



P R E S S   P A C K E T

JANUARY 8, 1979

FORMAT

OPENING STATEMENT -- Marlene Burda, Spokesman  
Allegheny County A.R.C.  
Pennsylvania Association for Retarded Citizens

FINDINGS OF DENTAL INVESTIGATION -- Jay I. Reznik, D.M.D., M.D.S.  
Director of Dental Services, Western  
Center

HISTORICAL BACKGROUND -- Elsie Schmidt, Past President  
PARC INVOLVEMENT

WORTH -- Developmental Disabilities Advocacy Network

MRS. GLORIA MITCHELL -- Parent of a Resident of Ebensburg Center

QUESTIONS AND ANSWERS

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I

A JOINT STATEMENT AND DEMANDS OF THE FOLLOWING ADVOCACY  
ORGANIZATIONS:

Pennsylvania Association for Retarded Citizens (PARC)  
Developmental Disabilities Advocacy Network (DDAN)  
Westmoreland County Chapter, PARC (WCARC)  
Armstrong County Chapter PARC (ACARC)  
Allegheny County Chapter PARC (ACC/PARC)  
Indiana County Chapter PARC (ICARC)

JOINT STATEMENT

Pennsylvania Association for Retarded Citizens  
Allegheny County A.R.C.  
Westmoreland County A.R.C.  
Armstrong County A.R.C.  
Indiana County A.R.C.  
Developmental Disabilities Advocacy Network (DDAN)  
Jay I. Reznik, D.M.D., M.D.S., Director of Dental Services, Western  
Center  
Mrs. Gloria Mitchell, Parent of Ebensburg Resident

Ladies and Gentlemen:

We have called this press conference today to bring to the attention of the media and through you, the public, a scandalous example of the gross physical abuse and official neglect of the dental needs of mentally retarded residents of Ebensburg and Cresson.

The pictures which provide the backdrop for this conference are neither abstract art nor hallucinations caused by drugs or pictures put together by a photographer for effect.

These are actual pictures of the mouths--the teeth, the gums, of people. These are people much like you and I in many respects. They are mentally retarded or developmentally disabled. They are residents of a State Institution for the retarded. Primarily they are people with pressing, serious, painful, dental problems. These people are the victims of long standing bureaucratic neglect of a basic health need--clean teeth, healthy gums, repair of dental problems such as cavities, abscesses, gum disorders, decayed teeth which hurt--which need immediate treatment.

This is not a problem which is new. The neglect you see didn't happen over night. The groups represented here have brought the lack of dental care in state institutions to the attention of the Department of Public Welfare and Officials for years. Little has been done to correct this situation.

Today you will see more. You will be given documents outlining what has been found. You will have documentation of our attempts to correct this situation--attempts which date back to 1975.

What you won't see are the faces of the people. You won't feel their pain.

Today we are demanding that immediate action be taken at Ebensburg and Cresson to treat the cavities, abscesses, gum and teeth disorders of the residents of Ebensburg and Cresson State Centers. This treatment must begin not 3 months from now or

6 weeks from now, but next week. We are demanding and we want guarantees that next week, people who need dental care will, in fact, be in the offices of qualified dentists receiving this care. Beyond this, we demand that a dental investigation be conducted in every institution for the mentally retarded by qualified dentists trained in dentistry for handicapped people.

We want to be assured, and we want the parents of the residents of Ebensburg and Cresson to be assured that these appalling dental conditons will be corrected immediately--that their children will be taken care of--now! We want a guarantee that in 6 months, a year, two years and henceforward,qualified, trained dentists will be providing quality dental care for all of the residents of Ebensburg, Cresson and other institutions for the mentally retarded.

These demands as well as several others are attached to this statement and we expect an immediate public response from the DPW.

All of us here today pledge that until these goals are achieved we will use every means possible at our disposal, and all the resources we have to put an end to present sub-standard dental care not only at Ebensburg and Cresson but at all Centers where such cases or physical abuse exists.

II

Excerpts from the 1975 PARC Residential Services Committee concerning conditions of Ebensburg Center and responses by then Secretary Deal and Superintendent Herman.



