VIIIC

STATE OF MAINE

HUMAN RESOURCES COMMITTEE

Hearing on Augusta Mental Health Institute Issues held on February 7, 1989, in Room 113 of the State Office Building, Augusta, Maine.

Norma Morrisette

I N D E X

Augusta, Maine
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9:15 a.m.

REPRESENTATIVE MANNING: Just to go over a couple of things, when the Senate comes down to the upper chambers -

SENATOR GAUVREAU: Over to the upper chambers.

REP. MANNING: Only a few times can you take a shot at the Senate. When the Senate comes down to the House, we will adjourn - we will recess or adjourn immediately, because at that point the Chief Justice will not be that far behind, so we will recess immediately and we will come back in, I would say, 1:15 this afternoon and finish up on the Human Services area. It was decided yesterday that the committee would go and hear the Chief Justice, because it is an important part of the legislative agenda to understand what is going on in the judiciary, so we will - if we adjourn quickly, please don't think that we're cutting anybody off. It's just that we will go back in - we will come back in this afternoon.

This morning we are going to be hearing from Peter Walsh and the people who did the investigation for the guardians of the wards of the state at AMHI, and I'll lead off with Peter and he can do the presentation from there. Peter.

MR. WALSH: Thank you, Representative Manning, Senator Gauvreau, members of the committee. My name is Peter Walsh, I'm Director of the Bureau of Social Services in the Maine Department of Human Services. On my right is Joyce Saldivar, who is the Director of our Adult Services Program, which is in the Bureau of Social Services, and on my left is Tom Bancroft, who is the Manager of the Guardianship Program in the department. Tom was

the team leader on the assessments that we conducted at AMHI.

To begin our presentation, and I would say that we are here mostly to answer questions, but we thought it might be useful for the committee to briefly trace the history of the guardianship program and tell you a little bit what its purpose and functions are.

The present statute that governs the guardianship program was enacted in 1981. Maine did have a public guardianship program since about 1973, but up until the early 1980s there were very, very few people who were in the public guardianship program. I remember back in the late 70s and early 80s that we had no more than four people who were public wards and had been assigned to the public guardianship program. After the revisions in the probate code, there was a change that affected the guardianship program, one of which - the change said that persons could come into the - become wards of the state for what is called limited guardianships, that is that the state did not have to take control of their total person but they could take limited control over, for instance, financial matters or some aspects of decision-making rather than becoming the total surrogate for the person, so that we could get involved with medical decisions or psychiatric decisions and not get involved with the total aspects of a person's life.

At about the same time, nationwide and in Maine there were a series of hearings leading to the Informed Consent Doctrines, which is the one that says that for people who are incapacitated or dependent, they needed somebody, surrogates, to help make

decisions, critical decisions about their lives. There were hospitals and nursing homes that started requesting public guardians for treatment purposes, where in the past nursing homes, hospitals, AMHI, public institutions had basically decided what types of treatment was required by people and then would provide that treatment. Now you had a change to where they wanted an outside perspective. They wanted somebody else to come in and say, yes, we authorize this particular type of treatment because we don't believe that this patient is capable of informed consent regarding the treatment. So in the early and then the mid 1980s we started getting a lot of requests from nursing homes and public and private institutions to provide the guardianship service. Along with the informed consent, at the same time people were concerned with liability issues, and this was again one of the reasons why they wanted somebody from the outside to come in and basically make surrogate decisions. So in the early 1980s we began to get a number of requests to do studies, guardianship studies, in nursing homes, at AMHI and BMHI and in other private institutions, and at that time we contracted with a consultant that we brought on board, because we were, in many cases, being asked to make decisions about people who had been long-term residents of these facilities. We did not know them, we had had no contact with them, so we had to do a lot of background information in terms of reviewing their records, contacting relatives. The law says that we should first try to find private guardians, that public guardians should be the last resort. So in late 1983 and '84,

we had less than 75 total cases of people who were wards in our public guardianship program. But again, that had gone up from about four, again, as I remember, in 1979 and 1980. We only had, again, four people. We essentially did not have a public guardianship program.

