

NARRATIVE REPORT

PARC Visitors: Marlene Burda, Chairman, PARC Residential Services Committee
Teddi Leiden, PARC Region IV Vice-President

Date of Visit: December 19, 1975

Time of Visit: 10:00 a.m. - 4:30 p.m.

Buildings Visited: Nos. 3, 4, 5, and 6 I. U. areas.

I. Physical Surroundings

A. Exterior

Buildings are Mansfield-type construction. Exteriors are well-maintained. Proper safety conditions on walks were evident, with snow removed and walks and steps salted.

B. Interior

The interiors of all buildings were clean and relatively odor-free. In all buildings, the entrance hall, staff and visitors reception rooms were brightly decorated for Christmas with tree ornaments, posters, and wall hangings. This was in marked contrast to the living areas of the residents.

The "day rooms" in all four buildings were sparingly furnished, mostly with wooden benches and mats on the floor. In some areas, there were square chairs constructed of a plastic or vinyl material. While these chairs appeared to be somewhat more comfortable than wooden benches, it was evident that they were selected because of their "indestructible" qualities. They added little to the appearance of the room, and were uncomfortable to sit in. In addition, there were no drapes or curtains nor were their curtains or drapes on the windows of the bedroom areas. These are certainly necessary to insure privacy for the residents. The bedroom areas were devoid of decorations, and there is little or no personal furniture for storage of personal items.

PARC has a number of recommendations which, hopefully, can be initiated by Ebensburg to remedy the severely sterile and institutional appearance of the living areas in Buildings 3, 4, 5, and 6. It is suggested that Ebensburg contact the School of Design of Carnegie-Mellon University in Pittsburgh. Students from Carnegie-Mellon were most helpful in working at Polk in improving the environment of many of the cottages there.

It might also be possible to purchase more comfortable chairs with residents' personal funds. This, of course, would have to be done in conjunction with some behavior-shaping, so that residents could learn the proper care and use of such furnishings. This should certainly be a goal for residents in these areas.

In addition, the floors of the day rooms are barren and cold to the touch. Many of the residents were lying on the floors. It is recommended that some effort be made to carpet some of the day room areas. Once again, this has been done at Polk with some effectiveness. Area carpets, in standard 9x12 sizes, and bright colors lend a great deal of warmth to a large day room. Since most of the residents in these buildings are toilet trained, carpets could be used without fear of soiling. The carpeting need not be expensive, and it is hoped that some monies can be found in the Ebensburg budget for such purchases.

It is extremely important that the staff who work on the wards be involved in projects designed to improve the environment. It is suggested that Unit Administrators appoint "environment" committees, composed of representatives of the aide staff, to help in the planning and refurnishing of the living areas. This is very helpful in attempting to reshape staff attitudes toward the residents.

All of the above take time, imagination, and the commitment of both administration, and staff to undertake and complete these projects. However, if the total environment, comfort, and privacy of residents is to be assured in these buildings, this commitment should be easily obtained. It has been done at other institutions in Pennsylvania. It can be done at Ebensburg.

The halls and living areas were quite clean, as were the cafeteria and kitchen areas.

II. Food and Food Service

Food is served in a central cafeteria in each building. Residents stand in line, get a portion of food, and carry it to their tables. When finished, residents carry trays back to a depository area, where the trays are washed off by aides. This is an extremely institutional approach to the serving of food, and one which should be changed gradually.

A more desirable approach is family-style dining. This does take time, and, once again, a rethinking of the institution's "old way" of doing things.

At one time, Ebensburg was moving in the direction of initiating family-style dining. Why were these plans not implemented? The Superintendent outlined these plans in July, 1974. To date, at least in Buildings 3, 4, 5, and 6 cafeteria dining is still in effect.