# Pennsylvania Association for Retarded Citizens

1500 NORTH SECOND STREET • HARRISBURG, PA 17102 • TEL. (717) 234-2621

MRS. ELSIE SCHMIDT  
President

PETER P. POLLONI  
Executive Director

January 9, 1976

The Honorable Frank S. Beal  
Secretary of Public Welfare  
Department of Public Welfare  
P. O. Box 2675,  
Harrisburg, Pennsylvania 17120

Dear Frank,

Enclosed is a report by the PARC Residential Services Committee concerning a recent visit to Ebensburg State School. The conditions found at that institution were quite alarming, particularly in the areas of: programming; drug abuse; restriction of movement by residents; staff attitude toward and knowledge about residents; clothing; medical and dental care; and privacy.

In light of the serious problems outlined in the PARC report, as well as observations made in a confidential report by several visitors from out-of-state, we are hopeful that you will read the material in its entirety and advise this Association of the Department's plans for correction.

Copies of these materials have also been forwarded to Ford Thompson, Deputy Secretary of Central Region.

We look forward to hearing from you in this regard.

Sincerely,

Elsie Schmidt, President

Marlene Burda, Chairman PARC  
Residential Services Committee

ES:MB:rmh

Enclosure

cc: Thompson  
Meyers  
Polloni  
Leiden  
Gorlow



## Pennsylvania Association for Retarded Citizens

1500 NORTH SECOND STREET • HARRISBURG, PA. 17102 • TEL: (717) 234-2621

MRS. ELSIE SCHMIDT  
President

PETER P. POLLONI  
Executive Director

January 9, 1976

Mr. Harry Herman, Superintendent  
Ebensburg State School  
Ebensburg, Pennsylvania 15931

Dear Harry,

I have enclosed a narrative report of our visit of December 19, 1975. The visit to Ebensburg was one of a series of on-site, unannounced visits to all State Schools in Pennsylvania which are being carried out by PARC, through the State Residential Services Committee and local ARC representatives.

The narrative report follows a format established last August by the Committee and has been applied to each visit. The narrative reflects conditions as observed during the time of the visit.

I wish to thank you and Mr. Smith for the courtesies extended to myself and Mrs. Leiden. Mr. Smith was most helpful. Your staff, too, are to be commended for their frank replies to our questions.

It was also very enlightening to be able to sit down with you and discuss many of the problem areas evident after the visit to Ebensburg. Your candor and eagerness to discuss possible solutions were appreciated.

As I told you, PARC is most anxious to bring problems to the attention of DPW, the Regional Office and the Intermediate Unit. If positive and constructive change is to come about, we would hope to be able to be a part of this change, through bringing problems to your attention and making recommendations for their resolution. Our only goal is to improve living conditions in every facility we visit, so that residents of that facility can experience maximum growth in an atmosphere of dignity and comfort.

There is much which must be done at Ebensburg to bring about this kind of environment. I am certain that you and your staff will concur with the findings of this report. Beyond this, I am hopeful that you and your staff will work swiftly and diligently to bring about changes at Ebensburg which will assure the rights, the dignity, the training and education which your residents need and to which they are entitled.

It is my earnest hope that PARC can be of some assistance to you in your endeavor to bring about these improvements at Ebensburg.

Sincerely,

*Marlene*

Marlene Burda, Chairman, PARC  
Residential Services Committee

## 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.

### 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 sparsely 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.

Program

\* 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.

COMMONWEALTH OF PENNSYLVANIA  
DEPARTMENT OF PUBLIC WELFARE  
HARRISBURG

FRANK S. BEAL  
SECRETARY

January 20, 1976

TELEPHONE NUMBER  
787-2600, 787-3600  
AREA CODE 717

RECEIVED

JAN 21 1976

Mrs. Elsie Schmidt  
President, Pennsylvania Association  
for Retarded Citizens  
1500 North Second Street  
Harrisburg, Pennsylvania 17102

PENNSYLVANIA ASSOCIATION  
FOR RETARDED CITIZENS

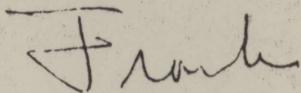
Dear Mrs. Schmidt: Elsie

This is an interim reply to your letter of January 9, 1976, concerning a recent visit by the PARC Residential Services Committee to the Ebensburg State School.

