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HUMAN RESOURCES COMMITTEE

Hearing on Augsuta Mental Health Institute Issues held on
February 9, 1989, in Room 113, State office Building, Augusta, Maine

Carmen M. Thibodeau

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10:35 A.M.

REP. MANNING - Good morning. This segment of the hearings on AMHI will be devoted to the people who have been identified as people who represent family units either at the Bangor Institution or the AMHI Institution or family units throughout the whole state. So at this time I would like to have Joan Pederson come forward and give her remarks to the Committee.

MRS. PEDERSON - Thank you, Rep. Manning, and members of the Human Resources Committee. I appreciate the opportunity to - I didn't know where to begin this morning, but thought that probably what I wanted to say was the concerns or the problems that are at BMHI because I realize you've had a lot of information about AMHI and understand that you had some questions about the extent to which we have problems at BMHI.

From my own personal experience, my remarks are drawn this morning. My first encounter with BMHI was in 1984 when at that time it became apparent to us that my son needed care that we couldn't continue to provide at home. We have a son who is thirty years old now and has had chronic mental illness since the age of about fifteen when he was in junior high school. We kept him home for as long as we could while I was working and then it became clear that he needed round-the-clock supervision at times and we were unable to provide that. We resisted the admission to BMHI because of the stigma attached to it, because I had heard such bad things about it. But it finally came to the point where I had considered resigning my job and staying home when my employer who was a very kind and very wise man sat down with me and said, what is it that you think you can do. And as we discussed it it became clear that it was more than I could do for him. It was - there were a lot of things at the institute that were hard to understand. Much of the things that happened to him seemed to me more punitive than therapeutic.

When he failed to carry out some of his activity programs, he was denied opportunity to go to leisure time activities. If he missed a voc - or vocationally oriented kind of activity, because they said he didn't call in and contact the right person and report that he wasn't coming, then he was denied participation in that program for five more days. I had a hard time understanding these things and so I sat down with people, asked who should I talk to and I was directed to go to his therapist. And you find that the therapist is the mental health worker. I said, well, now, who makes decisions here? Who does the assessment and designs this plan of care? Well, we all do. Who do I talk to when I come in here and want to know about his progress or how he is doing? Well, you talk to his therapist or his treatment team leader who might be a social worker. I learned over time that the psychiatrist primarily works in a consultant capacity and primarily deals with medication. This was very foreign to me, because I am a registered nurse and accustomed to the role of the treatment team in a general hospital and the leadership and responsibility of the physician overseeing the entire plan of care and this is not things that happened in the institute. It was fragmented. There was lack of coordination between the team members and I clearly was not well received when I started asking too many questions.

I'll skip to just the highlights to tell you an incident that I think will demonstrate my concerns. After my son had been there several months, it was decided that he was ready to be transitioned into the community, that he could live in a less structured environment and was sent to a half-way house which is on the grounds of the hospital. And while he was there the supervision in the house was minimal. There was someone in there for one of the eight-hour shifts. And this was in '84, so I'm not terrible accurate, details are in here (indicating her file). I think the coverage was during the nighttime. One day we went to the half-way house to visit him and noticed that a tooth was missing and I called the social worker in charge of the program and said, are you aware that my son has a tooth missing. No, he said he was not. I took him to the dentist and had it x-rayed and thought that it was broken, found out that he had, in fact, pulled that tooth. And it was the deep rooted front tooth, a strong tooth. I talked with them at that time about his need for closer supervision or the whole plan of this transitional house and the assessment of my son's behavior and said we saw the dentist, it was evaluated, it was not infected and so we said, well, we - it's an unfortunate incident but what could I do. He was being transitioned out and I thought - I had been told the sooner you can get him out of here the better it will be. And so I thought, well, he's on his way out and I'll watch the best I can. And about three or four weeks later or some such time as that he was still staying at the half-way house and still trying to go to these vocational programs and if he missed it, he couldn't attend for several days and when he didn't attend he was left in the half-way house by himself.

And approximately a month or four, five weeks later we noticed his jaw was swollen. There was dry blood in the corner of his mouth one morning when I went there. And lo and behold he had pulled a second tooth. At this time I went directly to the patient advocate's office and said, I demand that this program be evaluated. That was the beginning of a very difficult ordeal. The superintendent said that she would have the incident investigated and the patient advocate was very helpful and supportive of the - at the time. I called - would you believe I called my representative - my legislative representative and said I've got to tell you how things are here. I really don't know what to do or where to go with this and Rep. Patricia Stevens was extremely helpful to me. And for me she contacted other people and the state government and the Attorney General's Office to find out the extent to which I could advocate for my son in the absence of guardianship and I found that I couldn't do very much, but didn't really feel that it was appropriate to seek guardianship because it is so - it takes away so many of his privilege. I didn't think it was appropriate.

The investigation that was done of the incident speak of things like the - some of the treatment teams saying, quote, unquote, and I have the documentation here, that it was a routine loss of tooth. I never heard of a routine loss of tooth. He was twenty-five years old, healthy, he had - we had taken him to the orthodontist when he was younger in his teen-age years and had braces over the years to straighten his teeth and had his usual two monthly - twice a year, rather, regular dental visits. There's a comment in here by some of the treatment team that he'd had an abcess at the base of his tooth for a month and that was probably what was causing him to be agitated and pull his tooth. I said, that's not so, because two or three weeks ago I had him at the family dentist for a series of x-rays to see if there was a root left of the first tooth and he said that was clean pulled and there was no sign of infection, so that's not true. The mental health worker said, well, somebody said - reported to the nurse in charge that day that my son had pulled a second tooth and the nurse supervisor is stated as saying, don't bother to make out an incident report, because people lose teeth. And the person said, I thought it was just another - you know, teeth fall out. And I thought, my God, this sounds like people saying, well, people are dying at AMHI, people die there. I think they become so accustomed to this poor quality of care that somehow we become insensitive to it and it's accepted.

At the time comments began to be made that I was meddling in my son's treatment plan, that I was becoming overprotective, that my son probably wouldn't do well if he were discharged at home because of the family problems at home and that he was at that time - became eligible for SSI and there were payments that would be forthcoming and the recommendation from the treatment team said that neither my husband nor I could be recommended as being the payee, that that was not appropriate, that someone else needed to be sought out to oversee Bruce's - my son's SSI financial affairs.

It was hard enough to just live with mental illness in the family, to have this young healthy handsome young man become so ill and to where he would do these self-destructive behaviors and have to go to Bangor Mental Institute for treatment and try to understand what is happening because I had to pick up the supports when he was discharged and wanted to. And to be met with that kind of accusation was extremely difficult for us. It lasted over a period of months. I've given you some of the highlights of it.

Eventually my son did leave AMHI - BMHI rather and was placed in the community and it seems now in hindsight and at the time that the whole transition was a stress for him. Moving to a new environment that he knew would be temporary because there was a time limit onto the transitional housing of eighteen months and he was expected to spend twenty hours a week outside of the house doing some kind of meaningful activity and he hadn't even been able to accomplish twenty hours while he was in the institution with that much support and structure. It seemed an unrealistic expectation clearly to me and when I attempted to discuss that, there's a comment in here that I am not receptive and critical of the program and that I'm afraid that my son is going to get sick again and returned to the hospital or that he can't handle - I was concerned that it was an unreasonable expectation. I felt that was appropriate input for me. I was responsible for monitoring and coordinating his care and I needed to know what the expectations were and what the options were along the way.

Later on - and I was able to find - I've purchased a lot of pieces of my son's chart and I have asked for descriptions of policies and programs to try to understand them and to try to discuss with the people that in my judgment they seemed to be inappropriate. There's no doubt in my mind that that placed me in an adversarial position and I felt the repercussions of that.

One of his more recent admissions when we - oh, before I finish that, one of the results of the - after the superintendent said that she would have an investigation of the incident of his loss of teeth, several weeks later she called me back to the office and said the investigation did, in fact, reveal that there were some failures on the part of the staff to communicate information appropriately. Also, it was revealed that my son had not had a multi-disciplinary team conference where they would collectively determine what was an appropriate next move or placement for him. But she said to me, I promise you we will have one. He will have a multi-disciplinary team. You see, he had already been moved from the hospital already to a half-way house. So I awaited the notification to attend the multi-disciplinary team and when I opened the door and stepped in, I couldn't believe what I saw. The room was lined with people. I came home and documented that and I listed, I think, fifteen or sixteen people that were in the room. There were two or three psychologists, psychiatrists, several nurses, secretaries, an audio-visual machine was set in the middle of the room and it was extremely intimidating for us. My son became very agitated and didn't do well, obviously, in that kind of a situation. And I realized right then that I had to rethink whether I had done the right thing to try to get involved in this treatment for him, because by now people were coming to me in the hospital and in the system and saying, be careful what you're doing. Don't lose sight of the fact that your son may have to return there.

And one last thing. The part of that report that I received, I was instructed verbally at the meeting and then later in the written report, I was instructed not to go and talk to the superintendent again by myself without having one of the members of this treatment team to accompany me and one of the - and the report says that from now - if Mrs. Pederson is to talk with the superintendent again, either this psychiatrist or this social worker will be in attendance.

One last thing that was again a reminder to me some time in the last six or eight months or year perhaps, when we attended another conference around treatment planning or discharge planning probably, I was passed a copy of the treatment plan that says what are the goals and what are the objectives here for my son. The treatment - this is the form that came off his chart reads, problem 1, ineffective coping skills as evidenced by, (a) confusion, (b) history of street drugs, (c) delusion thoughts, (d) lack of general education diploma, has quit high school at tenth grade, (e) adult child of alcoholics. I again weighed my series of inquiries as to how this information - how people come by this information that becomes a part of the treatment plan that treatment decisions are based on and said that - and as I purchased the chart and began to read through it, there were lots of errors in the social history and in other documentation, in the medical history. I said, you know, given the fact that this is the base background that you use to development treatment plans and make decisions for care, I'm concerned of all of the errors throughout. What can I do about that. Do you have guardianship? No, I do not. Then you'll have to - your son could enter a statement refuting this or correcting this, a patient's right to add to their chart if they know something to be in error, but I do not have the right as a parent, you see, to do this in the absence of guardianship. And I am not - I do not think it is in my son's best interest for me to begin to counsel him about the errors and content of this chart toward having him to enter some kind of note in here and so we live with it.

That's my personal experience. And I walked around the house kind of late last night wondering what would happen after today, too, but it's hard for parents to admit to their families and to their neighbors that one of their children has chronic mental illness, because an awful lot of people don't understand it. They think there's some problem with the way they were raised or - that if we didn't contribute to it, then certainly we - if we didn't cause it, then we contribute it. And a lot of parents are in various degrees of being comfortable to come forward and to talk about this and when I decided to get involved in advocacy, it was after these incidents happened and I was not an active member of the alliance when this happened, but I realized so much had to be done that it was - I'd gone too far to turn back and I felt privileged that I had some insight into nursing and health care and that I had a bit of understanding of the way I think things ought to be.

I'd like to tell you one last thing that happened this summer and then I would answer your questions that you have. I was angry and disappointed and thought how typical when I went to the hospital - the institute this past summer during that heat wave that occurred and we rang the buzzer for them to unlock the door to let us onto the ward to visit and standing with us was a patient. It was a little bit before the hour. It was like five or ten minutes of the hour. It became pretty apparent to me that this patient was eager to get onto the ward before three o'clock because of the comments he was making and ringing of the bell and we were saying, oh, don't ring it too much, it surely will have to wait. We got admitted to the unit probably about on the hour as I remember. We proceeded down to the nurse's station where they were involved in some kind of conference, perhaps change of shift report or whatever. And the patient preceded us down the hall and he eagerly asked if he could have his cup of coffee. And I put it together and having had experience with my son recognized that probably because it had been common practice to reward them with a cup of coffee if they went and did an activity or if they got back on time or did what they were supposed to do, it seemed to me, and I have no way of knowing, it was just my impression, that he was looking for that earned cup of coffee. And the people said - just brushed him with a motion and said, go away, can't you see we're busy. And he started to say, but it's such and such, they said not now. So he looked frustrated, disappointed and slided himself around a bit and then walked on down the corridor talking to himself. And I thought how inappropriat that was.

As I was standing there waiting to be recognized and ask my question, another staff member came down the hall with a serving tray and on it were seven or so ice creams with chocolate sauce on it and they took it behind the railing into the nurse's station and set it down and staff proceeded to take the ice cream and chocolate sauce and eat it while patients stood around leaning on the countertop watching them eat their hot fudge sundaes.

Later on a Saturday morning my son called and said, could you bring me a pizza for lunch today, and I said, I don't know. Is that allowed, do you know? It was summertime, you know, we'd done it before. I said, you see if it's all right and I can bring it up, we can sit out on the grounds and you could have that. So he asked and he came back and he said yes. So I said let me speak with the person in charge just to make sure. So I relayed to him what I wanted to do. Oh, yes, he said, that will be all right as long as you take it outside and eat it, not on the unit. And I said, yes, that's what we were going to do. I said, is it true that you're having beans for lunch today as my son said. He said, oh, yes, they have beans every Saturday noon and he said, and they don't even look like beans. And I said, well, he wanted pizza. Well, he said that's probably because he saw the staff eating pizza. We sent out for pizza for our lunch and we're eating it so that's probably where he got the idea.

I wasn't very popular at some point later, I suggested that the staff eat their meals with the patients for - they certainly need to learn skills. I don't know why, but the individuals with chronic mental illness lose some social skills and it seemed logical and natural to me that it would be appropriate for staff to take their meals with the patients and roll model, if nothing else, in proper eating habits. And they said, oh, you're the one that suggested that we smoke only one cigarette an hour as a role model for them. I said, no, that was not me, because had you asked me I would have said you don't smoke at all in front of them.