There was also a feeding program in effect in many of the buildings at Ebensburg last April. This feeding program was observed by one member of the team during Parent Days in April. This program was also written up in Challenge, the DPW Magazine, in an article which covered activites of Parent Days. I. U. staff and aide staff were actively involved in feeding programs in various buildings, as observed last April. However, during this visit several aides revealed that the I. U. was no longer involved in the self-feeding program, and that the program was not being carried on as it was last April. What has happened to the program? Aide staff indicated that school-age children are returned to the living areas by teachers before lunch, and picked up again after lunch. Is there some reason why this very worthwhile program has been phased down?

It was also observed that each "ward" (1 West, 2 West, 1 East, 2 East) eats separately. The total time allotted for lunch is approximately 1 hour. This means that residents have little more than 15 minutes in which to eat. We observed residents being hurried through the luncheon meal in Building 4. This is certainly a very poor nutritional practice, and it would seem to violate the resident's right to eat meals at his or her own pace.

There was also some question as to whether or not seconds were available. In one Building, staff said that no seconds were available. The Superintendent indicated that second helpings should be available for all residents when requested.

It is recommended that former plans for family-style dining be revived and restudied. In addition, it would be helpful to call in a dietary consultant. Penn State University would be a useful source. It is also suggested that you might contact Mrs. Galloway, former head dietitian at Polk, who was successful in initiating many changes there, including

family-style dining. Once again, it is recommended that aide staff be involved, perhaps in a Dietary Committee, in each building in planning changes in the Food Service Area.

III. Clothing

In every area visited, the clothing of the residents ranged from poor to completely inappropriate and inadequate. It was also revealed that there is a laundry problem existing at Ebensburg, resulting in shortages of many clothing items as well as linens. In all of the buildings, aides noted that many residents did not have enough clothes, and it was necessary to "borrow" clothing from other residents' supplies.

This resulted in residents being clothed in clothing too large or too small, no brassieres for women in Building 5, and a predominance of "state made" clothes. In Unit 4, 1 West, no less than 7 young men were dressed in the same type and color of trousers and T-shirts. In Building 5, one young girl was wearing tight red shorts and a tight fitting short sleeve T-shirt, even though the temperature outside was well below freezing, and the young girl was, supposedly, in a school program.

Beyond this, residents' clothing was wrinkled and, in many instances, torn. The clothing worn by the residents, generally, detracted from their appearance.

The Superintendent advised us that a committee had been formed to look into the laundry problems, and that several solutions were being suggested. These include: buying more clothing, reviewing and revising distribution and pick-up schedules, and sending representatives from Selinsgrove to get other suggestions. Since this problem presents a definite hardship to the residents, including a possible health hazard due to lack of clean linens, PARC requests a complete report on the laundry shortage, and what positive steps have been taken to alleviate this condition.

In addition, it is recommended that Ebensburg request to purchase resident clothing from a commercial manufacturer, rather than Prison Industries. Clothing from Prison Industries, used in institutions across the State, is inferior in quality, style, and durability compared to that of commercial manufacturers.

As advocates for the residents of Ebensburg, the Ebensburg administration should insist that clothing should be of better quality and personalized as to style and fit for each resident. This matter should be discussed with the Regional Office. PARC would appreciate being advised of Ebensburg's efforts to purchase attractive and suitable clothing for residents. This is one recommendation outlined in the "Design for Living" which the Secretary of Public Welfare has stated, in writing, would be implemented.

IV. Linens

Residents of Ebensburg do not have a personal linen supply. Aides on several units advised the team that very few washcloths were available, towels had to be shared, and residents could not be kept clean. Washcloths shown to the team were thin and scarcely usable. This is an inexcusable condition, and one which must be solved as quickly as possible. The lack of washcloths and towels has serious health implications. Would you please advise PARC what action will be taken to assure an adequate and personal supply of washcloths and towels for each resident?

V. Appearance of Residents

In general, the physical appearance of the residents of Ebensburg was extremely poor. This is a result of a number of problems already mentioned. The first of these is clothing.