I am very concerned about the contents of the report and have instructed Mr. Ford S. Thompson, Jr., Deputy Secretary for the Central Region, to immediately review all of your findings and to initiate appropriate action. Mr. Thompson has informed me that he did visit Ebensburg on Wednesday, January 7, 1976, and that a thorough review of all aspects of your report will be undertaken.

Thank you for sharing this information with me.

Very truly yours,

  
Frank S. Beal



COMMONWEALTH OF PENNSYLVANIA  
DEPARTMENT OF PUBLIC WELFARE

EBENSBURG STATE SCHOOL AND HOSPITAL  
Ebensburg, Pennsylvania 15931

HARRY M. HERMAN  
SUPERINTENDENT

January 30, 1976

TELEPHONE  
AREA CODE 814, 472-7350

Ms. Marlene Burda, Chairman  
Residential Services Committee  
Pennsylvania Association for Retarded Citizens  
1500 North Second Street  
Harrisburg, PA 17102

Dear Marlene:

We were delighted to have you visit with Mrs. Leiden on December 19, 1975. Of course, you understand, I was not overly delighted with your report. In all truth, I feel there were many discrepancies in observations which will be addressed in the attached response and documentation.

I am personally grateful that PARC is anxious to take an active role in resolving the many problems institutions and administrators face. I am in complete agreement that there is much to be done at Ebensburg and I can assure you that this administration and staff is committed to bringing about improvements in many of the areas of deficiency which you cited in your report.

I sensed an implication in your comments of disinterest and insensitivity to the needs and rights of retarded citizens at Ebensburg. I wish to assure you that this is not so. I have been struggling to reverse an entrenched philosophy at this institution for the past two and one-half years and I am seeing change. I have spent 20 years of my life serving the handicapped young people - 12 of those years have been with the mentally retarded. This has been my choice because I always felt I was innovative and could certainly help to right the many wrongs in the rehabilitative process for the retarded. I am still actively pursuing that course.

I trust you will carefully scrutinize the attached material and come back to visit us for a more in-depth review.

Cordially,

Y.S.C. : j  
Harry M. Herman  
Superintendent

cc: Mr. Ford Thompson  
Mr. Frank Beal  
Mrs. Elsie Schmidt  
Mrs. Gloria Mitchell

III

HUMAN RIGHTS COMMITTEE MINUTES

The following are excerpts from the minutes of the Cresson Human Rights Committee meetings on January 3, 1976, September 14, 1976 and April 25, 1977.

## COMMITTEE MINUTES

Date 1-3-76

Page 1

PRESENT: IU08: Stephen Tomlinson, Sandy Fox, Cambria County P.A.R.C: Dan Sheridan  
Work Activities: Michael J. Seno, Social Service: James Kolar, Karen  
Schoeneman, FGP: Louise Hunter, Basic: Richard Rice, Personnel: Philip  
Berdine, Activities: Laura Zerbee  
Residents: Scott Mabon, Kathy Whitehill, Dewan Jones

The meeting was held Dec. 9, 1976, and opened with a reading of the minutes for the month of November and were approved. Suggestions from the previous meeting were then discussed.

Suggestion: pertained to the quality of haircuts the residents were receiving. Mr. Pilarz was ready with a report. He stated that from now on there will be no more short, or institutionalized haircuts except at the request of the resident, or other styles prescribed by parents of the mentally retarded.

Recommendation: that there be a written policy by Dr. Burrow.

\* The problem of dental care was then mentioned by Mr. Berdine. Mr. Berdine stated that he spoke to Dr. Brisini about the situation and that Dr. Brisini said that he thought adequate dental coverage was being done. Dr. Brisini also said that he has to spend too much time dictating information, and that he is no longer permitted to take residents to his office on Saturdays. Mrs. Hunter stated that the parent members of the Cresson Association are becoming concerned with dental neglect. The idea of taking the residents to a community dentist was introduced. Mr. Berdine also stated that most dentists will not accept Medical Assistance.