So we'd like for these folks to have the support in the community. We know that that's where they're best served, whether they can get on with things and to live as normally as they can in their - with their lives. We would like to see more programs in the community so that we would not need to use these institutes. I think there's some place that's necessary for these individuals because occasionally they have flare-ups of acute illness and at that time they need good quality psychiatric evaluation and treatment plans developed by people who know the object of care. Ideally, I'd like to see these be in psychiatric units in general hospitals. I don't think you can separate illness of the mind and the body. When one is affected, the other is affected.

We very desperately - families need some kind of respite program so that we have an opportunity to go away and just take a break from the situation and know that somebody will be keeping safe watch, however often or however structured that may be, to just fill in for us when we can't be there. It was - it's difficult and it's unpredictable because there are times the cyclic nature of the disease is such that there are times when it's perfectly comfortable for my son to be on his own for a good bit of the time and there are other times when it clearly is not appropriate and that change can occur within twenty-four, forty-eight hours, so it's hard to plan ahead for those things.

I think that I wanted to tell you - are there repercussions? Yes, there are. Do we need some help with treatment and quality of it in the institutes? Yes, indeed, we do. I feel as though I've made my point this morning. If you have any questions -

REP. MANNING - Thanks, Joan, I appreciate your candid and your very difficult situation. Are there any questions?

BY REPRESENTATION BY REP. PEDERSON

Q. Good morning, Joan. As you might know, Joan's my wife. And I think that our experience has been that you ought to make a statement about some of your experiences with the other family members that you're acquainted with and roughly some of the experience that you have knowledge about.

A. As I said before, there aren't - there are a lot of family members who are not comfortable to even identify the fact that there's mental illness in the family, to say nothing of commenting on what they perceive to be lacking in services or poor quality of care and I understand that and they talk to me and relay a lot of their concerns and experiences to me. In one instance a mother said to me, I cannot go forth. I wish I could be with you when you do this advocacy, but I can't. It's clear that individuals could taunt or aggravate, provoke my son into striking them, because he is of that temperament. And that where we - I'm told that sometimes that happens and patients are put in seclusion. And her comment was, if they were to provoke him to the point where he would strike them, they could send him to jail and I don't want that to happen, so when I go in their I wear a big smile and I keep things pleasant. Others have said, look, the Department funds our programs. We have social clubs or residential programs in our community and it's with - in collaboration with the Department that they have obtained money and split these programs in the community and we fear that these programs will not continue to be funded. It's for that reason that we have sought to have our funds that we have to maintain our operations somehow not go through the Department, that we sometimes have to confront with problems and strong criticism.

Q. I want to ask another question. And that was, you being a family member, being very active in the Alliance for the mentally ill, you probably are acquainted with a lot of stories that when clients have gotten out of either AMHI or BMHI that sometimes there's some pretty sad endings such as suicides or death that are indicated by the fact that they probably should not have been out. Is that - are you aware of several of those?

A. Yes, we're aware of several. The comments that lend some insight into probably a clear assessment that it was inappropriate for them to be discharged or to be released on whatever kind of temporary pass or provision has come from individuals within the institution who are staff members, who would be certainly in a position to make those assessments, but there have been comments made to me in confidence. I don't have the - I don't have the right to reveal the source and so it's for the most part hearsay.

Q. Can I mention a couple of those. Can you recall that there was one instance where a boy was hitchhiking home to the County and it was extremely cold out.

A. Yes, that was a story told by one of the family members that unbeknowst to her her first knowledge of the incident was that she was called sometime in January and told that her son had gone out on a two-day pass but hadn't returned and she said, I didn't know he was on pass and they said, oh, we put him on the bus to visit friends in - somewhere in Aroostook County and he hasn't returned. He was found later and had frostbite of his feet that ended up with him being hospitalized for a while and then spending a fair amount of time on crutches before he was able to put his shoes on. And things of that sort and also observations and comments made of the behavior of these individuals just immediately within days of these sorts of releases or discharged being made leave us to clearly question why these people would be released from care. And I don't have the answers. I don't know - I'm not saying that I know who's fault it is or that an assessment was inappropriate. I don't know. I just know that these things happen and then it seems clearly that they shouldn't have happened.

Q. Can you give us from your experience just an assessment of what you think would be the best thing to do for the mentally ill and what are the needs that need to be done?

A. Community services. Clearly the goal is to assist these folks to make friends and live in the community to the level that they can, supporting them and they can be remarkably well with the appropriate supports in place. We'd prefer for them to be in the community. They'd prefer to be in the community and have some unit of quality care for - acute care when that is needed, because it surely will be needed from time to time.

Q. Thank you.

REP. MANNING - Mary.

BY REPRESENTATIVE CATHCART

Q. Thank you. First I want to thank you for coming, Mrs. Pederson, and -- the courage that it has to take for you to be here. I was shocked in the beginning of your testimony when you spoke of being - of feeling that your son was receiving punishment really instead of therapy when he was denied leisure activities and you asked to speak to his therapist and found that was a mental health worker. My understanding is that mental health workers have high school diplomas and some small amount of training and I'm wondering if today - that's been about five years, d you see that that has changed any or is he still being seen by a mental health worker therapist. Do you feel that he's getting real therapy when he's in AMHI and - or is he getting medication, because some people have told this Committee that the only therapy in AMHI is drugs. I'd just like to know more about that.

A. On his most recent admission I talked with the admission team and in the course of discussing all the things that we would do to make this transition, we discussed medication and they said, bring the containers of the meds that he's taking now with you to the hospital and I said, yes, indeed, I intend to. And so we went to the hospital and I carried the meds and I talked with them about his treatment and these were intake workers in the admission unit who were master's prepared social worker level, I think. And I learned later that evening when I went to visit and ask on the unit what he was getting for meds because I thought that probably they would adjust his meds, given the fact that he had decompensated at home and couldn't be kept at home any longer and was interested and learned that they had retrieved his chart from when he was there two years ago and were told to give him the meds that were on that chart two years ago. I was flabbergasted that there wasn't an assessment made at the time or some consideration given to the meds that he was taking at home on the morning before he came in, because they were clearly different than what the chart was two years ago. The mental health workers are still the patient's side - first person that we talk to because they say to me, that's the person that sees him most often on a daily basis, because the mental health worker is assigned five, six or I don't know how many clients that they watch on a daily basis when they're on the unit and not floated somewhere else. They are - I understand that some - presently they are required to have a certified nurse's aide certificate. I've taught certified nurse aide courses and know that the content is directed toward physical care, predominantly elderly people who are bed bound or to a large extent immobile and that includes skin care and range of motion, assistance to walk and that sort of thing and absolutely no relevance to young adults who are walking around who can't concentrate and have delusions and have to disorders of thinking. And so they're still very much ill prepared and -

Q. Just to clarify one thing, when he was admitted this recent time, it was social workers who decided what medications he should have and - I mean, was he seen by a physician when he was admitted who reviewed the kind of medications he had been taking over the past five years and -

A. Okay. I need to clarify that. The intake information which is social history and reasons which brought the admission about were admission officers who are, I believe, prepared at the master's level, social work and - but after the admission procedure is accomplished, then it would - then a psychiatrist, an M.D. psychiatrist does make the decision about medication. I think the problem is that there aren't enough psychiatrists to see him at a time when I thought it was appropriate, which was then, to make the assessment and prescribe the meds and I think some period of time is allowed, twenty-four hours or some such a matter, during which the psychiatrist will see him and so it strikes me that they start some medication before a psychiatrist sees them.

Q. Just one other thing to clarify, you spoke of purchasing your son's chart, his treatment plan. Would you explain what that means?

A. I wanted to see how - I wanted to see how they delivered care, how they documented it and I just wanted to read in more detail on a day-to-day basis what happened and how they thought he was doing, because it was hard for me to find out and I had a lot of questions and so I purchased it to read it and I was hurt when I read in there the comment made by a psychologist when he said, we must be very careful not to be punitive in our treatment and that was along about the time when my son was having difficulty making it to these activity programs and I asked, you know - I asked to have a conference with these people and said, I know that my son tries very hard to meet expectations and he would not deliberately foul up his program because he understands clearly what the consequences are. Have you ever considered that he was confused and unable to get himself where he was supposed to be on time and they said, well, that's the step program and that's the way it works. I said, well, I think the program needs to be - I think that you need to think that through and so I wrote a letter, I have a copy of it, to the administration describing how my son was precipitously dropped from Step 3 to Step 1 of this program one day when he didn't do something or other and said, how does that happen? You know, what else do you do? Do you talk with him or find out maybe why that happens or do you provide some support or some guidance or - I said, well, that's just the way it is, so I went and talked to the next layer and said, well, we understand, Joan. We know that it's not good and we mean to fix that and we're going on a retreat in a few months here and that's one of the things we're going to work on. So I'm waiting for this revised plan. I've asked for that and that hasn't come yet.

Q. How long ago did you ask for that?

A. About two months ago.

Q. Back to the purchasing, just how much did you have to pay to purchase -

A. It's seven cents a page.

Q. Okay, so it's just like the cost of the copy?

A. Yes.

Q. Do you think that many families realize that they can ask for these records and do purchase them?

A. It's amazing, I'm finding that they don't know that.

Q. As a parent I would certainly think I was entitled to see what they were writing about my child. Thanks a lot.

SEN. GAUVREAU - Are there other questions of the Committee? Rep. Burke.

BY REPRESENTATIVE BURKE

Q. Because you are not guardian to your son, I assumed that they needed your son to sign off that you could have the parts of the chart that you wished?

A. Yes.

Q. So many family members because they're not aware that they can ask their child, sibling, whatever, to do this are unaware then of what's written in the chart also about them?

A. Yes.

Q. Do you feel as though your being classified as an alcoholic without benefit of ever having diagnosed you officially as one has, in fact, then affected your - the staff's dealings with you?

A. Yes.

Q. In other words, you walk in and say, I'd like to talk to you about my son's care and they say, there's that Mrs. Pederson the ETO8er again.

A. Yes.

Q. Being a nurse I also have had dealings with - sat in on - when reports are written up and at one point, just to share an experience with you in a sense in order to empathize. Experience -

I was in on one when they had a - again, a mental health worker type person, very few credentials, sit down and take a family history and it went like this. Is there any family history of diabetes? Well, I come from a very large family and a large extended family and so almost every single disease process that they could name I could say yes to. So when we received - when you looked at the report, the report read, patient has a family history of diabetes, high blood pressure, alcoholism, you know, and it went right down the line. And when I questioned it and said, that's inappropriate. That person really does not have a family history of all of that. They said, well, this is the information we were given and none of it in essence was then struck and it does in fact color the way the patient is then treated. The fact, too, that the staff also does not seem to understand the dynamics of positive reinforcement and a step program also colors the way the program has been administered. So it becomes punitive as opposed to positive reinforcement. Instead of saying - instead - for some reason it quickly changes to negative reinforcement that you didn't make it to such and such a treatment program, therefore, you can't instead of rewarding them when they are able to do those things, you have my full empathy. I - it is difficult to sit here and listen knowing that we are placing members of our society, members in places where the staff that is meant to treat does not understand the treatment plan and when we call it to their attention when we say we need to tighten this up, they become defensive and say, you're the problem.

A. Hm-mm.

Q. We do hope - I guess more than a question I have a comment, we do hope that through these hearings we are able to rectify not only BMHI and AMHI, but the entire system. It's a large task, but we really do hope - and I hope that you understand that we will do our very best to help the situation.

A. I do, and I do appreciate the fact that it's getting the attention that it is. Along those lines, I would say also that as soon as these programs are in the community, the individuals outside of the institutes, the therapists and the treatment team and the agencies are held to a higher standard than the state institutes. Many times the clients are bright, intelligent, accomplished individuals who learn how to get along. They learn what to do in order to get along and not be disciplined while they're in the institute. And on the agencies outside of the institute, it's been my experience that the therapists are much better prepared for their jobs and have far more success with the clients than I've ever observed in the institutes.

Q. Do you feel that that has to do with control?

A. I feel it has to do with the level of preparation for the - part of the therapists.

Q. Okay. Thank you.

SEN. GAUVREAU - Are there further questions of the Committee of

Mrs. Pederson? If not, we thank you very much for your presentation this morning. I have a list in front of me. I'm not sure if this purports to list the chronological order of the presenters. We have heard from Mrs. Pederson. There are four other people whose names are listed, Mrs. Ware, Mr. Bolduc, Mrs. Burns and Mal Wilson. Are there any persons amongst those here who have time restraints which would inhibit their ability to be here in the afternoon to make presentations to the Committee? We will envision going into the afternoon. Then unless someone has any objections, I suggest we just go through the list chronologically. The next presenter would be Mrs. Ware.

MRS. WARE - I should like to start by telling you that I am my daughter's legal guardian, so I haven't -

SEN. GAUVREAU - Can you please for the record also identify yourself and your place of residence?

MRS. WARE - My name is Lorraine Ware and I live in Freeport, Maine. And my daughter has been a patient at AMHI for several years. I'd like to go back for a minute - a few years back when Janice was first - when she first became a patient at AMHI. She was there for a few weeks and then she was discharged. Maybe two or three months later she was back in the hospital again for a few weeks and discharged again. This went on for a long time. In the interim when she was outside, there were so many things that happened to her, I couldn't seem to make anyone understand just really how ill she really was. It seemed as though every time she'd be in AMHI they'd keep her a few weeks and they'd say she's fine and throw her back out into society. So after going through this for quite a few years, I finally went to see Ed Muskie and after meeting with him a few times, he told me that the next time she would be committed that she would not be thrown to the wolves. So I was lucky in that respect because after her last commitment she's still there.