In addition, it was evident that the dental needs of the residents are not being met. In every building, there was evidence of severe dental problems. Residents' teeth were filled with cavities and yellowed by neglect. There is great need of corrective and restorative dentistry. The Superintendent indicated that a dental hygienist had been hired. This should help somewhat, but beyond this, there exists the need for at least another full-time dentist or 2 part-time dentists. The Superintendent also indicated that there was no dental equipment for the hygienist, nor any clinic space or equipment. What about the possibility of using community services?

It is recommended that a dental team from the University of Pittsburgh Dental School be asked to make a survey of the dental needs of the residents of Ebensburg, and that their recommendations receive top priority from the Department of Public Welfare. PARC requests that this agency be kept advised of efforts to upgrade the dental care for residents of Ebensburg, including results and recommendations of any studies conducted in this area.

In the area of personal grooming, a number of problems were observed by the team. In Unit 5, the hair of the girls and young women had been cut so short and styled so badly, that it was difficult to determine whether the residents were men or women. In instances where the hair was somewhat long or curly, it was matted, uncombed, and appeared to be dirty. There was no evidence of any effort to improve the appearance of these girls and young women through attractive hair styling. Men and boys likewise had "institutional haircuts". Many were unshaven, and their appearance was unkempt.

It was evident that the physical appearance of the residents was not a priority in any of the buildings visited. This not only denies the residents' right to dignity, it also connotes an institutional attitude toward the residents. There was little evidence of any personalized approach to improving the physical appearance of residents. This is intolerable. It connotes to others that these residents are less than human--that their physical appearance "doesn't count".

It is recommended that the Unit Managers in each of these buildings initiate a program of enhancing the physical appearance of residents. Haircuts which detract from the appearance of women should be prohibited, and beauticians who work with residents must be advised that hair will be attractively styled, not cut for convenience. A schedule for shampooing of hair, and a program of grooming skills should be devised in each area. Again, aide staff should be included in developing plans to help residents look as attractive as possible. There must be a commitment on the part of all staff to improve the appearance of residents. Certainly, this will help to enhance the resident's image of him or her self, as well as the image he or she conveys to the staff.

In yet another area, which is even more crucial, it was observed in each of the buildings that residents appeared to be excessively drugged. In general, they were lethargic and very slow to respond. Many of the residents were lying on mats, sleeping, or sitting on benches gazing blankly at the room. Very few residents reacted to the presence of visitors. They moved slowly, spoke very little, and appeared very tired. Considering that many of the residents did very little all day, and were described as "hyperactive", this suggested that most of the residents were being maintained on tranquilizing drugs. This was confirmed by several staff, and will be expanded in the section of this report dealing with medical and dental care.

It was also noted that many residents in at least two of the buildings (4 and 5) were marked with enough scratch and other marks so as to be quite noticeable. It is unreasonable to guess at the cause of these wounds. However, it is suggested that staff on these units look into this problem and suggest a workable solution. Once again, this area will be expanded upon in the section of this report which deals with programming.

IV. Program

It was extremely difficult to ascertain just what kinds of programming are available to the residents of Ebensburg. Aides were either very vague about what the residents "do" or were unable to answer questions asked about programming.

The I. U. Program is a case in point. Building 3 (1 West) has 31 residents. Aides indicated that 9 children participate in the I. U. program for approximately 4 hours a day. There was, according to staff, no programming other than some play therapy and re-creation for the other residents. One of the aides in this unit pointed out one resident who had regressed so badly in one year that he can no longer walk. Beds in this unit were cribs and were completely inappropriate for the age and size of residents.

In 2 West of this unit, the staff was again very vague and indicated that there was very little programming, but that four of the residents had just started in an "over 21" class. In 1 East, the PT team helps once in awhile. In 2 East, aides claimed that the PT team did toileting training, but very little programming was available for residents.

All of these areas (with a total of 124 residents) were locked. In each area, staff indicated that residents would "run away" if the doors were open. When questioned about behavior shaping in order to eliminate some of the locked units, aides claimed that they had no knowledge of any such program, had not been trained in any kind of behavior therapy, and could not cope with the residents if the doors were opened.

