet another sock, and the next day a "non-nutritive substance". The medical response to these previous episodes consisted of an order that he wear "muffs" (presumably some kind of restraint mitten): no evidence could be found that the use of the muffs was monitored, nor that the behavior in question had abated; neither was there any evidence of attempts to eliminate the behavior through appropriate training.

Item: M N expired in May 1978 from complications of congenital heart disease. The record shows that cardiology consultation to evaluate the possibility of corrective surgery was recommended by an orthopedic consultant in October 1974; another consultant again suggested this in July 1975. Examination of the record shows no evidence that even the possibility of cardiac consultation was ever seriously entertained for this purpose by Pennhurst staff, let alone the possibility of corrective heart surgery.

Item: D B , whose death in March 1978 was attributed to status epilepticus (autopsy report) was taking four different anticonvulsant drugs: despite persistence of seizures averaging about once per month, no reports of nor orders for anticonvulsant drug blood levels could be found in his record.

Item: M H , whose death in October 1978 was attributed to seizures, had had a series of severe seizures on May 18, 1978, at which time he was taking Dilantin and phenobarbital. The attending physician increased the dose of Dilantin the next day, but blood levels of phenobarbital and Dilantin performed three weeks later showed that both drugs were still being given in sub-therapeutic amounts. Despite this evidence of inadequate therapy, during the remaining 4 1/2 months of the resident's life the physician neither changed the dose of these drugs nor documented any reason for not doing so.

The cases cited above typify the standard of medical care shown in the records which we reviewed. Problems of this kind could surely be ameliorated by better coordination and standardization of medical and medically-related care at Pennhurst, together with more consistent efforts by all staff members to identify and respond in a more sensitive and individualized manner to each resident's needs.

In literally all the records reviewed, of Pennhurst residents both living and deceased, it can be stated that documentation of the process of medical diagnosis and treatment is scandalously poor. Though it is often possible to trace (and with the use of informed imagination, to justify) the management of acute ailments (pneumonia, etc.), it is just as often not possible to do so with chronic ones. Multihandicapped patients regularly receive long lists of medications of various kinds while having no stated diagnoses, signs, or symptoms which would explain the drugs' use. In Capitol Hall I, for example (which we visited because of its rather high incidence of resident deaths), we commonly found residents receiving from six to twelve or more medications,

of which many have serious known adverse side effects, with literally no identifiable justification for using them. Why, for example, does Ms. F receive Thorazine and Valium? Valium, it might be speculated, relieves her spasticity; but nowhere is there an observation as to whether her spasticity is in fact improved by it: instead, one finds Valium reordered, month after month, in a shopping list of medications written by (presumably) a nurse and signed, by rote, by a physician. Does Ms. F show or not show tardive dyskinesia, a known side effect of Thorazine? We cannot tell from the record; all we know is that Ms. F receives Thorazine for an unidentified reason. Why has she for at least the past fifteen months received Tagamet, a drug indicated for short-term (a few weeks to a few months) treatment of upper gastrointestinal ulcers or bleeding? The record is silent on this. While we ourselves might in rare cases use Tagamet for longer periods than indicated by its present FDA-approved labelling, we would insist on proper documentation of the reasons for doing so, and the result thereof. Such documentation is absent from Ms. F's record. And why does she receive Dyazide, a diuretic capable of further compromising her already borderline hydration status, when there is no documented indication for it in her record?

While in Capitol Hall I we reviewed the case of A R, who has multiple motor handicaps in addition to a seizure problem for which she receives Dilantin. In recent months Ms. R has been in a poor state of health: she was admitted to a Pennhurst infirmary unit several weeks ago, and while there the concentration of Dilantin in her bloodstream was found to be excessively high. This problem was treated with good results in the infirmary, according to the record, and she was transferred back to Capitol Hall I: since then, according to the record and to staff members whom we interviewed, her condition

has again seemed to deteriorate, with progressive difficulty in maintaining adequate oral intake of food and fluids. It is our experience that inadequate food and fluid intake can result in concentration of drugs such as Dilantin to toxic levels, but no Dilantin blood level test has been done on Ms. R since the beginning of her latest deterioration. To us this suggests at the least inattention to a known risk factor. If such is not the case, it is not documented in her record.

The effects of poor documentation of the medical diagnosis/treatment paradigm are extensive. Pennhurst currently utilizes an "after hours" (night and weekend) medical coverage system which places a premium upon the ability of part-time physicians to assess and treat acute problems in residents whose long-term medical conditions, and the rationale for medications being used to treat those conditions, is at best occult and obscure. The same may be said of Pennhurst's own medical staff when a resident's regularly-assigned physician is absent for whatever reason (vacation, sick leave, etc.), the result is clearly a dangerous situation for any Pennhurst resident whose medical condition is fragile. This problem extends even to the formal annual physical exams which we generally found on most charts: these exams tend to be extremely sketchy and superficial, and generally conclude only with a single diagnosis of "mental retardation", even where powerful drugs such as Tagamet and Dyazide, which have no known use in treating mental retardation per se, are being used. One can only conclude from such documentation that drugs are being prescribed irrationally, or as is more probably the case, that drugs which have or once may have had some relevance to medical problems are being prescribed without continuing evaluation of the client's present needs. (The problem is compounded, incidentally, by use of two different forms for physical

examinations, varying from client to client: one of these forms is really only a "review of systems" which is quite inadequate for such use, not having even space for such essential information as vital signs (blood pressure, pulse, respiratory rate, temperature).