I would like to also tell you about a few of the things that happened within the four walls of the hospital. I know we've heard a lot about needing more staff. That can't be stressed enough. They really, really do need more staff, not just RNs and LPNs and mental health workers, they certainly need a lot more people in maintenance. They have the new gym over there now which has to be maintained and no - there are no new workers there, so it's even worse than it was before as far as the physical care of the hospital.

Not too long ago I went in one morning and the stairs going up to my daughter's ward were so dirty and smelled so bad that I mentioned it to one of the mental health workers. Two days later I went back and the same condition existed. I mean, it was just awful. I can't describe it, the odor was so bad and the filth. For three whole weeks that lasted and finally I went to somebody and I said, that stairway has got to be cleaned. Well, we have nobody to do it and they're not likely to get to it for a couple of months. So eventually after about six weeks the stairway did get washed, but that's a small thing.

As far as my daughter's room is concerned, this last summer I went up with a pail and my Murphy's Oil soap and I cleaned about twenty-five years worth of dirt off the bed, the bureau. I mean, I can't tell you how terrible it was. I just couldn't stand it any longer and probably I changed the pail about nine times - the water - before I felt as though I'd gotten to the bottom.

Another thing, two years ago - I guess it was two years ago, I went up there one very hot summer day and the water fountain on the ward was broken. That was on a Monday. Thursday I went back, still no water fountain fixed. I asked about it. There was nobody to do it. They couldn't get to it. I mean, it was hot. My daughter is lucky because she's able to leave the ward and move about, but there are patients on that ward that do not leave the ward and they don't have the sixty cents to go to the machine and buy a cold drink. And that bothers me.

A couple of years ago, well, there's been many occasions that my daughter has tried to run away, but a couple of years ago she ran away and I was - I understand she was missing at about 1:30 in the afternoon, but I was not notified until almost midnight that night. I guess what they really called me for even then was just to tell me - to find out if she was home. And, of course, I didn't know she wasn't at the hospital. The next morning I found out that she had been picked up by the State Police. She had been badly bruised and she had been taken to a Brunswick hospital and after that returned to AMHI. Well, a few weeks later I got a bill from the hospital and I took it up to AMHI and said I'm not paying this bill. And they said, oh, well, you'll have to. We are not responsible for a patient once they leave the grounds. Well, if they're not responsible, I'd like to know who is. She was in their care.

I've probably already told a few of you about how I feel about the physical well-being of the patients. To me it's every bit as important as the mental well-being. I do have to watch out for Janice's hair care, teeth care, her laundry, her shampoo, when she needs it. Her teeth do not get brushed unless I'm there to see that they get brushed. I think if - I'm sure if they had more staff, those things would be paid attention to. I just know - I've been on the ward enough to know there just isn't enough. There aren't enough people there. There just isn't. And as far as the mental health workers, there's an awful lot to be desired. So many of them are so - some of them you can't tell the patient from the mental health worker because, frankly, their appearance is so shoddy. They're not even clean some of them. That bothers me. When I take Janice home for a couple days and I take her back at night - and this happened recently - a mental health worker unlocked the door, but I was sure it was one of the patients. She was just - it was just awful. There's no need of that at all.

Janice is a long-term resident and she's really not - she's not really considered a candidate for discharge, so I have to say that my chief concern is what is going to happen to the long-term patient who really will never go out into the community. I see all these wonderful things that are happening for the community, the patient that will be out there, but I'm really so terribly worried about those that are still going to be there.

I was also told by a psychiatrist a couple of years ago, they had tried putting my daughter in a half-way house and, of course, it didn't work. And when she was taken back to the hospital, a doctor said to me, well, you now, we're not babysitters. Well, I guess they're not babysitters, but I just didn't think that was the right thing to say either.

My daughter was in a room at one time with seven patients. I went in one day and there were her personal clothes folded on the floor and on a window sill and the room was in utter chaos. I mean, just - it smelled, it was so bad. And I don't think that under any circumstances you can expect six or seven people in a room to have a good attitude about anything with no privacy whatsoever.

The cafeteria is really - it's just a disgrace. I was over there Tuesday afternoon after I left here to a case conference meeting and went into the cafeteria to get a cup of coffee. It was just so filthy. They have a patient who goes around with a little cart to clean the tables and to take care of the rubbish, but that patient isn't capable of doing it. I mean, you just want to take a scrub brush and scrub down the whole place. It got scrubbed - I think it was last fall when there was going to be a tour of the hoapital. I couldn't believe it. I walked in one day and, oh, that cafeteria was just sparkling, but it had never been before and it hasn't been since.

And I know it would be nice to have an RN on duty in the ward at all times, but they are so short of staff that there are times when the RN is really needed on the ward, but she's been pulled away to another ward for something else. I witnessed one of the nurses being assaulted by a patient not too many weeks ago. There was nobody - there really wasn't another worker on that ward to come to her aid. So we talk about the patients being assaulted, believe me, it's not just the patients that I am concerned about within that - those four walls.

I've noticed also over the years - I don't really know, because I'm not a professional in that area, but it would seem to me that if they had one mental health worker to maybe every four patients, it would certainly improve things.

I personally would love to see something happen right away. I know it's wonderful to have all these plans that all these committees have, but plans are just that. They're plans. I'd really love to see some action, because I'm quite concerned.

There was a time recently when my daughter was given some Adavan after I had requested that she not be given the medicine.

She was given the Adavan three times in the course of a day and was pretty zonked out for twenty-four hours after that. And then when I asked to see the records, it said that per the patient's request she has been given the Adavan, per the patient's request, well, I wonder if that's using very good judgment. If my daughter - if she knew - could use good judgment, knowing that she needed the medicine or she didn't know the medicine, I just - I just question that - the mental health worker's right to do that.

A couple of weeks ago I noticed that Janice's ward had been cut back from sixty to forty-eight and I wondered about it, because they're told - they were told to cut back the number of patients on that ward and there's already - that was just recently and the thing is that when you're told to cut back the number of patients on the ward what happens is you throw so many of them out the door and what I'm wondering about is I'll take a particular incident that I know about where a patient was put in an apartment. Somebody is going to pay for that apartment, the first, last, the present month's rent. They had to do it, because they were told to do it. The patient was put out in the apartment and three weeks later the patient is back into the hospital, because the patient is too sick to know that they have to take medication. So the patient doesn't take the medication, so they're back into the hospital. And it would seem to me that that's an awfully big expense that somebody is going through just for the sake of cutting down the number of patients on a ward because somebody is coming in to check it out for whatever reason, whether it's for accreditation or whatever, just - it just seems to me to be such a terrible expense.

I think the - last summer when we had the terrible heat, I went up there, it was 94°. I had a case conference meeting that morning. Going up the stairs to the ward, every window was closed and I got upstairs and got to my daughter's room and her room was open about four inches and I asked one of the staff people if her window could be opened, please get it open before I leave here. I don't think there was any danger for her jumping out through the window since there's an iron screen, a metal screen in front of the window.

The case conference meeting was held in a laundry room that day. It was about 95° and there were about six or eight laundry carts filled with soiled sheets in that room where the case conference was being held and I asked, how can you people stand it? This was the only place there was to hold the case conference that day and it was just terrible, just terrible. And I spoke about the windows being closed and I didn't leave that day until all the windows upstairs were open. It's just that I could leave, but I know the staff had to stay there in that heat and it was terrible, just awful.

I guess that's about it.

BY SENATOR GAUVREAU

Q. Thank you for your comments, Mrs. Ware. Are you the guardian of your daughter?

A. Yes, I told you right at the onset.

Q. You are the guardian.

A. I am her legal guardian, yes.

Q. And you had raised an instance where she had requested certain medications, is that it, which were administered to her?

A. No, what happened was I had spoken to the nurse practitioner early in December and said that I would like her not to have any Adavan on December 24th, no Adavan, because I wanted her to enjoy Christmas. I watched the nurse practitioner write it in the book, the order that Jan was not to be given the Adavan December 24th, none. When we picked her up Christmas morning, she was so zonked, I could not keep her - I couldn't keep her awake all day Christmas, all day I could not keep her awake. And I kept her for three days and when I took her back to the hospital, I knew, of course, that somebody had given her Adavan. So when I took her back to the hospital, I asked about it and the nurse practitioner said, well, I wrote the order, let's go look at the book In the book she had been given Adavan at two in the afternoon, two Tylenol for a headache at four o'clock, another Adavan at nine o'clock that night and another Adavan at 2:30 a.m. per the patient's request. But if the order was already written, the mental health worker must have seen that written order. I mean, it doesn't - it just doesn't seem to me that she would go against that order.

Q. And you mentioned you would regularly attend case conferences regarding your daughter, is that correct?

A. Yes, I do. They notify me.

Q. How often are those held?

A. About every three months and in the past they didn't use to notify me until after the fact and I made it very clear that I wanted to know and I wanted to be there. Just this week when I had my case conference on Tuesday, I brought out the fact that Jan has been very lethargic for a few weeks. Every time I go up there she wants to sleep and she's not dressed and she's sleeping around in the chairs. And I mentioned it to a couple of the workers and they said, yes, she's sleeping all day. And I thought, well, what is going on here. There's been no change in her medication. So Tuesday of this week I brought it up again because she was sleeping then when I got up there, which was Tuesday afternoon. She was not dressed. I brought it up again and I suggested that maybe her blood count was down and when was the last time that might have been checked, because I'm anemic and she has a history of, you know, borderline anemia. So the - someone on the staff looked it up in the books and they said it had not been checked since early last summer. And I suggested that perhaps they could check her blood count. But it would - you know, it seemed to me that they might have done that without my suggesting it.

Q. Well, I guess my point was do you feel that you've been given a chance to work with the staff in fashioning a treatment plan for your daughter?

A. Yes, now, I make sure. But, I mean, you see, they are so understaffed that it's not always -

Q. What you're saying is that if you hadn't intervened and more or less been vociferous, you might not have had a chance to take part in the case conferences?

A. That's right, absolutely, I'm sure of it.

Q. But do you know of any other parents who aren't being given the same chances you are?

A. I don't know that, I really don't. I don't see an awful lot of parents around there, not on that ward anyway.

SEN. GAUVREAU - Rep. Rolde?

BY REPRESENTATIVE ROLDE

Q. Last September the Department came before this Committee and the Appropriations Committee with the problems there and we all agreed to give them some additional money for staff. Have you seen any changes between last September and now, as you've mentioned again and again their lack of staff. And that's one of the things that really puzzles me is we gave them a good deal of money to have additional staff.

A. I have seen - yes, I have. I've seen a couple of new people whom I've never seen before that I believe are activity workers.

Q. But as far as the care, you haven't seen any improvement there?

A. I haven't seen any change, no.

Q. Despite all the money that we gave them for new staff.

A. No.

Q. On the Adavan situation, is that - does that happen that patients themselves can request medication?

A. Well, that was my question. You know, I didn't know that in the past, as I say, but that was what the records -

Q. Was there a psychiatrist that had been monitoring this medication for your daughter? I assume that he had ordered or she had ordered it first.

A. Well, she'd take - she does have Adavan as, you know, one of her meds. It's not - she doesn't have it every day, but she does have Adavan. But I - because I know what it does to her, you know, I specifically said I knew she would be excited about coming home Christmas. You know, it was a natural normal thing that she would not be sleeping, but she's not a violent person. It just seemed to me if I were a mental health worker and I wasn't - the ward was not filled with patients because a lot of them had already gone for Christmas, I would have used a little more - if the order was right there, do not give the patient Adavan, I would have found another way to quiet that patient. Janice loves to play cards, they all know it, because she's been there a long time and I think a couple of games of Gin Rummy would have solved the problem and she wouldn't have been -

Q. So you think, in effect, what happened was that she maybe got a little bit hyper and they just decided to give her -

A. That's right, because it shuts the patient up, you know. She'll sleep and she won't bother us anymore.

Q. How old is your daughter?

A. She's thirty-one. She's been ill since she was eleven. But what I'd like to see happen within the four walls is to maybe have some kind of a program to improve the quality of their lives and respond to their needs for a structure, an organization of some kind. That's the most I can hope for.

SEN. GAUVREAU - Are there other questions of Mrs. Ware? Sen. Titcomb

BY SENATOR TITCOMB

Q. I have just one question. Can you give me an idea how frequently the mental health workers would be apt to provide medications without the supervision of someone who was qualified to make those determinations?

A. I don't really know. I really don't. I know that a mental health worker gives Janice her shots, her Prolixin shots.

Q. Do you know if she's the person who orders those shots or if that supervision comes from a superior?

A. I think it comes from, you know, the RN, the nurse.

Q. My question is on the Adavan that was given, do you think that decision was made by the mental health worker or by -

A. Yes, I do.

Q. Thank you.

SEN. GAUVREAU - Rep. Pederson.

REP. PEDERSON - Hello, Mrs. Ware. I have one question. I know that you've been here almost constantly and do you feel that you were adequately appraised of your rights as the guardian and was the testimony of DHS revealing to you as to what their rights were as being guardian?