From '83 to '84 and 1985, the number went from 75 to 121. Then the next year it went to 140. These were new cases that were coming in to us each year, so we were scrambling at this time to try to keep up with this whole brand new influx. We had to learn ourselves what it meant to be a guardian for somebody, especially people who had been long-time residents of institutions.

In 1984, as a result of a Mental Health Task Force Report, the Informed Consent Doctrine was extended to the mental health facilities, and at that time AMHI and BMHI could no longer treat without having the informed consent of the patients. So, in two to three years, we went from having no wards in our program from the institutes - in two or three years from zero to 50 and we now have approximately 45 to 50 wards at both AMHI and BMHI.

As one response to this in the Department of Human Services, in 1985 we separated our protective services and our guardianship program. Protective services is one where persons are - some persons are mandated to make referrals on abuse or neglect of adults, and we have a staff of people who go out and do an investigation to see if an adult is abused, neglected or exploited, and at one time we had - the guardianship program was such a small one that we combined the guardianship and the protective -

they were part of one program, and in 1985, to respond to the increasing number of guardians - wards coming in, we separated those two programs.

In 1985, we had 203 open guardianship cases, and 150 of those persons were in institutions. Now we had a fixed number of staff in our protective and guardianship program, so at that time we assigned three caseworkers to work with public wards in the facilities. Again, in 1989 we had 235 people in the facilities. So as you can see, over a decade we've gone from a zero really, basically, program, very small, to one in which we have now 235 persons in facilities, and we have about another almost 200. There's a total of 428 persons overall who are in the public guardianship program. Now many of these people live in boarding homes, adult homes throughout the community, or in other places, their own homes.

From 1982 to '85, the numbers of caseworkers in the guardianship program - in the adult services program increased from 29 to 43, and since 1985 we have had no increases in staff. This year, we're adding four positions within the next month or so, and we do have a budget request in as part of the budget for additional staff because of the growth in this program.

From 1983 to 1988, we've served over 700 people in the guardianship program.

There has been some talk about the committal process. How does someone get committed and how do they come into - become a part of the public guardianship program. As you are aware, the

involuntary commitment process is basically spelled out in 34-B. A person must be mentally ill or danger to self or others and inability to care for self. The Department of Human Services gets involved either because we come onto somebody through our protective services program and think that they need to be placed at AMHI or BMHI, or because the institute has a person whom they believe fits the definition of an incapacitated or dependent adult, and they request guardianship.

So if we - if through our protective process, if when we're doing an investigation we believe that someone is in need of placement, we would arrange to have that person evaluated at a community mental health center, and then the mental health center makes the decision about whether the person should be sent to AMHI or BMHI. In other words, we can recommend that a commitment be made, but the community mental health center does the evaluation and then actually, I think, has to have a district court judge send the person to AMHI and then AMHI does its own determination on commitment. So essentially it's a different process, I guess is the point that I'm trying to make, between somebody being - having the Department of Human Services as its public guardian and the committal process for a mentally ill person.

For somebody to be in the public guardian program, they must, in addition to being mentally ill and meeting those other standards, they must also meet the definition in the adult protective services law regarding incapacitation. They must be

unable to make decisions in their own best interest, and that's defined in the Probate Code.

So if a person is already in the guardianship program, if we have somebody who is at AMHI already, and I think that of the 45 wards at AMHI, 39 of them were already there and we were requested to become the guardian. In other words, we did not make a referral on 39 people. Some of them had lived there for years and years and years, and we were asked to come in in the 1980s and begin participating in the treatment planning for these people.

That's a brief overview of the adult services program and our involvement through the committal process. The next thing I was going to do was go through a chronology of events that led us into our evaluation of the wards at AMHI. I don't know if you want - if people have questions right now that they want to ask about the guardianship program.

SEN. GAUVREAU: Representative Dellert.

REP. DELLERT: I was curious, Peter. How would someone get out of protective custody, you know, if the family or someone wanted them out of it?

MR. WALSH: You're talking about the guardianship program?