Use of psychotropic medications is particularly problematic. Orders for these drugs are regularly written without a precise statement or description of behaviors which they are intended to control. The result is that staff who provide day-in day-out care have no specific information concerning behavioral observations needed to assist physicians in assessing the effects of these drugs: consequently behavioral observations, when recorded at all, are couched in vague and highly subjective terms. This problem extends even to those clients who are regularly seen by a psychiatrist: this consultant's notes consistently contain recommendations for psychotropic treatment based on sketchy information whose source is not documented. The record of one deceased client, L C , contains an unfortunate example of the kind of therapeutic chaos which can result from this situation. Mr. C 's monthly Team Leader Note for May 1977 complains that the attending physician refused to prescribe psychotropic medication despite the psychiatrist's recommendation to do so, and suggests that this refusal constituted a violation of Mr. C 's human rights. Four months later the Team Leader reported that the Unit Director had appealed to the acting Medical Director for institution of psychotropic drugs. Two months later still, and again three months after that, the psychiatrist noted that Mr. C was receiving no psychotropic medications but behaving acceptably. Finally, in utter confusion over this series of events, the psychiatrist recommended (April 6, 1978) that Mr. C should "continue with current medications", even though he was receiving none, because he was "adjusting well to modular". With documentation such as exists at Pennhurst, the psychiatrist's confusion is hardly surprising.

### III. Programming

In the above section of this report we emphasized inappropriate and poorly-informed use of psychotropic drugs at Pennhurst; we did so because such practices are generally symptomatic of inadequate program planning and program execution. Developmentally disabled people are often unable to arrange their environment to suit their emotional needs, and resort instead to maladaptive behaviors. Using drugs to suppress these behaviors may serve as a convenient substitute for programs designed to help alleviate disability, but the long-term result is that disability is perpetuated rather than relieved.

Psychotropic medication is overused, and used as a substitute for program on a large scale at Pennhurst. In Quaker Hall (second floor) twelve records were reviewed. Eleven individuals were on psychoactive drugs, and one of these, R G , was on five psychoactive drugs simultaneously. In no instance of any record examined was there documentation of less restrictive methods of behavior modification being tried, nor did any of the annual Program Reviews reflect any serious attempt to address the issue of replacing psychoactive drugs with more constructive forms of behavior management. Indeed, the annual Reviews are so lacking in medical input (other than routine health-maintenance nursing matters) that we have the impression that Pennhurst physicians are not really looked upon as part of the program team, but rather as detached professionals whose actions are beyond the realm of team discussion.

Finally, we noted that the Pennhurst infirmary is being used as a "last resort" placement for residents who continue to exhibit unmanageable behaviors despite drugging. In the absence of even a trial of a program of carefully designed behavior management, this practice is clearly highly restrictive and inappropriate.

#### IV. Health-related environmental issues

One of the most serious problems observed, and noted from the records, which affects not only the mental and physical health of the residents but also their continuing general development and well-being, was their universal and all-pervasive idleness. While ultimately affecting residents' emotional and intellectual development, the most immediate and obvious effects are accident, injury, self-abuse, and abuse by staff. We observed repeated instances of staff abusing residents by shouting across the room to residents and to one another - a form of abuse which while it may be unintentional is one against which many residents have little defense, and little capacity to respond except through self-stimulation and other maladaptive behaviors. The abundance of aberrant behavior is a sign of Pennhurst's emotionally depriving environment.

We observed one lunchtime meal in Capitol Hall I, and saw a number of problems. Many wheelchairs were not properly adapted either for posture or for use at mealtime: some were too high to fit under the tables, requiring their users to reach too far to feed themselves comfortably; in others a built-on tray was so high as to make self-feeding awkward. Unsupervised stealing of food was noted. Non-self-feeding residents were being fed hurriedly, using the dangerous technique of raking food off spoons by drawing them upwards over the upper teeth - an open invitation to choking and aspiration. Rarely could we locate prescriptions for proper amounts of fluid intake, or records of urinary output.

#### V. Record-keeping practices

We have already mentioned two problems encountered in Pennhurst's record system: lengthy gaps in records, and use of different forms for annual physicals, at least one of which is not suited for that use. Another problem

is the way seizure records are kept. Staff members are instructed to record seizures individually on small slip-like forms which are later taped into the record, often mixed in with laboratory reports and other forms of similar size. While the convenience of this system may help insure that seizures are in fact recorded, we suspect that it may also be detrimental to medical management: instead of being able to see a running summary of seizures written down in a single place, the physician, in order to observe trends in seizure frequency and thus to correlate them with previous modifications of anticonvulsant regimens, must riffle through page after page of slips, abstracting dates along the way. Such a procedure is time consuming, and ultimately must interfere with timely and comprehensive anticonvulsant review. The fact that numerous deaths from seizures have occurred at Pennhurst suggests that this record-keeping practice is not only inconvenient but dangerous as well.