The same conditions and responses to questions were echoed by staff in Buildings 4, 5 and 6.

In Building 4, the team was advised by Staff of 1 East that there are 32 residents under the age of 21. Only 26 of these residents have classes part-time, 4 are in deaf education, and 5 attend school all day. In Building 6, 1 West, only 3 of 36 attend a full day of school.

Another out-of-state observer noted lack of programming (see attached letters to Charles Inlander).

In view of the Right to Education mandate, PARC requests a full accounting of the educational program of each Ebensburg resident. If this mandate is not being met, it should be brought to the attention of both the Local and State Task Forces on Right to Education. I. U. 8 is responsible for providing a full day's educational program for each resident at Ebensburg to age 21. If this is not being done, the Ebensburg administration should assume an advocacy role and enter due process proceedings against the I. U. in each case.

Limited classroom space is available at Ebensburg. However, it is the responsibility of the I. U. -- not the institution -- to provide an educational program for each resident. It is the responsibility of the administration of Ebensburg to make certain that the I. U. meets its responsibilities.

Beyond the educational deficiencies evident at Ebensburg, it is evident that the School is in desperate need of assistance in the area of behavior modification and programming. At least 480 residents of Ebensburg are literally "locked up" daily because staff cannot cope with behavior problems. This is an appalling statistic and is cause enough for grave concern by PARC for the residents of Ebensburg.

Over and over again, staff (including aides, two Unit Administrators, and I. U. staff) repeat their view that nothing could be done about the locked doors in 16 wards of Ebensburg because: "the residents would run away", "we couldn't handle them", "they'd be on Route 22 in minutes", "half of the staff would quit if we opened the doors", etc.

Upon questioning, aides indicated that if any behavior modification or training was going on, they were not involved. Yet, the Superintendent informed a team member that "there are 609 behavior modification programs written for the residents of Ebensburg". PARC has a number of questions:

- A. When were these programs written?
- B. Who was involved in developing individual programs?
- C. Who is responsible for implementing individual programs?
- D. Has aide staff been trained in utilizing behavior shaping techniques on every shift? One shift?
- E. Why are these not being implemented?

If individual programs have been written to deal with the hyperactive behavior of residents locked in Buildings 3, 4, 5, and 6 this is indeed an important first step. Providing staff with the training and expertise to implement these plans, however, is a challenge to which Ebensburg, Central Region, OMR and DPW must make a complete and immediate commitment and provide outside consultation, training programs, and whatever else is needed to move this institution forward programmatically. It is recommended that OMR, the Regional Office, and the Administration of Ebensburg meet immediately to discuss what must be done to initiate action in this critical area. There exists expertise in Pennsylvania, as has been proven with a similar problem at Western State School. Beyond this, the use of expert consultants in other areas of behavior modification is also suggested -- especially if such experts can be involved in staff training.

The I. U. Staff is attempting to deal with the more severe behavior problems referred to one class by the Psychology Department and Behavior Modification Committee. The class serves 10 students, while 108 referrals have been made. This would suggest that Ebensburg might bring this problem to the attention of the I. U., the Local Task Force, and the State Task Force, if necessary. Most certainly, the Department of Education should be made aware of the need of these 108 residents for an educational program emphasizing behavior shaping.

The head of the I. U. program also indicated that his program is hampered because of a lack of cooperation between his staff and the medical staff. He expressed concern about the effect of excessive drugging on the students in the class. He also cited several examples where medication was changed, without notification to the teachers. This resulted in dramatic changes in the students' behavior, while staff were at a loss to explain this change. The problem of drugging was discussed again with the Superintendent and will be expanded further in the section of this report dealing with Medical and Dental care.

The problem compounding the lack of behavior shaping programs for the residents of Buildings 3, 4, 5, and 6 is the total lack of programming -- period. The majority of these residents have very little or no meaningful program at all. Their day is spent confined to the wards, with sporadic play therapy, physical therapy, or recreation. This presents the classic institutional syndrome: residents with nothing to do; staff untrained to provide meaningful programs; inadequate staff to resident ratios (on the average, 3 to

30 on the 11-3 shift); residents drugged into a state of lethargy; an environment which contributes to the residents' handicaps and causes further regression, acting out, and aggression.