REP. DELLERT: Guardianship. I'm sorry, guardianship.

MR. BANCROFT: If I may, Representative Dellert, we would proceed back to probate court for a motion to dismiss, and so it would be another hearing to dismiss, and we do terminate many guardianships, many for reason of death, many elderly people. We have a 20% -

we have a lot of elderly people, a high percentage, about 70%, so many terminate just that way. We terminate many, as many as we can, at least, because we have a mandate toward less restrictive alternatives, we terminate many if incapacitation no longer exists, so we go back to court to do that.

REP. DELLERT: Thank you.

PANEL - PETER WALSH, TOM BANCROFT, JOYCE SALDIVAR

EXAMINATION BY REP. PEDERSON

Q. Do you have a liability in becoming guardian? Do you have any liability when you become the guardian?

MR. WALSH: Whatever liability we have is protected through statute. I don't believe we've been -

MR. BANCROFT: Our best advice is, I guess, that we are somewhat protected by the Maine Tort Claims Act. How much we are hasn't been tested yet, as yet. I hope that's not to be tested, but it hasn't been tested yet.

MR. WALSH: But certainly I can foresee that there will be circumstances where people will disagree with our decisions. We've been involved in a number of controversial cases; for instance, the Gardiner case, we were asked to provide our recommendations regarding that particular case. We're involved in a lot of really new kinds of things about right to die and ethical questions and, you know, at what point do we stop providing treatment or even basic support systems to people. So we as the public guardian are daily making decisions about provision of treatment, provision of medical treatment, provision

of mental health treatment, right to die issues, so it is an area that I'm sure is one that is going to be tested further in the courts.

SEN. GAUVREAU: Generally speaking, the department would be immune under the Maine Tort Claims Act, and someone would have to bring a civil action and actually seek leave of the legislature, such as you will see on the Senate Calendar today, this lady on Item 1-6 is seeking leave of the legislature to allow her to bring a civil action against the Department Human Services and its employees, but absent that, the members of the department will be immune under sovereign immunity.

REP. PEDERSON: The other question, I had a question on committal law. You've done a lot of work with that and I think that there's a lot of concern about maybe some change in the committal law, and some of it might be to your advantage when you work as a guardian. Can you comment on the committal law and ways that it might make it easier to get treatment for clients, ways that would be more justly done, or anything of that nature?

MS. SALDIVAR: That would probably take an hour to really address - even begin to address adequately. But when we talk about the committal, briefly, Peter addressed prior two, but once people are in AMHI, for example, they do go through the recommittal process, and those are two separate kind of -

Q. Do you think that - I'll have to ask you this, do you think there might be changes in the committal law that might work better for all the people concerned?

MS. SALDIVAR: I guess I'm really not qualified to answer that.

MR. WALSH: We don't have a position on that. Again, we recommend through the existing committal process and we receive requests to have people put into our guardianship program, but we really haven't taken a position on that. We would have to see what the proposals were and see how they affected our particular work.

The committal process up until now for us in terms of our perspective on it with our wards, I don't think we have major problems with the way it operates now. That's not to say that somebody other - some others who are more involved with it shouldn't comment on it.

Q. What do you do now when you have - you're the guardian and your client refuses treatment?

MR. BANCROFT: Acting as guardian, our mandate is to act in the best interests of the ward, not necessarily what the ward might have wanted themselves. I don't think most of us would agree voluntarily sometimes to some of the treatment that's being offered, but in their best interests, we make decisions in collaboration with the treaters at the facility, so that we act in place of the patient as surrogate.

Q. So sometimes you make a judgment that they really do need the treatment whether they want it or not?

MR. WALSH: Yes.

MR. BANCROFT: That's right.

MR. WALSH: When a person is in our full guardianship, again, not one of these limited guardianships, we do act as the person, and

again it's another step beyond mental illness, it's a step that says the person is not capable of making their own decisions, that they are incapacitated or dependent, so we will make that step. Now if we have somebody in the community that we believe is incapacitated or dependent, we don't always necessarily - those aren't always mentally ill as well, so we will often go to court - we have to go to court if a person is going to be placed into our guardianship program, and we have to prove to the court that the person is incapable of making their own decisions, is incapacitated to that extent.