Physician progress notes are extremely difficult to follow because they are kept in different places, using different forms. Infirmary progress notes may or may not be on a form provided for that purpose; residential unit notes are kept on at least two different forms, one of which contains parallel columns for notes and orders, the other being for notes only. Physicians and nurses alike use these forms, and many of the nurses' notes appear to be substitutes for physician notes (for example, the nurse might record that "Dr. Jones examined Mary because of fever. He found such-and-such and prescribed so-and-so". This practice we consider hazardous, and believe that it should be used only in unusual circumstances, such as when the physician is called to another area for an emergency before being able to record his own findings. The net effect of these progress note practices is to fragment the record of the resident's care, making it difficult to audit and difficult to use, particularly for "after hours" physicians who may not have continuing familiarity with the case.

#### VI. Summary and Conclusions

Medical care at Pennhurst, for a variety of reasons, is inadequate. Viewed in terms of traditional medical care, Pennhurst residents do not receive periodic comprehensive assessment of their condition, their progress, and their long and short term medical needs. This leads, for example, to rote reordering of and exposure to side effects of drugs for which the original need has long since become obscure; inattentive seizure management; failure to evaluate chronic life-threatening conditions which may be highly treatable; and failure to take effective action to eliminate known life-threatening behavior.

In terms of contemporary standards of practice in a residential facility for the retarded, medical services at Pennhurst suffer most on account of almost total lack of participation in an interdisciplinary process of resident program planning, implementation, and review. The single most pervasive effect is that maladaptive behaviors are overwhelmingly dealt with by use of psychotropic drugs, which do nothing to promote development and may actually retard it, rather than by using behavioral and educational programs which if well-designed and carefully implemented can be a powerful adjunct to promoting development. The problem is compounded, however, by the apparent lack of the other services crucial to implementation of the interdisciplinary model, and by a sense of professional distance - even antagonism - between Pennhurst's physicians and its other disciplines.

#### VII. Recommendations

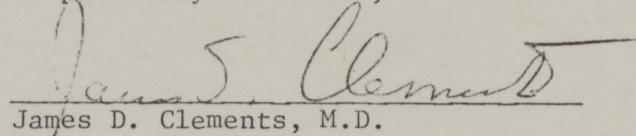
Many observations are offered in the sections above whose need for corrective action, and the nature of that action, will be readily apparent. Those offered below are intended to complement the foregoing.

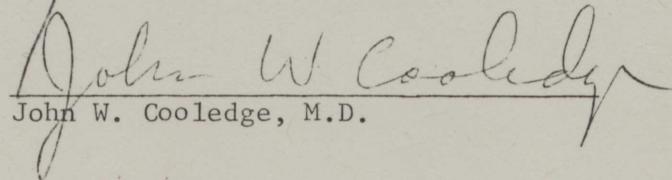
- 1) There must be a careful orientation of the new Medical Director to problems of Pennhurst's medical program.

- 2) Provide a continuum of "sensitivity" raising medical grand rounds monthly for one year. Then the effectiveness of this, including the need to continue, should be evaluated.
- 3) Provide a mandatory continuing education program for all physicians, emphasizing the interdisciplinary and developmental models. These programs are offered in many of the so-called University-Affiliated Centers.
- 4) Physicians' case loads should be no more than 100 clients.
- 5) Use of separate physicians for night coverage should be discontinued. Physician assistants might be employed full time to assist in night coverage as well as for other "physician-extender" functions including interdisciplinary team meetings.
- 6) Verbal orders by physicians should be minimized. When orders are written, the purpose of the order, expected results, and the more frequent side effects of the drug, if pertinent, should be recorded.
- 7) Progress notes of all disciplines, including physicians, should be melded, whenever possible, to present a more accurate and meaningful status report of the resident.
- 8) A critical review of long term medication should be done at least monthly, stating the purpose of the drug, results, and reason for continuing the drug.
- 9) There should be a monthly review of accidents, injuries, etc. for the purpose of instigating general preventive measures. Some of these might be the addition of programs (particularly behavioral programs), removal of hazards (slippery floors, etc.), better staff coverage at critical periods (getting up in the morning, bathing, feeding, etc.)

- 10) A clearer definition of use of outside resources such as outside hospitals, consultants, elective surgery, restorative surgery, etc. should be developed by the medical staff.
- 11) Ward records should be regularly reviewed for continuity, clarity, and pertinence.
- 12) The service of a nutritionist should be obtained to assist in ordering individualized diets from a standpoint of total calories, protein, fat, carbohydrates, minerals, vitamins, consistency, liquid intake, etc.
- 13) Staff who feed residents need special training in feeding techniques.
- 14) Provision should be made for adaptive equipment including, but not limited to, wheelchairs, walkers, crutches, braces, feeding devices, etc.
- 15) Monitoring of the use of psychotropic drugs should be considered at the meeting scheduled for July 21, 1980.

Respectfully submitted,

  
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