In summary, the lack of meaningful programming for the residents of Buildings 3, 4, 5 and 6 has contributed to their retention in one of the most restrictive types of institutional environment -- the locked ward. This is a critical problem at Ebensburg.

VII. Dental and Medical Care

There exists a crucial need for an emphasis on dental care for the residents of Ebensburg. Little more than basic dental care is provided, and this consists of basic checkups, fillings or extractions. The needs of the residents for corrective and restorative dentistry is evident.

There is also a critical need for dental hygiene. Although one hygienist has been hired, the Superintendent indicated that the hygienist will be hampered by lack of space and equipment.

This, again, is an area which should be looked at very carefully by both DPW and the Department of Health. Neither Department has adequately fulfilled their obligations to institutionalized residents in the area of dental care. The result has been undue suffering and hardship for residents in all State Schools. Clearly, institution staff must assume a more assertive advocacy position in making certain that this basic minimum of care is provided for Ebensburg residents.

In the area of medical care, an even more urgent and pressing problem was brought to the attention of the team by aide staff, I. U. staff, and the Superintendent. This is in the area of drug usage at Ebensburg. Aide staff claimed that residents were heavily drugged with high doses of tranquilizing drugs. I. U. staff made the same claim. The Superintendent confirmed the drug problem was so widespread that Staff was in the process of doing an in-house study of drug usage by doing individual studies of residents' drug charts. According to the Superintendent, the idea of the drug study was to gather data about drug usage at Ebensburg and, to quote the Superintendent: "to ask some questions of the medical staff about excessive drug use".

It is the feeling of this Association that even the suspicion of over-medication on the part of the staff and Superintendent is a problem of such significance that it should be investigated by a source outside the institution. PARC must ask:

- A. Was the Regional MR Commissioner informed of this suspected drug abuse?
- B. Was the Regional Deputy Secretary informed of this problem, and asked to send in a team to investigate?
- C. Was the Secretary of Welfare asked to investigate this problem?
- D. Did all of the above refuse to act on the problem, assigning the investigation to an in-house committee of Ebensburg staff?
- E. When was this study begun?
- F. When will the results be compiled?
- G. What will be done with the results of the study?

The alleged abuse of drugs presents many serious legal and ethical questions. It seems that the Ebensburg Administration, if a drug problem was suspected, should have sought investigative help, advise, and legal counsel from the Department of Welfare and Department of Health. Many serious medical and legal ramifications could be involved if, indeed, drug abuse is occurring at Ebensburg. This seems like a heavy burden to place on a committee. If drug abuse was suspected, experts in this area should have been brought in to thoroughly search medical records, rather than relying on an in-house staff survey.

PARC, therefore, asks for a full and complete investigation of alleged drug abuse at Ebensburg by qualified medical experts from the Department of Welfare and the Department of Health. PARC requests further that the results of this investigation be made available to PARC, upon completion, and that such results include necessary actions which must be taken to eliminate drug abuse, if such abuse is, in fact, proven.

The Team did not have a chance to survey medical records to determine if proper medical care is being provided. However, in light of the allegations of drug abuse, and the apparent physical malaise, lethargy, and thinness of the residents of Buildings 3, 4, 5 and 6 PARC is also requesting that a medical survey of Ebensburg be conducted by the Department of Public Welfare and Department of Health in order to assure that basic medical needs of these residents are being met.

VIII. Staff Attitudes

The team both observed and talked with staff extensively during the visit. There is no question that aide staff at Ebensburg has been provided with a bare minimum of training. Staff expressed very negative attitudes about residents' ability to live in unlocked wards. Staff indicated that they were not included in developing individual programs, were not informed about educational programs, and were not trained to be involved in programming for individual residents.