We've seen many stories. We're involved in every one of those newspaper stories where you see that there's an elderly person living in her own home, the home is filthy and she's lost the capacity to take care of it and she has 20 dogs and the community, you know, wants the state to come in and get rid of her, we've seen all these stories over the years. We will be involved in most of those cases, and we have to walk a fine line between respecting the person's own ability to make decisions and seeing if it gets to a point where we believe that they can no longer make those decisions. And when we get to that point, we then have to go to court with witnesses and others and prove that we think that the person is no longer capable of making their own decisions.

REP. PEDERSON: Thank you.

SEN. GAUVREAU: Other questions? If not, why don't we proceed then to a narrative on events which led to the department's

investigation of AMHI conditions in October or November.

MR. WALSH: In May and June there began to be concerns about adequacy of treatment at AMHI from a variety of different sources. First of all there was the Medicare decertification. Secondly, Judge Mitchell, who is the Probate Judge who sits over at AMHI and is involved with the monitoring of many of our treatment plans, raised some concerns about some individual patients and some of things that he thought was happening to individual patients. In a June meeting that we had with the advocates in an inter-departmental meeting, it was identified that there were two specific wards at AMHI that people had some concerns about. In July of this past year, we investigated the two specific cases that were identified in that meeting, and at that point we made the decision that we should look into more than just those two specific wards.

In August, there were the deaths at AMHI, and then in August also, we received correspondence from the advocates for the disabled essentially asking us to do an investigation of all the patients at AMHI, not just our public wards. So as a result of all of those things coming together, our own investigation that we had started, our assessments of what was happening there, we decided that we should do a full-scale assessment of each one of our individual wards at AMHI and BMHI. We decided that we needed to take a look, the program had been growing so fast and there had been such complaints. So at that point Commissioner Ives ordered us to do an immediate assessment of all of our wards at

AMHI and BMHI, beginning at AMHI, and at that point, we started doing our assessments. As a result of the first assessments that we did, we found that there were some significant problems with the first few patients that we looked at, and as a result of that, we decided to speed up our investigation, and at that point we pulled people - we were just working with the people in the adult services program. So at that point we put together a team of persons. We brought people in from our child and family services program who had experience in investigations and had experience in this type of work, brought in a psychologist consultant as part of the team and some other members, and we did a - over the next month or so we did a review of all of the public wards at AMHI.

As a result of that review, we came up with a plan, first of all, a detailed number of problems that we found in regards to care and treatment of our wards at AMHI, and we listed out a number of recommendations for improved care and treatment for those wards.

I think you may have seen the summary that we have distributed.

SEN. GAUVREAU: There's a question from Representative Boutilier.

REP. BOUTILIER: As you proceed through - when you presented memos, when you presented a plan, could you give us the month, and if you can be exact, give us the dates that you did those things, because we have other time lines that we've been using, and it would be appropriate, I think, at least for me, and I think other members, so we would know exactly when these different proposals were presented?

SEN. GAUVREAU: We should have that report in our packet of materials.

MR. WALSH: I'm just a little bit unclear. Do you want me to go over it memo by memo? I've got a lot of memos that I gave to the commissioner.

REP. BOUTILIER: Well, for instance, you just mentioned you devised a plan of care and treatment and you submitted that. What date was it that you did that?

MR. WALSH: Okay, I'll start back in June. On June 13 Judge Mitchell raised some concerns regarding a couple of patients at AMHI, that was on June 13. On June 29 - and there were things that happened in between these, but on June 29 we did have a meeting with the Office of Advocacy in which they identified a couple of specific wards that they felt were in danger. In July, I don't have a specific date, but we did have our people investigate those two specific cases. It was an ongoing investigation through the month. On August 23 we received a letter from the advocate for the developmentally disabled again stating the problems that they saw and asking us to do a review of the - all of the - everybody at AMHI, but we just felt it was beyond our scope and capacity and that we didn't have the authority to do that.