A. Hm-mm. I do. There is one thing that I didn't mention that I would like to mention as far as advocacy is concerned. You know, we cannot get my daughter to brush her teeth. I can, but it doesn't seem as though anybody else is very successful. But I think the reason is because I do hear this all the time, because I'm there two and three days a week. I hear this, you don't have to do anything you don't want to do and I think that can be very dangerous when that is said to a person who is so ill that they cannot, are not able to make any kind of a judgment for themselves. But I do hear that and I think there has to be some kind of a little line drawn there as to what the patient's rights are and what their - because I do believe my daughter has rights. She's not a person who is in a position to make too many judgment - any judgment for herself one way or the other, but my fight when I tried to get her back into the hospital the last time for her last commitment which was eight years ago, I said, she has a right to be protected from society and I do believe that. But for somebody telling her constantly, you don't have to do anything you don't want to do, that's difficult. That's a very difficult thing. That bothers me.

SEN. GAUVREAU - Are there any further questions of the Committee? If not, we'd like to express our appreciation - Rep. Cathcart, one final question before we break.

REP. CATHCART - Just one question, Mrs. Pederson earlier told us that because she asked so many questions about her son and asked to see records and being part of conferences, she was treated as though she were meddling and she felt that that might have had repercussions on the treatment of her son and was a little bit afraid to say too much. Have you had any sense of that?

A. No, I really haven't. No, I've been speaking up for a long, long time and any little thing that bothers me, I don't mind - but I really - I know that Janice is well-liked and I know that she seems to get a lot of attention from, you know, everybody. She has a lot of privileges and I think it's because she doesn't really make any waves, you know, she's very pleasant. That helps.

REP. CATHCART - Thank you. Thank you for testifying today.

SEN. GAUVREAU - Again, thank you for your presentation, Mrs. Ware. At this point the Committee will break for the lunch recess. There will be a press conference, I believe, held by the Home Health Agencies at noon today in Room 334. Mr. Frank Schiller is here from that organization and we are all invited if we have a chance to attend that press conference, which again will be held in room 334, which is the Legislative Council Chambers. We will break until 1:30 p.m.

HEARING ADJOURNED AT 12:00 NOON.

XII

STATE OF MAINE

HUMAN RESOURCES COMMITTEE

Hearing on Augusta Mental Health Institute Issues held on February 9, 1989, in Room 113 of the State Office Building, Augusta, Maine.

Norma Morrisette

INDEX

Augusta, Maine
February 9, 1989
1:40 p.m.

SENATOR GAUVREAU: I'd like to call the committee to order, and before we resume the testimony of families and relatives, I'd just like to do some procedural matters. Representative Manning has a commitment in Portland with his Architectual Subcommittee on the new jail in Cumberland County. Representative Dellert has obligations, I believe, with the Committee on - oh, she's here, so we're pretty set otherwise. Representative Rolde has other committee responsibilities as well.

We have the following situation. The Appropriations Committee is scheduled right now to meet next week on Tuesday for the purpose, among other things, of considering the supplemental budget as it relates to the Department of Mental Health and Retardation. And as you know, the department has as of, I guess it was yesterday, or the day before, suggested an interim funding mechanism of around $250,000 through June for 48 new positions, and I have heard and understand that the Appropriations Committee needs our counsel, obviously, as far as policy points of view on that issue, so I think we probably should come in in workshop and I would suggest that we meet in the afternoon on Monday. Is that convenient for everybody here on the committee? Are there any conflicts that you know of? You know, I may have conflicts too, but as far as I know - this calendar - I've got a legislative calendar and a legal calendar and I can't transpose everything, so I just looked at my legislative - anyway, in the afternoon, why don't we say at 1:30 p.m. on Monday, February 13 for the work session, and it will deal - I think we can deal with generic issues on AMHI and Mental Health. We certainly should be prepared to focus our attention on the specific interim proposal which Commissioner Parker has advanced. The hearings will end today, hopefully, and we'll be able then to resume meeting in our committee room from this point on for the hospital bills.

The other issue I wanted to address before we begin was that yesterday there was a meeting between the Governor's office and legislative leadership, and as one might surmise, the topic of AMHI was considered during the course of that meeting, and I think it's fair say that due to the sensitive nature of this area, from a programmatic and even a political point of view, there were some frank and candid discussions. I think that was helpful. I think it only demonstrated the sincerity of all parties to the table on this very important issue, and I think that as a result of that there was a suggestion which was advanced. I think John Martin made the suggestion and it was discussed, and from what I understand there is consideration to setting up some sort of a legislative liaison with the senior management staff at the Department of Mental Health and Retardation. This is in conjunction with the RFPs that Commissioner Parker had spoken of earlier in her remarks regarding bringing in an outside firm to assess the management of the department and perhaps the wisdom of any structural changes within the department. And this is an idea that is being discussed, and I don't want to give it any more weight than that, it's being discussed. It's an option, it's an alternative. Frankly, I think it's one of many good ideas which can be discussed to address this issue. As you know, Peter and I had suggested another mechanism that did arouse some attention, and I think that was probably one - one of our purposes was, clearly, to bring into the discussion on this issue an alternative. Our objective, clearly, is to make sure that we have a party outside government and outside the political fray, if you will, come in and give us some very candid and professional advice on how we ought to deal with the problems which beset AMHI and the department, and so this idea, as I say, was advanced and the Governor, I think, is receptive to the idea. It was advanced by Speaker Martin, discussed by all those at the table, and so I think that's a very good sign. But, even having said that, we still have to discuss the short-term issue which, again, is of the department's request for 48 new positions, which, as I mentioned to the others, is going to be scheduled, I believe, Tuesday or Wednesday of next week before Appropriations. So why don't we schedule a workshop at 1:30 on Monday for the purpose of discussing the short-term funding request of the department.

REP. ROLDE: Are we coming in on Monday?

SEN. GAUVREAU: We as a legislature?

REP. ROLDE: Yes.

SEN. GAUVREAU: No, we're coming in - my thoughts are, Neil, that if - this may change, and if, in fact, Appropriations does not schedule their workshop on Tuesday but later on in the week, it may be possible for us to delay our workshop, but if they're coming in on Tuesday to consider the issue, we're going to have to have some time to discuss the issue and give the Appropriations Committee a policy.

REP. ROLDE: A workshop on this specific request, or what are we going to workshop?

SEN. GAUVREAU: Are you familiar with the request which Commissioner Parker advanced on Tuesday of this week, the 48 temporary positions through June? That is the item that Appropriations wants our counsel on.

REP. ROLDE: Excuse me. Will we have some research on what has been done with the money that we've already given them and what positions have been hired? I mean, this was a question that I asked today, whether there was any perception by one of the parents whether anything had been done with the money that we had given them, and the answer was -

SEN. GAUVREAU: If time permits, why don't we give staff today specific requests, if you want, so that we can have that information available to the members of the committee on Monday.

REP. ROLDE: I'd like to know what's been done with the money for the community services programs, and perhaps even more so than just how the money has been spent, what kind of impact that has made, if any, because apparently it doesn't seem to have made much.

SEN. GAUVREAU: Ed?

REP. PEDERSON: I wondered, do we have that letter that went to the Appropriations Committee -- the Human Resources Committee that outlines whatever Commissioner Parker's request is? Do we have a notebook to put it in, or something that when we come for the workshop on Monday that it will be available - in front of us to discuss?

SEN. GAUVREAU: That's a good question. I've got a copy of that letter. I think it's on my desk up in the Senate. Why don't we make sure that everyone has a copy of the complete departmental proposal along with the letter.

REP. BOUTILIER: Were you ever sent the letter directly to you and not a copy of it - of the letter sent to Appropriations, were you sent that same proposal as Chairs of the committee?

MR. ROLDE: No, it came from the Appropriations Committee.

SEN. GAUVREAU: There's been a lot of discussion about that and it's not precisely clear in my mind what transpired. I have no doubt that Commissioner Parker transmitted it to the legislature and I don't recall seeing the letter. I think it was addressed to Senator Pearson and Representative Carter, and Peter and I, as Chairs of this committee, received copies of that, and we received that on Tuesday, because when I was at my desk about three or four in the afternoon I saw the letter, and there was obviously a question of protocol. That same question arose in August of last year in a slightly different fashion dealing with the specifics of the department's request in the special session dealing with the $6.5 million request that was ultimately funded. At that time, AMHI, BMHI, their Overcrowding Commission was meeting and there was a little bit of contretemps around whether the details should have been submitted to that committee prior to

Appropriations. It's a question of protocol, and so, anyway, the most important thing I need to mention is that this has been all resolved. I think there were some concerns, I think we've met around the table the last few days, and basically I think we're back on track and we're working in a collaborative vein, which really is by far and away the most important issue.

SEN. GAUVREAU: Brad?

REP. BOUTILIER: Did you want committee members to provide you with questions that the department would then answer at this work session?

SEN. GAUVREAU: As is the usual procedure on any workshop, if you want information, just let us know now and let the staff know now so that they can provide the materials.

REP. BOUTILIER: What do you want the parameter of the request to be? Only certain subject areas you want to talk about?

SEN. GAUVREAU: I think we clearly have to be able to respond to the supplemental budget item. That is by far the most important item, and it may take the better part of the afternoon to do just that, so if you want to go beyond that to - I would think we should confine our discussion to short-term requests in terms of staffing and so on and in terms of longer-range issues probably defer that until later on in the week whenever we next come in for a workshop. I would imagine we're going to spend the better part of the workshop dealing with the department's emergency request. Neil?

REP. ROLDE: So if we don't hear from you, then we are expected to be here Monday at 1:30, is that what you said?

SEN. GAUVREAU: Yes, yes.

REP. ROLDE: Unless we hear otherwise?

SEN. GAUVREAU: That's right, and make sure you leave with the committee clerk your home telephone number and so on so we can reach you over the weekend if things should, for whatever reason, change.

Before we resume the hearing, I want to make one more statement. The last couple days have not been without some degree of tension and some degree of dissention, but I think that as a result, certainly the meetings that went on yesterday, I think that people recognize (a) the severity of the problems that beset AMHI, and (b) I think the sincerity of all persons to the debate, and I think that is probably the theme we really have to leave with today, that we are all concerned, we have common objectives and that we may or may not disagree in terms of how we reach those objectives, but it's very important that we maintain a collaborative effort and work with one another. So with that, why don't we begin the afternoon session, and I believe that the next presenter scheduled is Mr. Bolduc. Good afternoon, sir.

PRESENTATION BY MR. HECTOR BOLDUC

MR. BOLDUC: I'm Hector Bolduc. I live in Winslow. I was born and brought up in Winslow. I have a son that is now at AMHI, he's been at AMHI since 1977, and for the last five years - the last time he was committed was about four years ago and he's been more or less locked at AMHI in the wards ever since.

It bothers me an awful lot, I've read an awful lot in the papers. It bothers me to read so much against AMHI. I'm not saying that the last three years that conditions were good because I can understand that there was a great need for change in the last three years, but it bothers me when I hear that AMHI is a place that I wouldn't have my son or my daughter in, because as a last alternative, I had to put my son at AMHI. When this happened, and my youngest son, he's one of three in my immediate family that were hospitalized, so that wasn't new to me, mental illness in the family, when I found that my son needed help. He was 13 then, and having had experience at AMHI 20 years ago, when AMHI was the only place that you could put a mentally ill person, there were no facilities in the community, the experience that I had then was such that my son went to AMHI as a very last resort. We exhausted everything. First we took him to what was Thayer Hospital at the time. For the period that he was there, the end results were, we cannot do anything with your son, he's a very sick person, he needs long-term treatment, and AMHI was the only place that I could take him to and I couldn't take that, so we took him to Eastern Maine, where he was there for probably three times the length of time that he was in Waterville, and the same thing happened, they couldn't do anything for my son. He was a sick person, needed long-term help. We managed to try to get him into Sweetser. He was there five days and we had to go get him. He ended up at the Augusta General Hospital, and again - finally, I had to have him committed. It was a point, crisis, where we had to commit him at AMHI. That was in 1977, the end of 1977, I believe, or the early part of '78.

He was in the adolescent ward. While he was in the adolescent ward, after he'd been there for a little while, I felt very, very comfortable with the care that he was getting. I felt a big part of his treatment. We met with the staff weekly, we had families that met together weekly, and this was all on tape, I do believe, they may have those tapes now. We met, probably, in the - he was in the adolescent ward from the time that he was about 16 until he was 20. He did go in the community, but it was just weeks, or at the most a month at a time, so in the four years that he was in the adolescent ward, he probably stayed in the community less than two months. He was always returned back to AMHI under commitment laws. There was nothing in the community for him. Every time that he'd go in the community there was nothing for him.

Going back to the treatment and the adolescent ward, he had been tutored at home for two years. When he went in the adolescent ward, he got his GED. Although they didn't help my son, I felt that anything, anything that was available, whether at AMHI or in the community that could help him, I felt that it was available, this was my feeling.

He was then transferred to the adult ward, and again, up until about 1984, I guess, or '85, probably, I felt I was a big part of his treatment. We met with the doctor, the doctor was available. I could call him, and I felt that everything was being done. Again, I felt comfortable with the treatment that he was getting, because what can we do. So after what I've heard and read in the paper, it's like if you say anything good about AMHI, it's like shooting yourself in the foot. God, you've got good people working there, and I've had people from way back, and you have good people.

I've seen the change myself there at the end, before Garrell Mullaney left and before the change in administration, so blaming the administration or blaming this one or that one, I think it's been overdone myself. And again, getting back to when I saw a big change myself at AMHI - it was a gradual change. I felt the morale was low, I felt that there might have been some - things weren't right, and when that Taylor woman was murdered by Addington, a big change took place. Of course, you read the papers, how pressure was put on AMHI, AMHI was in the news there for months, a big change took place.