\* Ms. Schoeneman then gave a report on the study she had done from the residents' charts. She stated that Dr. Brisini has seen the residents twice in the past year, and that a Dental Technician also observed the residents once in the past year. She also stated that the notes Dr. Brisini wrote on the charts were very vague - not stating any specific teeth to be filled, and that no follow-ups were being done. Ms. Schoeneman spoke with nurses who stated that they were not satisfied with the dental care given. They seemed to think that there should be some in-service training done for the staff. Mr. Berdine and Mrs. Hunter both stated that advertising had been done to obtain professional dental staff, and that the ads were unanswered. Mrs. Hunter stated there are no State requirements for dental care. Mr. Tomlinson stated that the reason for the lack of dental care might be caused by the lack of funds and equipment. Kathy Whitehill, a resident, then stated that her teeth had been repaired by Dr. Brisini. Mr. Berdine said that he would check with Vo-Tech for dental students willing to work with the residents.

The subject of modification of wheelchairs was then mentioned. Mr. Berdine stated that Gene Ramsey is head of all modifications, pick-ups, and repairs.

Mrs. Hunter stated that she needed volunteers to do articles for the Skyliner, and to do a review of the Residents Rights.

Mr. Berdine brought up the subject of shortage of staff. He stated that Dr. Burrow is well aware of the problem. Dr. Burrow said that positions have been frozen and his hands are tied. Mrs. Hunter stated that Dr. Burrow received a letter from Harrisburg stating that residents will receive minimal care. This is to be state-wide. Thomas Oyler, a resident, asked why his funds were frozen. Mr. Berdine answered saying that there had been a misappropriation of funds at an institution. He stated that this problem is nation-wide. Mr. Seno questioned whether this was a violation of residents' rights. Mrs. Hunter stated that lawyers are looking into the legalities of fund freezing.

## HRC ADVISORY BOARD MEETING (cont'd)

\* Discussion was then held on the general lack of a good comprehensive dental program. Staff commented that many of the residents are frightened of the dentist and will not cooperate in the procedure. Because of this some residents are pre-medicated but this does not always induce cooperation. Mrs. Riden commented that many of the residents would require anesthesia for dental procedures. A list has been compiled stating which residents would need anesthesia, and the institution has begun arrangements to purchase this service from a local dental clinic.

\* There was discussion on the problem of insuring that residents' teeth are not pulled when they merely need to be filled. Staff decided there is no adequate overseeing procedure, and that it would not be proper for non-professional staff to question the judgment of the dentist. Staff commented that we have had some good results in using some outside dentists. For emergency dental services residents are taken to either Altoona Hospital or Altoona Mercy Hospital emergency rooms. Mrs. Hunter asked if there is an in-service program for continued training of unit staff in dental care. Miss McHail replied that a dental hygiene consultant visits two or three times a year. In addition, annually she presents in-service training to unit staff. She has also taught in some of the program areas to staff members who are holding oral hygiene programs. Staff agreed that it has been a difficult problem to locate a dental hygienist who will work for the state on a regular basis. Ads have been placed in various journals with no success. Dr. Burrow commented that he is in the process of trying to work out some sort of an arrangement whereby dental students from Pitt University could work with some of our residents. He is also going into negotiations with the Blair Dental Clinic to use its equipment at hours when the Clinic is not open to the public. Mrs. Hunter recommended that the efforts to recruit a dental hygienist be continued and that program staff who are involved in oral hygiene training be invited to all dental in-service programs.

Mr. Seno then reported on the status of the election of a new Human Rights Committee. Mr. Seno is assigned to the Nomination Committee. He reported that he had canvassed a great many people and had found they lack interest in becoming members of the committee. He has less than the nine names needed for nominations to the nine-member board. Efforts will be made to recruit outside agencies and parents who might be interested in joining the committee. Mrs. Hunter commented that it would be a good idea to find out the status of the proposed guidelines set forth in the Pennsylvania Bulletin as to the composition and functions of the Human Rights Committee. She will write to the rules docket clerk to find out the current status of these proposals.