Many staff could not even outline who was in what program, for how many hours, what the program included, etc. It was even difficult to determine how many residents were in school programs and for how long each day. Aides in every building denied any knowledge of any type of behavior modification programs and stated that they had received no training in behavior modification techniques. Two Unit Administrators stated bluntly, "If we open the doors, the residents would run away. Half the staff would quit!"

In Unit 5, the Unit Administrator showed the Team a very well decorated and pleasant room. There was a Christmas tree, many new toys on shelves and on the floor, and five cushions on the floor. She explained that residents would be brought from the locked wards "four or five at a time" to "play with their toys" in this room. These residents would then be taken back to their locked wards while the next five were brought in, etc. While this is a laudable attempt on the part of the Unit Administrator to bring some Christmas pleasure to each resident of Unit 5, it would seem that with 60 residents on this East wing, using the room 5 at a time would average out to each resident (hopefully) being allowed to play with these new toys for 1 hour on Christmas Day. This would have taken approximately 12 hours.

Did these residents have even 1 hour to play? Was there enough staff on hand to "supervise" them?

Just this incident points out the terrible need at Ebensburg for staff retraining and staff involvement in the individual programs for every resident.

To further illustrate the incredible difference between staff expectations and resident involvement, in each of the buildings visited, the halls, staff lounges, visitors' lounge were creatively and attractively decorated for the holidays. Sporadic Christmas posters were hung on the walls -- at least at an 8 foot level -- seemingly so residents could not destroy the decorations. In Building 6, the team asked if the residents had seen the decorations in the halls. Staff didn't know.

All of the above incidents confirm a staff attitude. This attitude seems to be based on fear of the residents' behavior. There was a pervading atmosphere of helplessness and hopelessness in these areas. Aide staff seemed incapable of coping with residents' behavior and seemed to feel nothing could be done to control the residents.

These incidents confirm the teams contention that Ebensburg staff is in need of a great deal of re-training. Aide staff seemed concerned, but helpless to change conditions. They simply do not seem to have the know-how to deal with the residents on any other basis than minimum custodial care.

This is not to say that staff members were uncaring. Many of the staff expressed their concerns at their inability to deal with the needs of the residents. Their basic concern seemed to be that they had to control the residents and to keep them from hurting themselves or others.

In addition to training, staff need to be involved in every phase of the residents' daily living -- his or her program, medical program, dietary program, recreation, dental hygiene, self-help skills, etc. Aides are now excluded from this process, and seemingly left to a "catch-as-catch-can" approach to meeting the needs of the residents. It is easy to blame staff for lack of programming. However, at Ebensburg, this condition is so pervasive that blame must be directed toward each area which should be involved in teaching aides the skills they need to work with residents.

IX. Residents Rights

A perusal of this report would indicate that the rights of residents of Buildings 3, 4, 5 and 6 are violated daily at Ebensburg. The team did not examine the residents' rights to receive mail. However, it can be assumed that residents who are locked up daily in wards do not have access to telephones. It was observed that residents' personal possessions are locked up. It was observed that residents' rights to privacy were violated. It was observed in Building 4, East 1, that residents' rights to a full lunch hour were violated.

Residents rights in Building 3, 4, 5 and 6 were violated so often as to render this section of the report redundant.

X. Summary

The Team felt that Ebensburg State School, in Buildings 3, 4, 5, and 6 were in such complete violation of every standard known, that the lives of these residents were threatened beyond acceptable limits. This is not to say that these residents reside in any kind of physical threat to their well-being (such as fire and safety hazards). However, beyond this, residents of these buildings live in the most restrictive environment possible in an institution (the locked ward) without the programming they need to free them from this environment.

This Association demands that action be taken within the next 90 days to alleviate all conditions detrimental to the welfare and well-being, as well as growth and human dignity,

of the residents in Buildings 3, 4, 5, and 6 outlined in this report. Further, this Association requests that it be informed of plans to alleviate the very serious conditions outlined in this report and be kept informed of actions taken to correct these conditions.

Respectfully submitted,

Marlene Burda, Recorder