SEN. GAUVREAU: Peter, can I stop you right there? I mean, that is a rather extraordinary request. Did the department correspond or communicate with the - they were then the advocates, now they're the Maine Advocacy Services, did you folks correspond with them and

indicate what concerns you had, and did you inquire why that entity would want the State of Maine DHS to do a broad survey of all the adults at AMHI?

MR. WALSH: We had been meeting with them, so we had been communicating with them about the various issues there and we did respond to their requests, and I'm looking for that letter. She wrote to us on August 23 regarding a report that was mailed to Commissioner Parker on August 19, with a copy that was sent to Richard Estabrook. And then she requested adult services to conduct an investigation into the deaths of the patients and that the division conduct an investigation of conditions relating to the safety and medical of the remaining residents at AMHI and that we provide protective services as necessary. So we wrote back and said that we were referring the deaths, including Mr. Poland, to the medical examiner and the office of the Attorney General, and that we would, under the mandates of the Adult Protective Services Act and the Probate Code, we were planning to focus on our public wards that were residents of AMHI and BMHI. And we said that we would conduct assessments of safety and medical care of the 47 DHS public wards at AMHI and 50 at BMHI and that we would notify Commissioner Parker of our pending assessments and offer cooperative efforts regarding the remaining residents at AMHI. So that was on August 31, actually, that we responded to the letter from Laura Petovello.

On August 26, again, Commissioner Ives ordered the immediate assessment of all the wards at AMHI and BMHI, and on August 29 we

sent a letter to the deputy superintendent at AMHI notifying them of our intent to do this. We received excellent cooperation. Tom was the team leader and he was the person who was over there supervising and involved in the individual assessments.

SEN. GAUVREAU: Representative Burke, I believe, has a question.

REP. BURKE: Did you say you referred some of it to the Attorney General's office?

MR. WALSH: Yes.

MS. SALDIVAR: The deaths.

MR. WALSH: The deaths, right.

REP. BURKE: Oh, just the deaths?

MR. WALSH: Right.

REP. BURKE: So no one, in actuality, did a complete assessment of the entire facility, except in light of your wards that were there?

MR. WALSH: Right. That's not our job in adult services -

REP. BURKE: That's fine, I'm just trying to clarify that. Thank you.

MR. WALSH: On September 2, Commissioner Ives sent the letter to Commissioner Parker detailing our plans for the assessments, and on September 4 we began the assessments of the remaining wards. So that assessment took September and October, and a preliminary report was written and issued on November 10, and in that preliminary report we had an assessment that each one of our - we had a team that looked at each patient. We reviewed the records and in some cases talked to staff and in some cases,

where we could, talked to the patients - we talked to every patient. We came up with a series of conclusions and recommendations and we summarized those conclusions as follows:

We found that of the 45 patients, 12 were receiving treatment supervision and programs that we felt were commensurate, the team felt was commensurate for their needs and that they did not require any additional followup at the time.

We found that 33 wards required additional assessments or evaluations as follows: We referred 8 to our adult protective services program because of alleged patient to patient altercations with resulting harm or alleged neglect. Okay, now this is our guardianship program, and we found that there were some allegations of patient to patient altercations and we referred those to our protective services division for further investigation. We referred 7 - some of these are duplicates. These numbers don't all add up to 45. We may have had the same people that had two or three multiple referrals. Seven were referred to our adult services case manager. This is the person, the guardianship person who has responsibility for those persons to reassess the case plans, to coordinate with AMHI staff regarding those case plans, or to provide advocacy for the public ward. Fifteen cases were referred to a medical consultant to review medical issues such as incontinence, further diagnostic exams, seizures or review of medical notes. Sixteen were referred to a consulting psychiatrist to review their treatment plans, medication orders, diagnoses, use of seclusion and/or restraints and medical progress

notes. Eight were referred to a consulting occupational therapist to review individual program plans for less restrictive placements, transition plans and to develop or suggest approaches to difficult behaviors. Twenty one were referred to the AMHI superintendent to request that he review progress notes, medical notes and incident reports, notifications, the process that is used to notify guardians, especially when the guardian's authorization was required for treatment. I'll just say parenthetically, there are a lot of other people at AMHI who have guardians who are not the public guardians. Family members can be guardians, or other persons appointed by the courts. Treatment plans, conditions of living space, staffing levels and implementation of doctor's orders, and we said that this was a preliminary report that we were doing and that a final report would be completed when the results of the additional assessments or evaluations are received.