Ms. Schoeneman reported she had spoken to Ms. Just in the OT Department concerning the privacy of toileting Altoona Center residents. Ms. Just indicated that the recommendation that some of the residents use their private bathrooms for toileting is not being carried out as yet. She believes it will be quite difficult to provide this experience due to lack of staff.

Ms. Just also reported concerning Thomas Oyler and William Ritchey. Mr. Oyler is now coming to programs much more regularly and Ms. Just considers this to be no problem. Mr. Ritchey is still not attending regularly but is coming more frequently than he previously did. She indicated that the two men lack meaningful male oriented activities to do while in OT, and this seems to be causing their boredom. She is in

QB

PRESENT: Philip Berdine, Steve Tomlinson, Alice Quay, Dick Rice, Louise Hunter, Edward Kolar, Sandy Fox, Laura Zerbee, Jerry Martini, Dewan Jones (Resident)

The meeting was held on April 14, 1977 at 1:30 P.M. at the Altoona Center. Mr. Berdine opened the meeting with the subject of fire drills. He stated that Mr. Ziegler, Altoona Fire Marshall, will conduct several fire drills. Mr. Ziegler suggested that he may start fire in the building, and let the employes put it out. He will also make safety inspections. Mr. Berdine went over the fire regulations. He stated that the building will be marked and identified.

\* The dental problems arose. Mr. Berdine stated that a committee was formed from the Board Of Trustees for dental problems. Dr. Strollo wants the cases written in detail and documented. They will then be submitted to the committee thru her by May 2, 1977. Also the people that do write these cases must be present at the Board Of Trustees meeting on May 10, 1977 if any questions arise from the Committee Members.

Mr. Berdine brought up the resident use of the multi-purpose room on weekends and holidays. Mrs. Hunter stated that since last fall there have been many questions about residents being placed in the multi-purpose room as large unattended groups at various times during the year. It was suggested that small groups of residents go to the multi-purpose room instead of a large number. Mrs. Hunter requested recommendations which lead to the problems of being understaffed. It was suggested that we have volunteers, but they would have to be trained. It was felt the need was there for volunteers for the weekends. Mr. Rice said that there was a paper circulated about training programs in Special Education to colleges. It was commented that it is hard for the staff to take the time to train volunteers on the job.

Mr. Berdine commented on a suggestion by the Committee that along with the dental program, the possibility of hiring a dentist to conduct an In-service program to curtail gum diseases, mouth disorders, etc.... This in-service program was a proposal.

Mr. Berdine stated that he would bring up the problem of the dirty State cars and their condition to Mr. Yobbagy. Mrs. Hunter brought up the incident at Kaufman's store in Altoona, in which two aides were shopping with two wheelchair residents. The owner of the store asked the aides to take the residents out of the store and come back later to resume shopping because the wheelchairs were blocking the aisles. Dr. Strollo said that we should see that all Downtown Merchants know that it is the right of all people regardless of their handicap to be in any public area. The only cause for removal of residents from stores are if they are abusive in language, destroying property and/or any other unlawful act. Mr. Berdine said letters would be sent to the owner of the store, the Chamber of Commerce, and Downtown Merchants Association.

The Human Rights Committee has been neglecting to jot the comments/suggestions into a proposed recommendation as in prior meetings. At the next meeting, this will be discussed.

PARENT LETTERS

The following are letters from parents  
describing the inadequate dental care which their  
children are receiving at Ebensburg and Cresson  
State Centers.

Philadelphia, Pa. 19111  
September 14, 1975

RECEIVED

Mrs. Elsie Schmidt  
# Pennsylvania Message  
1500 North Secord Street  
Harrisburg, Pa. 17102

SEP 16 1975

PENNSYLVANIA ASSOCIATION  
FOR RETARDED CITIZENS

Re: # 1265-  
Ebensburg State School

Dear Mrs. Schmidt:

"Ebensburg" Board of Trustees jumped out at me when reading about your election as President in the Pennsylvania Message.