When my son was placed - from what I can see, and again, it's only my own - what I felt was happening then, my son was being placed according to needs rather than age. There were three units that he could go into. They had what they called a base unit. When he got to a point - my son was a very, very hard patient to deal with. He was hard at home, he was hard at the hospital, he was a very sick person. When things were at a point of crisis, he'd be placed in what they called the base unit, and there was one-on-one, up until the time that he could leave that unit and go into another unit, which again was more restricted, but he could function somewhat, and as he progressed, he'd go into another unit which wasn't locked, where he had more privileges, and, of course, he, a good many times - and I don't blame AMHI - he'd get to a point where he'd have to be placed back in the base unit. He'd just go the other way, and it's not that they weren't trying, because, like I said, we'd meet every week. I felt a very good part of the plans then, treatment plans. Well, for some reason the whole thing changed around. They closed - they didn't close the ward that my son was in but they converted that ward to the forensic unit. They went from a three-bed forensic unit into a 30 or 33 beds and took my son - and I was told, I'm his legal guardian, and I was told what the changes were going to be and they tried to convince me that these changes were for the benefit of my son. We'll put them according to age, and this, I couldn't - I felt very, very uncomfortable with this change. I went down and I saw my Representative, Don Carter, and I told him what they were doing and I felt that they were taking away from my son and putting him into this forensic unit. I said, there's a big change taking place. I know that my son is getting the worst end of it, he's not getting the treatment that he was getting. He's being overmedicated, they're understaffed, and so he said, well, it can't be, we've appropriated money for this. And during this time they had - I'm not saying from this, but a short period after that they had put temporary help, I don't know, 13 or some odd, and then the commission to look into the overcrowding was put in place. I'm not saying it was from this, but this is what followed through. So even though I felt that my son was not getting the care that he should, at the very least, and knowing the system, having been in the system for that long, I knew that something would come out of it if enough effort would be placed. Then they came out with a task force that would look into the community. Although I was very concerned with the hospital and his needs there, I was just as concerned with the needs in the community, because I feel very strongly had the needs been there years back in the community, that my son wouldn't be in the condition that he is today. That is my honest feeling.

What was taking place, I felt at least we tried - I was involved in a good deal of these committees that were taking place whether invited or not. I had an opportunity to talk with the commissioner, with the people. I don't know, they say you can't talk with these people. It seems to me that they've visited every town, that they were available at times when you wanted them. If you wanted to speak with any one of them, I felt I could, and I did. Right now and with these deaths that did happen, placing yourself - January of that year, if somebody would have come up to you and said we need air conditioning, we need this or that there because - you'd say, well, you've lived there for the last 50 years, why are you coming up here? Hindsight is a very good thing when you look back. Although things weren't handled right, there were a lot of human errors in there, but again, let's see that it don't happen again. But to put blame for what happened, to me it doesn't make sense, in that sense of the word. I think there is a need for change there. I think since you appropriated that money, the questions that you asked -

I hadn't been able to keep a conversation with my son in the last three years. I'd go up and see him every week at least, and then some, and a lot of times I'd have to turn around and go back. Since that money has been put in place, we've seen a big difference. I've seen myself a difference in the staff. I've seen a difference in my son. My son right now is doing a work project, something that he hasn't done since he's been up there. He's never done that, he never cooperated. He was one of the hardest patients. He wouldn't cooperate with them, now he is cooperating. I don't know how they got to him. I don't know, but maybe tomorrow things may change, but at the very least, he is doing well compared to what he had been. I can't for the sake of me - I've heard these hearings, read the papers, and I know that you people want to do the right thing, I know this, but for myself, I think that what is in place now on a long-term basis is about the best thing that we've seen yet. I don't know how it's going to work, but by God, trying to improve the quality of care in the hospital, as well as the community itself, I think it's about the best that we could do for our mentally ill right now.

My biggest concern right now, knowing the conditions at AMHI, I'd hate to see my son go back in the community with what's out there. If it's choosing the lesser of the evils, as bad as you said the conditions are, I'd hate to see my son back in the community because it's been a revolving door. My son was committed 11 or 12 times. He's been in front of the courts, district court, for an extended commitment, I think, about a half a dozen times, so these procedures, I know how they work, I know - and I wouldn't change a thing. A lot of the complaints that I've heard right today or I've read about is complaints that I don't believe that you yourself can solve. When a person is of age, he's got rights. It makes it awful hard, awful hard for the providers to even deal with them, because a person as sick as my son refuses medication, won't cooperate, can't force him to cooperate, and it takes a special kind of person to deal with them.

I've seen myself at times when my son was at home I couldn't keep a mirror, I couldn't keep nothing in the house. I've seen one time there I had to hold him on the lawn for about 15 or 20 minutes until the officers would come because I was afraid he may hurt himself. I could hold him then, I wouldn't be able to do it now. I don't know, but I think myself that to do the right thing there, it's not a quick fix. If you think you're going to appropriate money and next year things are going to be well, they're not, but things can be better, there's no doubt that they can be better, but if you think you're going to cure it by next year, I think you're missing the boat.

SEN. TITCOMB: Thank you very much, Mr. Bolduc. Just a quick question of you before we open it up to the rest of the committee.

You said that with the influx of the money last year, you saw a difference.

MR. BOLDUC: I definitely did.

SEN. TITCOMB: Can you explain a little bit more?

MR. BOLDUC: Well, it seems to me, and I was in and out of AMHI and I was involved with the families, and it seems to me that the morale did change somewhat. You had more people. My son was given more attention to start with. I know that he was given a lot more attention than he had in the past. He could go out to the cafeteria. It seemed as though there would be somebody to see that he would go out, or go out with someone, at least that's the way I felt, where before people were not available.

SEN. TITCOMB: Thank you very much. Are there questions of the committee? Yes, Representative Pederson.

EXAMINATION BY REP. PEDERSON

Q. Good afternoon, Hector.

A. Good afternoon.

Q. Hector, you evidently have been at the hospital quite a bit visiting your son, and have you noticed the difference in the hospital? Did you notice any one area cleaner than another area?

A. I don't think that has changed any, and I even commented myself last week there that I was going to bring this up to some of the - in fact, I commented about it to my wife, and when I heard that -- she said, yeah, this is what you were saying, but I think that that's one area, and I don't see coming over here. I think that can be straightened out, it should be. Some of the things, even myself, I sat at that cafeteria time and time again and the last time I was with my other son, we had visited Matt, and I said, by God, the next time that I see some of those people, we're going to see if we can't get this place cleaned up. So I think -

Q. Hector, there's another stigma that the families have had to deal with over time, and probably when you first had to deal with a mental illness, at that time the families were pretty much to blame, they felt that it was a disfunctional family or it was something the family did. Did you have to deal with that?

A. Oh, yes, and even to this day, and I was told by some of the professionals that I was to blame myself, and this has turned me off against some of these providers. Nevertheless, I understand their -

Q. Do you still get some of that occasionally?

A. Not now, but I did in the past. I was told that I was part of the problem, and the providers are still out there today.

Q. I noticed that some of the families have commented that they still hear that today occasionally.

A. Well, if I was to hear it, I think they'd have another thought coming now anyways.

Q. Are you fearful that your son would have to be on the outside?

A. Yes, yes, very much so. I was fearful in the past. Like I said, he was out a number of times and I found that my biggest - although it is a big problem in there, I know that things need to change there, there's a big, big need out there for them, for those in my son's condition. They always fall through the cracks, and the reason being that they don't function - when they get to a point where they can't function by themselves, you cannot force them. Or if they refuse to do anything, then they'll deal - and no matter if you got apartments or jobs or whatever you have, they're always full now, and you'll deal with the people that you can deal with. Those that you can say, well, we've had so many successes out of this, and when you start a program, and it's anybody when you start, but once you get to a point - in any program that you will start, the numbers will go up or you can't take care of probably half of those that you should, then these people get caught in the cracks.

Q. Hector, are you completely - do you feel that you're completely knowledgeable about your rights as a guardian?

A. Oh, yes, definitely.

Q. You completely understand your liability also as a guardian?

A. Yes, definitely.

Q. Okay. Do you involve yourself with the treatment plan?

A. I did up until, oh, about 1986, it became more and more difficult. It was harder to get to the doctors and then speaking with one, I've only got about five minutes with my patients during the week, so how often did he see my son? Probably five minutes a week when he needed it, and this I understood. There's a shortage of staff, a shortage of professionals, overcrowding, where at one point in time I could have called the doctor and say, gee, I saw Matt today and I don't like the way he looks, could I talk to you, and appointments would be made well within reason, and I did find that in the last couple of years awful hard.

Q. And did you - how did you handle medication? As a guardian, you must have considered maybe medications or changes in medication. Did you make any decisions on your own on that or how did you handle it?

A. I could have. Yes, I did at times, yes, because I have another son that's - he's been mentally ill for the last 20 years. He's been on medication. He's been doing very well the last seven years, and he's on medication and he, himself, handles his own medication now. We've sat with the doctors, the staff, we've discussed whatever information was available as to what medication worked, what didn't work, try this, tried everything. I was in on it. I never had that difficulty.

Q. Are you presently involved in your son's treatment plan today or last week? Do you supervise -

A. About three weeks ago they said, well, we're going to arrange a meeting, but they -

Q. They haven't called?

A. They haven't, but in the past I was very much. Like I said, we'd meet at least once a month with the staff and doctor and discuss the past month and what they felt they should do next month, and that was pretty regular.

SEN. TITCOMB: Representative Rolde.

EXAMINATION BY REP. ROLDE

Q. Mr. Bolduc, you mentioned the adolescent program that your son was in.

A. Yes.

Q. And you said that was a very good program.

A. Yes.

Q. And I also in the past have heard - in fact, I even had constituents who told me that was the best program in the country. What's happened with that program, because you seemed to indicate there's been some changes at AMHI since then?

A. I don't know because my son was transferred. Once he became of age, he was transferred into the adult, which, again, this was a different program.

Q. But you seemed to indicate too that you felt a change in AMHI about '85 or '86 or sometime like that.

A. That's about the time, I guess, when they stopped taking voluntary commitments and took only involuntary commitments. The overload - I mean the overcrowding at AMHI.

Q. So right now they only have involuntary?

A. Involuntary. At one point in time they would have voluntary - a person that had been at AMHI could return to AMHI. And again, about the time that I had seen the change, when they were talking about the peak of overcrowding, they were closing wards, so it seems to me that there was a knowledge of understaffing or the need for it and the reason why it wasn't there, I don't know. But this is about the time where I had complained, where I felt that there was a big change taking place.

SEN. TITCOMB: Thank you very much. Are there other questions from the committee? Representative Burke.

EXAMINATION BY REPRESENTATIVE BURKE

Q. Mr. Bolduc, I appreciate your telling us that you appreciate the situation at AMHI and that you feel as though your son has received good care, and I especially appreciate the followup with us about how we desperately need community services. I just wanted more to comment than to question, that there's not one of us here on the committee that wants to blame anyone at AMHI. We just want all patients to receive the good quality care that they deserve whether or not they have a guardian who is as intimately involved as you appear to be. Not one of us is trying to just assign blame, but we do want to establish that any person within this state who goes into that hospital will receive the kind of quality care that they deserve, and that we will try also to make sure that we can avoid having them placed in that kind of a setting if we can do it through support in the communities. The focus on the air conditioning in particular, I think it should be pointed out that a lot of those patients, they may have avoided the need for air conditioning by taking the patients off the medication which put them at risk, but the problem of course, was that neither option was chosen, placing a number of patients at risk, and for a physician to leave patients at risk needed to be evaluated. I just wanted to assure you that not one of us here wants to just assign blame. We want very much for all patients, whether in the community or outside the community, to make sure - I mean or in the hospital, to make sure that they get good quality care.

A. I understand what you're saying. When I said myself that I felt that there was blame being put, it was papers that you read, it wasn't in the committee here, because I know - I feel very certain what you people are trying to do is for the patients first. If I did sound like I might have said it's trying to put blame, no.

REP. BURKE: Thank you. And again, thank you very much for coming. I know it must be a very painful thing to have to talk about and you probably don't get enough support yourself from the community in terms of the pain that you have gone through yourself, and I applaud you.

SEN. TITCOMB: Thank you, Representative Burke. Are there other questions of the committee? If there are not, then thank you very much, Mr. Bolduc. We really appreciate your input. The next person up on the agenda, if I have this correct, is Mrs. Burns.

PRESENTATION BY JANICE BURNS

MRS. BURNS: My name is Janice Burns and I have a daughter that has been at AMHI for almost nine years. She's on Stone South Middle; that's for ages 18 to 31. Her treatment has been less than adequate. For the first four years that she was there, almost four years, I was never allowed to see a doctor. Doctors were changed, I wasn't notifed. At this time she was an adolescent. She went in when she was 17 and she's 26 years old now.

SEN. TITCOMB: Just to stop you for a second, when was that?

MRS. BURNS: 1981. I was never notified, doctors were changed, caseworkers were changed. When I would call the hospital, they would say, well, that's not her caseworker anymore, this is her caseworker. Why wasn't I notified, well, no answer. That's not her doctor anymore, she has doctor so and so, well, when can I get in touch with him - he's at a meeting, he's at a conference, he's on his rounds, he's out of town. At the end of three and a half years, I got a call from AMHI saying that a doctor wanted to see me. I was so excited. Finally I'm going to see a doctor, I'm going to meet a doctor, discuss my daughter's case and find out what was going on with her. I was led into this room with the doctor, case manager, a physician's assistant, a social worker and nurse, and I was sitting there talking to him and they went to get my daughter out of bed, and she doesn't like to get out of bed, and I heard her screaming her down the hallway and I recognized her voice and the doctor turned to me and he said, tell me, does your daughter always act like this when you're around. I had been through this for many years, and luckily at that point I had stopped blaming myself because I got enough of it from the professionals, and I just simply told him that my daughter acts this way when I'm around or when I'm not around according to what mood she happens to get up in that morning. I got nothing out of that meeting except for the standard response when I say how is my daughter, she's a very sick girl. I know she is a very sick girl or she wouldn't be in AMHI. This isn't a dude ranch. This is the standard reply, she's not well, she's a very sick girl.