So what we did at that point was we first identified various medical, psychiatric and occupational consultants that we wanted to basically come in and give us a second opinion. That's what these referrals are all about. And we contracted with a psychiatrist, a physician, an occupational therapist and a psychologist to come in and review what we had found, review the records, review the referrals that we made to them. We're still getting those reports back. We have some of them back but we don't have them all back yet.

REP. BURKE: So who did the study for you, or was it people from your department went over and looked at AMHI?

MR. WALSH: Yes.

REP. BURKE: And then the records that you needed to review you showed to a second panel?

MR. WALSH: Not a panel.

REP. BURKE: A psychiatrist, medical doctor and occupational therapist?

MR. WALSH: Just on specific incidences where we felt there was something - their professional judgment.

REP. BURKE: Those people never actually went over to the facility to -

MR. WALSH: Oh, yes.

REP. BURKE: They did.

MR. BANCROFT: Right, at our request.

REP. BURKE: The same people who are looking at the charts also went over to the facility to -

MR. WALSH: No, we first had a team.

REP. BURKE: From your department.

MR. WALSH: From our department.

REP. BURKE: So there was no physician, no -

MR. WALSH: There was a psychologist that was a member of the team, an outside psychologist under contract with the department, not somebody who works for the department. Who are the other team members, Tom?

MR. BANCROFT: We did an assessment to determine - first of all, we did the assessment. The assessment team we set up as social workers and myself acting as public guardian, and several

other members were - I have a Master's Degree in Psychology and there was a BSW, a Bachelor or Social Work on our team. There was a casework supervisor, who is a certified licensed social worker, and there was one of the caseworkers who carried most of the cases over there that is a licensed social worker. We had the department aides coordinator, who was lent to us by Peter. We had a child and family services specialist and another child and family services specialist, but the idea originally was for us to go in more or less as lay people acting on behalf of the public ward looking for what might be missing or what - any questions that we raised, it was an assessment, it was not a professional evaluation at that point. When we saw questions that we felt needed to be answered, and we read the records thoroughly, we met with every patient regarding a ward that we were assessing and we saw their living conditions. If we had any questions whatsoever, we referred those to what we thought might be the appropriate people to professionally evaluate them, which might be a psychiatrist in the case of some medication reviews, or it might be an MD for what we thought might be unfollowed-up medical referrals, the occupational therapist for least restrictive living alternatives for somebody who might not need to be there in the first place, and the psychologist for possible testing for closed head injuries, for somebody who might not need to be there. So we raised the questions and then we brought in outside consultants to evaluate them.

REP. BURKE: Okay, thank you. I didn't mean to interrupt your

presentation. I was just getting confused.

MR. WALSH: And that's what we're receiving back now. We are now receiving the reports from the persons what we brought in for second opinions, and we are - during all this time Judge Mitchell asks for - to see the report, the initial report by the assessment team, the preliminary report, which we gave to him, and he has now asked us to give him followup reports on all of our wards on a regular basis. So as we get in the second opinions, we are forwarding those particular pieces of information to the Judge as well.

When we started this, it was our intention that we would first have the preliminary report that would identify the issues, identify recommendations, and then we would have the followup information that would come in from protective services, the various medical personnel. Then we would have the same thing happen at BMHI. We have started our assessments at BMHI, and then we may find that we need to have some outsiders come in there. So at the conclusion of all this, we will issue a final report. We are in the process right now of putting all of this information together. We knew that it was going to be an extended period of time that we would be involved with this, and at the same time we are beefing up our own staff, because our caseloads have just been too high. Given the growth of the program that I talked about and the lack of additional staff, our caseworkers themselves who have been over there just have had too many cases, so we're in the process of hiring additional staff right now for

both AMHI and BMHI for our protective program and our guardianship program.