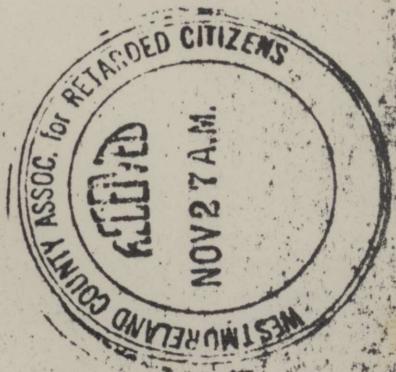
My daughter, Lisa, has been at ESSH almost 10 years and my only real concern has been about seeing her teeth and gums--perfect at admission--deteriorate so badly. Her breath odor is terrible most of the time; her gums bleed; the only times she has had real restorative dentistry were on the two occasions I brought her to Philadelphia, had her admitted to a private hospital (where she could be anesthetized). Even though my husband and I both lost several days from work, and paid the doctor and hospital ourselves (over insurance) the only important involvement was how the trip upset Lisa--she was terrified at the hospital, with strangers, and she is very strong. It was a pretty bad experience--mentally and physically--for all of us!

I have received a great deal of sympathy from State officials, and some quite constructive and active help---(Mrs. Elizabeth Tredway; Dr. Rusynyk), and from time to time, Lisa has been helped. But it is a matter of nag, nag, nag--and I feel that this is in direct violation of her right to treatment. Most of the retarded look forward to eating, to treats, as the biggest event in their lives! To let the majority turn into toothless individuals is horrifying. Look at their mouths, their teeth, the next time you're at ESSH! Oh not the "good" students, who comprehend, who can be told to "sit still" in the dentist's chair, etc. But the kids like mine.

I have a thick volume of a 9-year correspondence and can send you a copy if you like. My biggest problem seems to be a resentment by the department most involved, and I can't understand why, as I only want to help and improve both that department and the condition of the residents at Ebensburg State School & Hospital.

Very truly yours.

R.D. 5, Box 163  
Altoona, Pa. 16601  
November 22, 1978



Mr. Steve O'Donnell  
Westmoreland County Association  
for Retarded Citizens, Inc.  
34 West Third Street  
Greensburg, Pa. 15601

Dear Steve:

The purpose of this letter is to document our dental experience concerning our son, [redacted] was admitted to the Cresson Center in 1970. To the best of our knowledge, he had no dental work whatsoever until August of 1976 when we took him to a local dentist, [redacted] who was known to have worked on retarded children. [redacted] was seen again by this dentist one year later and it was recommended to us that we contact Dr. Negley in Huntingdon. Dr. Negley has had considerable experience in working with the retarded. In particular, he has set up operating facilities in the J. C. Blair Memorial Hospital in Huntingdon. Since [redacted] was particularly hyperactive and would not sit still in the dentist's chair and reacted rather violently, it was determined that he would be admitted to the hospital, given general anesthesia, and have his dental work taken care of in this manner.

The following is a short chronology of events regarding this admission:

	<u>Cost</u>
11/77 - Trip to Huntingdon for Negley consultation	\$15.00
1/78 - Trip to Huntingdon for Dr. Lidston medical examination (Note: Dr. Lidston is a pediatrician and hospital procedures required a pediatrician be involved in the case).	\$9.00
1/3/78 - Examined by a local pediatrician, Dr. Sponsler, after two false starts to the hospital (due to overcrowding conditions, our appointment was canceled twice).	\$10.00
5/2/78 - Admitted to the hospital	\$586.85
5/3/78 - Discharged.	

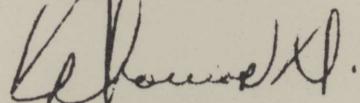
Dr. Negley bill for 5 fillings - \$85.00,  
X-Ray - \$5.00, cleaning and fluoride treatment -  
\$10.00. \$100.00

We needed help to handle . . . . during his hospital visit. Paid \$25.00 to an aide for accompaniment and assistance on the trip.