At the end of five years I got a call from AMHI. A person told me that there was a new law, that adults that didn't have the capacity for their own treatment would have to have a legal guardian, and if I wasn't willing to do it, the state would do it. I said I'd do it, and they told me that I had to pay money for this. I live in Portland. I went to a lawyer and he said it would cost something like $400. I didn't have the $400 dollars. It was right before Christmas, I was a single parent, and so I just told AMHI, I'm sorry, I don't have the money, I can't do it, you'll have to do it, so I assumed that they had done it. Several months later when I called and asked them, they said, oh, well, that hasn't gone through. So I immediately found out that I didn't have to pay any money, all I had to do was come up to the court room and ask to be her guardian, so I got legal guardianship in 1985, and in 1985, that's when I began to find out things that was happening with my daughter and what was going on.

We went to court three different times. I had asked for a CT scan and an EEG when she first came in in 1981. First I was told it was ordered, then I was told nobody knew anything about a CT scan. Then I was told, do you realize how much a CT scan costs, and so we went to court and they told us that she would not hold still for a CT scan. And so we asked them at the time, does the patient have to be conscious to have a CT scan. They said no, she could be medicated. My husband and I assured them we'd come up, we'd sign permission for them to medicate her; furthermore, we would come up and go with her. We went to court and after three times we finally got the CT scan, because, believe it or not, the first time the judge ordered the CT scan and an EEG. They gave AMHI six weeks to do this. At the end of six weeks we had to go back to court. I assumed it was all taken care of. Not only did they not even start either one of those procedures, but they used records that were six years old stating that they had tried to do the CT scan and she wouldn't cooperate. That was in 1981 that they did the CT scan. This was in 1986, and they used this as an excuse. Our lawyer happened to jump on the bandwagon and got them to admit that this, indeed, was not present, this was in 1981 that this was done. So back another six weeks, we came back again, we went with her to Kennebec Valley General Hospital. We got the CT scan and we got the EEG.

In the meantime, I had been coming up to visit my daughter every week. Her floor was covered with urine, it is today. Her bedding, if there was bedding, one time I came up and there was a sheet under the bed covered with urine, stuck under the radiator. There was no pillow, no blanket, no bedspread. I ran out into the hallway and grabbed some worker. It's hard to tell who's who up there because they don't wear uniforms and they all dress in everyday clothes, so you don't know who's a nurse, who's a staff worker, who's the laundry person who's the cleaning lady. I went out and said to this lady, could I have some sheets to make my daughter's bed. I was really upsent. And she said, let me tell you right now, patients are responsible for the upkeep of their room and their laundry, to which I flipped right out, because if my daughter was able to do her laundry and the upkeep of her room, she certainly wouldn't be in AMHI today.

I went there one day on a Saturday, they had a skeleton crew on. I came in the door, she saw me across the hall, she was holding her pants up. They weren't her pants, as a matter of fact, they were a man's pants, size 36 waist; she has an 18 inch waist. She had them rolled and rolled and rolled, and when I waved to her, she let go of her pants and waved back and there was no underwear and there were these male patients sitting there. So I went up to this nurse and I said to her, my God, doesn't my daughter have any clothes that fit her, because if she doesn't, I'll go out and buy her some. And she laughed and said, well, you know these people, they beg, borrow and steal, and she thought it was very amusing but I'm afraid I didn't. I went home and I called the superindentent of AMHI. Needless to say, he was busy, but I will say his secretary did handle it. She called the unit, she gave them for what, I got a call from AMHI with an apology. An apology was not what I wanted. I just want decent treatment for my daughter.

When we went to court at one time, a psychologist got up on the stand, and we wanted to take my daughter out, she hadn't been outside the facility for five years, not even on a walk. Her reasoning was we shouldn't be able to take her out because she was dangerous and she was too sick, and when the hospital lawyer asked her why she was too sick, she stated that my daughter slept on piles of dirty laundry, it was nothing to find her sleeping on piles of dirty laundry, or running around the ward naked. And when our lawyer asked her why my daughter was able to behave like this, her response was, well, she's been here so long and she's a free spirit, so we just sort of go with the flow, instead of saying that until she causes problems, as long as she doesn't bother them, she's up to her own devices, whatever, whatever goes on goes on.

At one time they had public pay phones on the ward that the patients didn't need any money, they could just call home without a dime or twenty cents. We used to get calls at three or four o'clock in the morning from my daughter, long distance, say would you accept a call. And when I called to complain, I was told that was the patient's right, they had a right to call. I explained my mother was elderly and ill and that she had been calling my mother and everybody that she could think of calling, not to mention clear across country. I was told that that was up to me just to tell the operator no. And when I asked who was minding my daughter at three or four o'clock in the morning and why she wasn't in bed, I was told that if she doesn't want to sleep, she doesn't have to sleep. I said, I realize that, but who is taking care of her when she's supposed to be in her room and she's down the hall at the pay phone, and I was given a big long lecture about how overworked they are, how they don't have enough staff, they're doing their job and if I didn't like it I could come up and do their job for them, and if I thought I could do it any better to come on ahead and do it.

The PRNs, which is medication whenever needed, she's been overmedicated. She's had as much as 40 to 50 PRNs in a little over a month, usually on the night shift. My question was this, and I wasn't trying to be facetious, but perhaps the late show is a lot more appealing than a patient walking around the ward or causing problems. It's gotten to the point that my daughter's condition has deteriorated since she's been up to AMHI. She was put in seclusion, which is SRC, single room care, it's sort of a padded cell without a pad. She was put in there and left 24 hours one time. When I got indignant about that, because the rights of recipients state that every 15 minutes they're to be checked, every two hours they're supposed to be toileted, offered a cigarette if they smoke, I was asked, what did they expect me to do, wake them up and take her to her own bed. So she was locked in seclusion for 24 hours.

These times when she has to go to the bathroom and nobody will come when she kicks the door and hollers and screams, I asked her where do you go to the bathroom. She said, on the floor, and so this has sort of become a habit because she does it in her room also and is allowed to do it.

The only treatment plan my daughter has had since 1981 is activity of daily living, which means combing your hair, brushing your teeth, personal hygiene, and that hasn't even been attempted until recently, when we demanded that if that's the treatment plan then we want it done, we want it monitored. We got a two-hour argument. I said I want it put in the record, I want it monitored. If this is the only treatment plan that you can offer my daughter, then I want to know she makes her bed, I want to know she combs her hair, I want to know if she brushes her teeth, and he said, that's a lot of paperwork. All I said was just one sentence will do, ADL is offered, patient refused; ADL offered, patient complied. Well, what do you want us to do, punish her? I said, no, of course I don't want you to punish her. I just want to know if she's regressing, if she's improving, if she's doing any better for herself, if she's doing any worse. To this date, we haven't got it. From time to time they come up with something, but most of the time we haven't gotten any progress on that. She had beautiful teeth, her teeth - after seven years we go into court to get her teeth cleaned. Then we were told they didn't have the money so the dentist wasn't there anymore, no Medicare funds, so she did have a dental hygienist clean her teeth.

In 19 - last year, I was asked if I would give an interview to the Maine Times. At that time I decided it was time that people knew what went on at AMHI and so I said yes. A lady interviewed me over the phone, quite lengthy, and I told my story. The following week a photographer was coming up to take pictures of my daughter, I said he could. He made the mistake of calling AMHI first and asking them if they could, and they said absolutely not, she was to have no pictures taken because she would not agree to it. But I am her legal guardian and I told him to meet us up there anyway and never mind what they said because I was her legal guardian and they had no right stating such a thing. Well, they must have anticipated it, because you would not believe that ward that we walked on that morning. That wasn't where my daughter's been living for the last nine years. They had washed, buffed, waxed the floors, bussed most of the patients out on a field trip. There were six people on the ward, all of them lucid, down in the dayroom. When I went into my daughter's room there was new curtains hanging up, a new bedspread on the bed, and hospital corners on this bed. I know my daughter didn't make that bed. There was an old metal cabinet in there that held her clothes, they took that out. They even found a little fluffy bunny and put it on top of the dresser. When I opened her dresser drawers, which usually is covered with dirty, stained clothes, what few things were there, they were all folded very neatly and nicely. My husband and I were crushed, because we could no longer say to ourselves that perhaps they neglected her out of not knowing or perhaps they're shorthanded. We made excuses to ourselves and we made excuses for them, but when you try to cover up a situation like that, that says to me that they knew they were neglecting her and they were covering themselves. So the article went out in the Maine Times, "AMHI, the Shame of Maine," and that was my daughter. She was a beautiful girl at one time, she's not the same today.

She ran away several times on the adolescent ward, on the average of two to three times a week. They never notified me; I notified them that she was in my kitchen, and they laughed and said, oh, that's where she is, well, we wondered when it was med time where she was. One time I was at work and she called me from a pay phone in Boston and I could hear traffic. I said, where are you, and she said in Boston, so I called AMHI in a panic and I said, my God, my daughter is in Boston, did you know that? Well, no, but if anybody is interested, I'll pass that along, and that's exactly the words. You would have thought I was telling him there was a sale at Macy's. I couldn't believe it. I called the Bureau of Mental Health, and thank God somebody over there located my daughter, unconscious, in the middle of a five-lane highway, drug overdose, took her to the hospital in Boston until the people from AMHI could get her. Last week she ran away from AMHI. Thank God she came to Portland, called me from Longfellow Square, said I'm down at Longfellow Square. I went down to pick her up, she wasn't there. I panicked. I went to the police station. I called AMHI because they said they had an APB out on her and an air search and whatever, and asked the physician's assistant to please call the Portland Police Department because they had no APB on her down there and they can't pick anybody out without an APB, and they said it was going to take quite a while to get through the channels to Augusta to find out. He said he would. In the meantime, she thought to call my mother and my mother sent a cab for her. We took her to my house, I called AMHI, and because of an omission by AMHI, they never took her for recommitment, they never recommitted my daughter, so she was considered voluntary, and so we were told, in effect, you're on your own. You either keep her at home or take her to P-6. We managed to take her into going to P-6. Unfortunately, they couldn't keep her, because P-6 is not equipped to deal with long-term mentally ill people, and she was like a fish out of water. My husband and I were compelled to feel we had to apologize for her being mentally ill on a psychiatric ward because her illness was so severe. She soiled herself, she wet herself. It appears she needs potty trining all over again. This was not the case when she was put in here.

I just got a bill yesterday from P-6 for three days' treatment. I don't know how we'll do it, but we'll do it somehow. When I called AMHI and asked if they could send some pills down, something, she hadn't had her meds since morning, he said he'd call it into the CVS. He sent three pills, that's all, and we were basically told we were on our own. The next day I was called at work and told that she was discharged from AMHI because, obviously, she couldn't be in two facilities at once. I had tried to tell him that she couldn't stay there, there was no way that my daughter could stay there, they're not equipped to deal with long-term mentally ill patients, but he said they felt it was in the best interest for her to be discharged. If she needed to come back, of course she could. Well, needless to say, after the end of three days the doctors at P-6 called me and said they were very sorry but they just could not keep her. She was disruptive to the whole ward, she caused chaos, they're just not equipped to deal with her. So I had to sign commitment papers and now my daughter is waiting to be recommitted again.

I called the advocate at AMHI, I keep in close contact with him. He said that he didn't even know she was missing until I informed him but that he would go see what he could find out. On a confidential report dated February 2, 1989, the day she disappeared, it says short leave granted. I don't know what that means, because I'll tell you right now, my daughter didn't have any short leave, because they wouldn't have had an air search or an APB out here, and I certainly would have been notified if she had had a leave, but she's not allowed a leave because she needs a legal guardian because she's not competent.

The lies and the deceits and the coverups have got to stop. I just don't know - I used to leave here for years - every time I would come up here I'd leave here crying, heartbroken and crying. I don't cry anymore when I go home, I'm damn mad - I am damn mad, because I feel that in this country it is against the law to abuse and neglect children. I guess the state is the only one that is capable of doing that and getting away with it, because if I kept my daughter in the condition that AMHI has kept her, the state would walk in and take her out of my home in a minute. What gives AMHI the right to treat her like this?

SEN. TITCOMB: Thank you very much, Mrs. Burns. May we ask you a few questions? Do you mind? We'll take a brief intermission here for a second.

(OFF RECORD)

SEN. TITCOMB: We truly appreciate your coming here and speaking to us. Again I'll reiterate what Representative Burke has said. I think you know what our intentions are and try to keep that in mind as we ask you these questions.

EXAMINATION BY SEN. TITCOMB

Q. While your daughter is at AMHI, what are her restrictions as far as access to the grounds?

A. She's on a locked ward and up until the last year or so she wasn't allowed out of there, except for my husband and I. Now she'd go on supervised walks with the staff to take her to the canteen. She enjoys going to the canteen.

Q. Was there ever any indication as to how she slipped out of -

A. She was on a supervised walk.

Q. Which meant?

A. That's what they told me. They called and said your daughter eloped - you know, escaped. I said, how, and he said, she was on a supervised walk.

Q. Was this a one to one that she was on?

A. I think there were other people with her. I'm not sure.

Q. Her care package, if there is such at thing, at AMHI dealing specifically with your daughter, what percentage of her care is provided by which mental health workers? Who does your daughter see the most?