We wish to state that teeth were terribly stained and were literally green - no brushing whatsoever was evident and he was given lots of sweets. A brushing program was finally started when he entered the IU-08 classes in the Altoona Area School District in September, 1975.

Please let me know if you need additional information.

Very truly yours,



Thomas D.

MEMO

TO: Steve O'Donnell, Executive Director  
Westmoreland County Association Retarded Citizens

FROM: K. -- Parent of a resident of Cresson Center  
for 13 years and 5 months

DATE: November 20, 1978

RE: Dental care of

I wish to submit a written statement of my remarks presented to the Cresson Center Board of Trustees Meeting of March 8, 1977:

My first statement was one of concern--as a parent and as a registered nurse, regarding oral hygiene for patients and residents in institutions who could not provide this service for themselves.

Realizing that shortage of staff is one reason, but the resident does not need more problems added to his existing ones and good prophylactic dental treatment and care would be less costly in the end, resulting in better health and appearance for the resident.

After hearing dental-related concerns of others present, I asked to relate my personal experiences.

I was present, along with Social Service and Nursing Staff members, when my daughter Lisa was examined in the Cresson Center dental office by Dr. Sam Bricini in the late summer of 1975.

(Cresson Center dental records would reveal the exact date.)

Lisa was tranquilized with medication prior to the exam.

Dr. Bricini said he found a couple cavities and he would check her again in a few months.

I envisioned the cavities worsening due to lack of brushing daily and as Lisa resists any kind of treatment, there would be more pain and consequently more difficulty in handling her.

Staff--all present, asked Dr. Bricini to at least attempt to clean and fill the cavities as she had been medicated.

I agreed with staff. He patted my shoulder saying "You worry too much. She'll be all right." then asked for the next patient.

Needless to say, I felt pretty low after a fruitless journey of one hundred fifty-four miles (round trip).

Steve O'Donnell, Executive Director  
November 20, 1978  
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On March 24, 1976 at 9:30 a.m. I traveled through the snow to Dr. Bricini's Johnstown office to be present for Lisa's dental appointment.

Although she had been tranquilized, she had inadvertently had breakfast, so was unable to be anaesthetized--work again was postponed.

Once again, I expressed my concern for the residents lack of preventative dental hygiene--at the same time telling staff, that was present of my gratitude for the difficult tasks they perform and acknowledged the shortage of staff persons.

Dr. Bricini replied: "You shouldn't worry so much. There is nothing you can do for these people." (meaning residents)

He added "I'm not being paid to take care of her" (Lisa). "I wish you would take her somewhere else."

I wondered then and asked Dr. Bricini if he really liked what he was doing.

He replied "Frankly no."

On July 9, 1976 at Pittsburgh's Childrens Hospital, Lisa had a total of fourteen surfaces filled, gum treatment and a cleaning done, with anaesthesia.

On March 7, 1977 her teeth were scaled and cleaned-without anaesthesia.

On July 18, 1977, teeth were cleaned and one was filled savis anaesthesia.

Dr. Sears at Childrens Hospital asked, after looking at her mouth, why residents teeth are not cleaned--added that parents should not accept this situation.

We were told that due to inadequate dental hygiene, premature loss of teeth will occur due to periodontal disease.

Cresson Center was informed that Dr. Nazif, Director of Childrens Hospital's Dental Department would send their staff to Cresson to give Inservice training on dental hygiene to Cresson Center's Nursing Staff--in mid '77. In July '78, Dr. Nazif said he had received no response.

Lisa is unable to return to Childrens Hospital for treatment as she will soon be twenty-one years of age.

I am willing to provide dental and medical treatment for her as long as I am able but am concerned for those who are handicapped and have no one to champion for them.

Steve O'Donnell, Executive Director  
November 20, 1978  
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May I add my sincere gratitude to all at Cresson who have helped us through the years. Institutions, like parents aren't perfect. May we all do better.

Sincerely,