A. The physician's assistant. In fact, she has a doctor but I don't believe he treats her because he relies solely on the physician assistant for all the information that he gets, and the last team meeting that we went to, the doctor was present and he said four words, he said, how do you do. And he sat there and all I could think of, he acted like he was the patient under discussion. The team, my husband and I sat there and discussed my daughter's treatment plan while he sat there and said nothing. I have gotten no input from that man whatsoever.

Q. Have you accessed her records?

A. Accessed?

Q. Have you gone in and gotten copies?

A. Not recent copies but I intend to. I meant to mention that Charles Pray appointed me to the Maine Commission on Mental Health and I'm very honored to be on that and I take that job very seriously. In the past when I would go up on the floor, of course it's locked and you have to wait, you ring a bell, they come and answer, let you in after a while, in the past whenever I went onto the ward I was told go in this room and don't go any further than this line right here. I tried to tell them I'm my daughter's guardian, I have access to her living area. Now, through the Maine Commission on Mental Health, I not only have access to that ward but I have a signed letter from Dr. Rohm saying that I can go up there night or day and the keys will be available at the switchboard, so they can't stop me from going on the ward anymore. It's just a matter of what they don't want you to see and how easy it is to cover things up.

Q. One last question. What sort of behaviors would bring about seclusionary punishment?

A. Screaming.

Q. On the particular occasion that she was in seclusion for 24 hours -

A. Screaming. It doesn't take much more. Of course, if you're combative, if you're a danger to yourself or others or the staff, hitting, but it doesn't take much more than screaming, because mental health workers don't like the screaming out there. I have seen it myself. My daughter was in seclusion when we arrived, and we saw another patient get out of control screaming and four staff members rushed over to her to drag her off to seclusion. I asked at the last team meeting that this not be the case. In a case where she's going to be dangerous to other people, the staff, other patients, fine, but because she's screaming, I don't see any reason for her to have to go into seclusion. The last time she was in seclusion she gashed her head wide open. Nobody knows how it happened. I was called at quarter after four - I was called and said this happened at quarter after four, it was almost seven o'clock before she was taken to Kennebec Valley General Hospital, because, obviously, they couldn't take her down there in her condition, which makes me wonder, are they embarrassed about the patients going down to Kennebec Valley? That's how it seems to me. And nobody knows, I got three different stories of how she gashed her head open, because the only thing in there is a mattress on the floor and that's it. I don't know.

Q. So you never got a final report to you as to why she was injured?

A. No. They said it happened in seclusion.

Q. Who is they?

A. The mental health worker that called me, the nurse, it was a male nurse, and he said that she had gashed her head open, and I said how did it happen, and he said about - well, he said, we put her in seclusion, and I said, what time did you put her in seclusion. He said, quarter after four. I said, what time did this happen; he said, quarter after four. I said, well then, nobody knew what happened; they said, no, and I still don't know what happened until this day. She required four stitches. Unfortunately, my husband and I have become very suspicious and we called Kennebec Valley General Hospital. It's not the point that we don't want to trust the people at AMHI, it's just gotten to the point, the lies, the deceit, the coverup, I can't really believe what any of them tell me anymore, and I just feel that my daughter deserves a treatment plan. She deserves records kept. I was told that that's a pain in the neck, that doctors and nurses are busy, they don't have time to keep records. Well, I'd like to know how you would know whether a patient is any better or any worse if you didn't keep records. And if the doctor couldn't make it and a new doctor came in, how would he be able to treat that patient if there were no records.

SEN. TITCOMB: Thank you very much. Are there other questions of the committee? Representative Rolde.

EXAMINATION BY REPRESENTATIVE ROLDE

Q. Mrs. Burns, where is your daughter now?

A. She's at AMHI waiting on IE papers - they're called IE papers.

Q. So she is at AMHI now?

A. I had her shipped up here.

Q. I was just wondering how we could, as a committee, get more information about this specific incident, and whether that would be appropriate for the committee because it is rather shocking.

REP. PEDERSON: Could you ask the advocate to look into it and perhaps give us - with her permission.

SEN. TITCOMB: Could we see you after the meeting today and maybe we could work something out?

MRS. BURNS: Yes. Also, I just wanted to make one more point. In the past my daughter has been - her civil rights have been violated. She has been committed without her legal guardian present or notified. I don't know if I'll get notified this time or not, because the last time my husband happened to pop up here, my daughter called the night before and said - she said, mama, are you coming up, I said, I can't, I have to work, why. She said, I have to go to court. I said, no you don't. She said, yes, I'm going to court, they're going to commit me. My husband believed her. He came up, sure enough, they were getting ready to commit her, and my husband halted the proceedings and the judge would not hear the case because the legal guardian was not present to this action. This has happened I don't know how many times. Now I'm waiting to see if they'll notify me after the five working days.

SEN. TITCOMB: Okay, if you'll stay around after, and we do have some other questions, I can see, if you'll just wait around, I think maybe the committee chairs would be best to deal with how to proceed with this. Rep. Boutilier.

EXAMINATION BY REPRESENTATIVE BOUTILIER

Q. Janice, thanks for coming today. It was obviously - you're courageous to come and give us that story, and I just had some specific questions to ask. We've talked about a number of incidents in general terms. You've elaborated on a specific case. We have heard some specific cases, but a couple of general things happened, one of them was the heat spell that we had last summer.

A. Yes, I was here.

Q. That's what I was going to ask. I'm assuming that you probably, because of that case, would have been up there with your daughter trying to help her through it.

A. I took her out.

Q. Okay, and I was going to ask you, what was the condition up there while you were there and did you - what did you do with your daughter?

A. It was stifling and every time that I would come up, I would bring a pair of shorts and a sleeveless blouse and take her out of that hospital. It was like - one day it was 98 degrees outside. I don't know how hot it was in there, it was terrible, and she came out of her room, she had a pair of long heavy cords and a flannel shirt with fringes on it. I don't know whose they were, they weren't hers. In 98 degree weather, that girl was stifling. I took a pair of shorts up and a blouse and I took her out to eat and I took her shopping and I took her for a ride around Augusta to get her out of the hospital.

Q. Now before, and maybe I misunderstood you, did you say that she had been in isolation before, in a locked area? Did you have difficulty moving her to take her out of the heat?

A. No, because at one time we had - the physician's assistant, since we took them to court, has put in a standing order that when the parents come up we're able to take her out. That's one of the reasons why we went to court, because the girl was never allowed off the ward. She is never included on the field trips, she's never included on the bus trips because she's too difficult, they say.

Q. There was a period from '81 until '85 in which the state didn't take up their role to be a guardian and you felt you couldn't and didn't proceed because you thought the state had done it, so there was a period of four years where literally she had no guardian, correct?

A. Well, while she - essentially, while she was an adolescent, of course I was her guardian because she was under age, but once she got to be an adult -

Q. When she became of age -

A. I thought that they had done it. They said that Human Services would do this, and when I showed up at court, the lady from Human Services was there and I just plain told her that I intended to take over my daughter's case. And the judge explained to me what a guardian does and - I didn't know. My husband and I are not only involved in the treatment plan, we are the treatment plan. Unfortunately, we go up every week. Once a month we get together and we tell them, and you're not going to believe this, what medication should be reduced and what medication - I've studied psych courses at USM, I've gone to seminars, but I'm not a psychologist, I'm not a psychiatrist, I am scared to death that I am going to make a mistake, but my daughter has had so many megadoses, and I said to them, I'm worried about tardive dyskinesia, and what they said was, well, it's not as if she's going to get out of here tomorrow. In other words, what difference does it make, she's going to be here the rest of her life, is essentially what she said. I'm not going to have my daughter have tardive dyskinesia if I can help it. I don't know, maybe ten years - maybe she will be here the rest of her life, but maybe ten years down the road or five years down the road there may be a cure. I don't want my daughter in that condition, if I can help it.

So we basically go in there and they say to us, well now, what do you want to do this time. I can't believe this. I'm an executive housekeeper at a hotel, my husband is an attendant in the garage, and these professionals are asking us, now what do you want us to do this week.

Q. That was my last question. You, obviously, since you've become a legal guardian, have attended case meetings -

A. Oh, yeah.

Q. And discussed with - who has been present at those meetings, how many people and what kind of input did they have?

A. The physician's assistant, the social worker, two mental health workers and a nurse.

Q. And the physician who has been there periodically -

A. I saw him once.

Q. He was there once, and he did not have any input. The person running the meeting between the PA, the social worker, the two mental health workers and the nurse, who, basically, ran the meeting?

A. The PA.

Q. Can you give me the name of the PA?

A. Yes, Bill Nevins. He has been very cooperative. The only problem is, when I want something done, I have to go through him. I've been asking for almost nine years for my daughter to have her eyes checked, and I told him again yesterday when I was up here, you know, her eyes are bothering her and it may be the medication but it's been a long time since she's had her eyes checked, I'd like her to have her eyes checked, and I said we did tell the nurse the last time we were up here, and he said, oh, you have to tell me, because maybe it gets in the chart and I miss it.

Q. Has the physician's assistant, Mr. Nevins, ever said to you, I'm the one running your daughter's case, or has he said items to the effect, well, the physician gave me this order, the physician gave me that order?

A. He says that basically the doctor comes to him for the information about my daughter, that basically I'm to go through him if I want anything like an eye checkup or her teeth taken care of. One time he got rather angry because we were up there and I had words with one of the mental health workers and he said to me, I thought it was understood that you're to go through me, and I said to him, I didn't think that was your job, but that's basically who we see.

Q. Based around the meetings, you've had some discussions about particular types of things to happen and then I guess it's denigrated to just a lifestyle activity, combing your hair and brushing your teeth and so forth, but at some point there probably were other things mentioned. Did you find they just never were done by the other people - the other staff, the mental health workers and the nurses involved?

A. Well, I found that whenever we asked that something be done or Rende be included in something, the standard reply is, well, she doesn't want to do it or she refuses to do it, but on those several occasions, such as the CT scan, they said she refused to do it. We took her to Kennebec Valley General Hospital, and to have a CT scan done, you have to lie perfectly still. This girl is really ill. She did, she laid perfectly still. She had the CT scan. They said she wouldn't have an EEG because she has got a thing about her head and they put electodes on your head. She was perfect. Whenever they say to us, well, she refuses to do it, I can't always believe them because I've found some cases where she has done it. Rende does not want her picture taken from the Maine Times. When the photographer came on the ward and I said to her, Rende - and I introduced him and I said he wants to take your picture, would you like to have your picture taken, we were standing outside her bedroom door and she said, fine, and we all started to run in and she grabbed us and threw us out and said to him, come on in - she grabbed him right in there and said, here I am, snap away. But we were told that she absolutely refused to do this, so I think a lot of times it saves them a lot of work if the standard reply is, Rende refused treatment.

Q. And just the last one. Do you remember the time when you went in - and I think all of us were very shocked to hear about what had been done when the Maine Times went into the ward finally, was she wearing her own clothes at that time?

A. No. Nice clothes, too, I had never seen them, because all her clothes get stolen, they're gone. I have bought thousands and thousands and thousands of dollars worth of clothes, and I keep getting told they're lost in the laundry, but you don't wash shoes and you don't wash sandals and you don't wash boots. They're always gone, but then they make a big deal when you come in to process these things, everything has to be labeled, and it's about three weeks before the patient gets them. It has to be sent down to the labeling room, and they're gone. I saw a patient wearing my daughter's shirt and pants one day, and she walked right past me, and I'm talking to the mental health worker and I said, geez, where's Rende's shoes; he said, we can't find them, they got lost, and this girl passed by and I said, there's my daughter's clothes right there and he said, are you sure, and I said, I'm positive. He said to her, Margaret, whose clothes have you got on; she said, Brendy's, and Rende said, I said she could, Ma, and I said, well, that's all right, but they're gone. I mean, I'm not rich and I can't afford this, and whatever I buy her, it disappears, and I'm told that they can't violate patients' rights by searching their rooms, but what about my daughter's rights? She has a right to be clothed.

REP. BOUTILIER: Thanks, Janice.

SEN. TITCOMB: Are there other questions of the committee? Representative Cathcart.

EXAMINATION BY REPRESENTATIVE CATHCART

Q. Mrs. Burns, has your daughter ever had any psychotherapy?

A. No.

Q. Since she's been at AMHI?

A. No, just ADLs.

Q. In nine years. And as far as you know, has there ever been a treatment plan? Have they told you this is the treatment we are giving her and we think she will make progress or anything?

A. No, we were very shocked when I took over guardianship and found out that that had been the treatment plan for seven years, ADLs. I've worked in a nursing home. My husband and I are both former certified geriatric nurse's aides. I couldn't believe it. This is the only treatment plan they have for my daughter. I believe that if my daughter had got the treatment she needed when she was first there, she wouldn't be in the condition that she is today.

Q. That's what I wanted to ask you. You said her condition had really deteriorated and you really believed that had she been somewhere else and given proper care, she might not be this bad off.

A. Yes.

REP. CATHCART: Thank you, and thank you for coming today.

SEN. TITCOMB: Representative Burke.

EXAMINATION BY REPRESENTATIVE BURKE

Q. How much use of PRN medications is there with her?

A. One time I asked the PA - I demanded to know how many PRNs had been used that month, and he said, forty in a little over a month.

Q. So more than once a day they are giving her - is it Adavan?

A. Pardon.

Q. Is it Adavan or do you know what it is?

A. Thorazine.

Q. Thorazine as PRN?

A. IM, intermuscular, which is ten times the potent effect of the regular dosage.

Q. And they still have to put her in seclusion now and then for screaming?

A. Oh, yeah, she gets put there on a regular basis, and the problem with that is, you see, when you put someone in seclusion, a nurse has to unlock the door, no one else can unlock the door, and if a nurse doesn't happen to be on that floor, then you have to wait until the nurse does come on that floor.

Q. Can mental health workers give Thorazine IM?

A. No.

Q. Okay, who gives that?

A. Usually the PA, a nurse, RN.

Q. And they document why they feel the patient needs it?

A. I don't know if they document it or not. I'm not sure. I haven't checked her records lately. I was getting to that this week, but I don't know if they document it or not. But I know a whole lot of times it's because she gets rowdy and loud.

Q. Is she on maintenance, just Thorazine or anything like that?

A. Oh, yes, and Moban.

Q. When the heat was present during the summer, did they caution you at all about Thorazine. Did they warn you about taking a Thorazine patient out into the sun?

A. No, and until I read that article, I thought how stupid we were, but I didn't know. The day that we went to the hearing and we asked if we could take her out, that afternoon the court said we could, we could take her out, downtown. We went - instead of going to a restaurant, we went to a little pizza place and bought some pizza. She wanted pizza. We went down by the river, it was a hot, sunny day, and sat down there and we were only there 15 minutes and her arms turned beet red, and she is light skinned anyway, and I assumed it was because she hadn't been in the sunlight for so many years. And so I said to my husband, we have to get her back to the hospital, she's getting burned. I did not know about that until I read that in that article about Thorazine, and her tongue had started to swell a little bit and I didn't know.

Q. No, no one told you, you shouldn't have been expected to know. In terms of the advocates on the ward, do you feel as though you had access to them, do you feel as though there are enough of them?

A. I don't know what I would do without the advocates.

Q. Okay.

A. And really, if you're going to start someplace, those people could use some help. They can't possibly do everything for every patient on that ward or in that hospital. I don't know what I'd do without the patient advocates, because they're honest and they're forthright with me. They're there and see things that I don't see. They've called me at home. I always have access to them.

Q. They've called you at home?

A. Yes.

Q. Tell me, do you feel other patients' families are as aggressive as you are about -

A. They're intimidated like I used to be when my daughter first got there. I was intimidated. If the doctor said she needs a thousand milligrams of Thorazine, whatever you say, that's what - I didn't know. We went to that hearing and there were these other parents there about their children that day, and, of course, by that time my husband and I were old hats, so we were all stirred up and we were getting on the bandwagon and everybody seemed to think, gee, I don't know, they were intimidated by the professionals and they don't really know their rights and they don't really know their childrens' rights, and my daughter never knew that she didn't have to take her medication because they never told her.

Q. And they never told her about the side effects of the medication?

A. No.

Q. Anyone take your daughter's vital signs, ever, blood pressure, pulse? You have no idea?

A. I don't have any idea. I asked about - a few months ago at a team meeting I asked about a physical, when was the last time that she had a physical, and he looked it up and said, well, her weight was 85 pounds, she was 4 foot 11, and her blood pressure was such and such and her pulse was such and such.

Q. And that was her physical?

A. I don't know if she's ever had a Pap smear in all the years she's been here. It has just gotten to the point that she - her mind is sick, yes, and that's why she's here, but this is a hospital, and I think that her physical well-being should be just as important as her mental well-being.

Q. I almost don't know where to go. I am sickened by the

Maine to pick it up, and thank God the legislature did. It's now called Community Sport Services.

All over the nation families are crying for help and you're our last great hope, because let me tell you something, if you get into privatization and you send the mentally ill to the private hospitals, we'll have no recourse, think about that, and that's the trend today. Let's close the state hospitals and give the treatment to the private hospitals. Believe me, there's a lot of trustees in private hospitals that don't know a damn thing about mental illness and don't care, and at least we can come to you people and you have an open mind, and thank God you listen, because families are getting damn tired of being the fare givers in the hospital and the support system and paying everything.

When I think back of $6,000 a month for McLean hospital for psychiatric care, $6,000 a month for three and a half years, and then you tell me I don't get mad, I think the system is so damn fractured. Maine's got an opportunity. Fuller-Torrey* rated this state high, don't forget it. We are a good state. North Carolina and Maine spend the most money per capita based upon per capita income of any other states for mental illness. I'd like to see mental illness kicked out mental health. Mental health is everything else, it's from flat feet to ingrown toenails. It covers a myriad of things. Mental illness is a particular illness, there's no cure but there's better treatment, and the National Alliance for Mentally Ill is working for such shows to overcome stigma like this great show called Promise that James Garner and

*Spelled phonetically

situations you described, and I realize that some of these are long-term situations, you know, obviously from 1981 until now. Changes are obviously in order and I'm glad to hear that you are on the Commission for Mental Health and glad to know that we have someone else fighting with us in this, and I'm glad you became aggressive, I'm glad you became less intimidated, and hopefully we'll be able to do something to change the situation. I know I keep saying that.

A. I hope so, too. And as I said, if anybody needs any help at that hospital, it's the advocates, bless their hearts. I mean, I don't know, they don't really have time to do everything with everybody and answer every complaint and look into every situation, only most heinous situations get answered because they don't have the time.

Q. They were never notified that your daughter had eloped?

A. Tom Ward, the State Advocate, who used to be at AMHI, he knew that Rende escaped, I don't know how. He told me yesterday at the commission meeting that he had heard.

Q. But the internal advocate -

A. But Ed Simms, at AMHI, when I called, I thought he knew and he said no. He felt foolish, he didn't know anything about it. But on her report it said short leave granted.

Q. Do you feel that that was written at the time, or did you feel like that appeared on the chart later or -

A. I don't know when it was written but it's false, because, first of all, she has a legal guardian.

Q. So they can't grant short leave.

A. And second of all, if she was on a short leave, they wouldn't have had an air search up here or an APB put out on her and the wardens and the forest service out looking for her if she was on a short leave. Short leave indicates that she had a furlough to go home, and in that case, the guardian would certainly be notified. I was told she escaped on a supervised walk and that they had all this activity going on up here in Augusta.

REP. BURKE: Thank you.

SEN. TITCOMB: Thank you. Are there any other questions of the committee? Okay, if there are not, thank you very much. We appreciate very much your input. We have one more person who has agreed to provide us with some information, but I might like to remind everyone that we are back in session at four o'clock, so if we could perhaps attempt to conclude this hearing at approximately ten minutes of, it would give everyone at least enough time to race up to the third floor. Mal Wilson.

PRESENTATION BY MR. MALCOLM WILSON

MR. WILSON: I'm Malcolm Wilson from Sidney, Maine, from Maine, not Sidney - the country. I don't want to take a lot of time. I just think that there are certain positive things that I'd like to say.

Two years ago I ran for the National Board for the National Alliance for the Mentally Ill, and with the help of Lorraine Bowdoin here as my campaign manager, I was successful in making the National

Board. Maybe I come from a different perspective and I just wanted to relate to you people that the hospital problems are quite common across the United States. NAMI, which stands for the National Alliance for the Mentally Ill, represents 80,000 families across this vast United States, and this year we will hit 1,000 AMI groups, that's Alliance for the Mentally Ill. This, to me, is a support group, it's a self-help group. I've been running around this state for five or six years organizing self-help groups. Joan Pederson is now doing it. I got her to take the job because I was getting tired and worn out. And one time she said to me, I'm damn mad about the system. I said, you'd make an ideal president, Joan, let's get you in, so that's how it started.

Sometimes the mental health system reminds me of the guy that drove in to a filling station with an old car that was sputtering and burning and everything, and he said to the guy, what do you think I ought to do, and the fella says, sell the car and keep the gas. This system is fractured, it's fractured all over the United States. Dr. E. Fuller-Torrey,* who wrote this marvelous book, Surviving Schizophrenia, is the bible of the families. He is the only psychiatrist that I ever listened to that makes complete sense. He says that families have been neglected by the treatment systems for years. Mental health centers have not done the job they should do. There's no question that there's a lot of things in the hospital, and I don't want to delve on that, we're short of staff here, we don't have enough psychiatrists, there's a lot of things going on that aren't right, but

*Spelled phonetically

you've got to think about balance, and I really think, I honestly think that the commissioner, for the first time, of any person that we've had here, was on the right track, because the problem in the hospital is basically, first, the problem in the community, and we're looking at the hospital from the wrong end when we look at admissions. We should look at the other end of the hospital, like the horse's rear end, because when you put clients out into the community with nothing there, 60% of the people who are readmissions, don't forget this. There's no place to go, so the family becomes the hospital.

My daughter spent three and a half years in McLean Hospital in Belmont, Massachusetts, a very prestigious psychiatric hospital connected with Harvard University, supposed to be the greatest in the country, and there were a lot of things there that I didn't like, and when we started running out of money, I said, let's get her the hell out of here, and that's when we did it, and we gambled, and then she came back and she fell down again and she spent over a year at AMHI, so we've four and a half years of hospitalization. But about that time I began to realize, the same these other people, and I want to thank you very much today for letting Joan Pederson, Lorraine Ware, Hector Bolduc, and also Cathy Burns tell their story. There's nothing more I can say about stories. All I can say is that case management is lacking, we're just getting into it, crisis intervention, I can remember when the CSP program that was funded by the federal government was cut off and 14 families came into a session and said we want

James Wood played in where the older brother takes care of the younger schitzophrenic. We're working through Congress. When we go down there, we call upon those people just like our people call on you. If we don't change it through the legislative system, it's doomed. I want to thank you. That's all I've got to say.

SEN. TITCOMB: I'd like to thank you. Are there questions? Yes.

EXAMINATION BY REP. PEDERSON

Q. Do you have an initiative for stigma that you're working on? That seems to be a pretty big problem, doesn't it?

A. Yeah, I'm chairman of the Communications, Anti-Stigma Committee, on the National Board, and we're contacting NBC and ABC to do away with killer shows that show the mentally ill as killers, but what you're running into today with the consumer movement is that there's no standards on television anymore. You can write anything, and all you've got to do is look at some of the shows. That's the problem. The problem has got to be everybody's problem, not just the families living with mental illness. Mental illness is everybody's problem, because I believe that if it costs $6,000 a month to house a person in AMHI, if you took that money, or you took a good part of that money and put it into the community, Maine could save money. That's a - I won't say that. They could save money in the right way - they would put it where the need is.

REP. PEDERSON: Thank you.

SEN. TITCOMB: Are there other questions? Representative Burke.

EXAMINATION BY REP. BURKE

Q. I just want to clarify, you're not saying don't improve conditions at AMHI, improve conditions at AMHI but also fund the community system, is that right?

A. Yeah. I know there's conditions at AMHI that are bad. Hector is better qualified than I am because he has a son that lived through that and he's seen deterioration in the system.

Q. Right. So when we heard from Jay Harper, who is the Director of the Bureau of Mental Health, and he had requested $8 million in his Part II Budget for community services and it was taken out by the Governor, you feel as though we should put that back in and fund the community services the way they need to be funded?

A. I think it should be more like 12 to 16 million, that's really - I bet you, 12 to 16, in that neighborhood.

Q. But we need to fund it is the point -

A. Absolutely.

Q. As well as improve conditions at AMHI.

A. I'm very proud of Maine and I want to see Maine be Number 1 in the nation.

REP. BURKE: I agree. Thank you, Mr. Wilson.

SEN. TITCOMB: Well before we close this hearing for today, I'd like to thank you, Mr. Wilson, and all of the other family members and friends who agreed to come and share their stories with us. I don't think it needs to be said that it's not an easy experience to share really heart-rending feelings with this committee. We are accepting written testimony, if there are people who would like to submit that, and I really can't even tell you an exact time. I would say as soon as possible would be a good time to try to get that testimony in. But again, I'd like to thank all of you for your attention and for your very evident concern, and here is our good chairman. I'm going to let him adjourn for the day and do all the dirty work.

SEN. GAUVREAU: I have good news. I think that an agreement in principle and in concept has been worked out, subject to the review of the legislature, and along the lines that I had mentioned at the outset of the hearing this afternoon. I think that what should happen is that probably - actually after the hearing here, perhaps the Republican members can go speak with Noreen and Democrats can speak with leadership on their side of the aisle to further articulate the contours of the agreement, but basically there will be - there's being very seriously discussed an oversight committee which would consist of legislators from both parties working with senior management staff at the Department of Mental Health and Retardation in concert with the independent Mental Health Commission, which would work in securing the services of a management agency to assess - do a thorough assessment of AMHI, and also to oversee the articulation and long-term implementation of reforms which are suggested. This is, I think, very positive development. I think it shows that notwithstanding some of the emotions and understandable rhetoric over the last fews days, I think we've made a lot of progress, and I really believe that if this does come to fruition, it will constitute a major step toward improving conditions, not just at AMHI, I think, but for the entire mental health system, including the Bangor hospital, so I think it's a very positive development. As we now come to conclude these hearings, I want to, as chair of the committee, thank all the members of the committee who have worked dilligently over the past two weeks, you've all done a very commendable job. I want to thank all those who presented to the committee during the course of the last two weeks, I know that there have been some difficult times for some of the presenters, but I think they all served a very important role and the chair appreciates the efforts of all in this regard. So with that I will close the hearing. Again, I thank all those people today also who presented to the committee, and before we break, I would suggest that we are still on for Monday afternoon at 1:30, because although we have in concept, I think, agreed to this long-range solution, the immediate problem of what do we do about the short-range positions exists, so we'll have to deal with that issue on Monday. If you haven't already, please indicate to staff what information or questions you may have regarding Commissioner Parker's short-term 48-position request.

HEARING ADJOURNED AT 3:30 p.m.