SEN. GAUVREAU: Peter, when do you contemplate the final report might be available to the - to your department or to the legislature?

MS. SALDIVAR: It really depends on when we get all of the followup information, and there have been some delays in some of them.

MR. WALSH: At BMHI we've just started.

MS. SALDIVAR: And then the whole followup case. Also, while we -

SEN. GAUVREAU: Well, the committee, we have to be concerned, obviously. We're not interested in particular cases with identifying materials, that clearly is confidential under our statutes, as well as federal statutes, but we obviously are keenly interested in what direction the department might take, and in that regard I was going to ask, is it possible or does the department contemplate, perhaps, moving individuals from their current environmental milieus depending upon the results of the report?

MR. WALSH: Right. Just let me answer your first question. I do not believe it is going to be - it will probably be six months. I don't want to say it's going to be two months and then not have it done. We have to complete the assessments at BMHI. But each one of these chapters in the final report, so to speak, basically, in some ways stands on its own. We've done our assessments. We have our recommendations and now we're receiving

back information on what we should do next. So the final - and we have already made some determinations about how we're going to change our practice in terms of our involvement over there. So the final report is going to take us - finishing, getting back all the second opinions, conducting the assessments at AMHI, doing whatever followup will be necessary there, and then putting the final report together, so that's why I say, we've just started the assessments at BMHI, so it's probably going to be, I would say, six months to be safe.

SEN. GAUVREAU: The second part of my question was, do you expect moving any patients from their current location based upon your assessments?

MR. WALSH: We have looked at a couple of individual patients - Tom, do you want to speak to that?

MR. BANCROFT: We are contemplating moving one patient - well, we are moving one patient if we can get the funding, and we are contemplating moving some others in cooperation with AMHI. The one that we've determined that probably doesn't need to be there is a closed head injury, a young man who suffered - in his record it was noted that he had suffered a closed head injury, alleged closed head injury someplace in Texas when he was a young man and it appeared that his behavior problems stem from that and it's relatively - it's a relatively common event in closed head injuries that the symptoms - and I'm not a psychologist, this is from an educated lay person's point of view - they mimic mental illness, some of the symptoms, so that this young

man was being treated at AMHI, very appropriately treated at AMHI, but he didn't have a major mental illness. His problems stemmed from closed head injury. So we got an evaluation from a neurologist and then we made a referral to an outfit in Massachusetts called New Medico, who specializes in closed head injuries, and they did - came up from Massachusetts and did their evaluation, which was very extensive. The evaluation for a closed head injury is a series of separate evaluations. We've been through all those evaluations and he has been determined to be a closed head injured patient who could benefit from their treatment program in Massachusetts. However, the Medicaid funding mechanism which might pay for this has contracts with five closed head injury facilities, three in Maine and two in New Hampshire, and we had to go through a series of refusals from those facilities as being inappropriate for their facility because of his behavior in order to now go back to - and we have those five refusals and now we have to go back to Medicaid and make a case for Medicaid paying $754 a day in Massachusetts for this treatment. That's where we are now.

SEN. GAUVREAU: Okay. Well the thrust of my question -

MR. BANCROFT: If you asked us are we considering moving, there's one.

SEN. GAUVREAU: That's one patient, but I guess -

MR. BANCROFT: There are others who while suffering from major mental illness might benefit from less restrictive placements in the community if those existed, and the Department of Human Services,

of course, has the Bureau of Medical Services Licensing and Certification Division which licenses adult boarding homes. In our own department we're looking at funding some specialized boarding homes, and the Department of Mental Health, I understand, although I'm not privy to a lot of the information, I understand they are looking at also funding of specialized boarding homes which would need much more clinical expertise in order to deal with some of the difficulties from deinstitutionalized patients.

In our own Division of Adult Services, we have been trying for the last year to put together a specialized boarding home of this nature, and we have the beds assigned to us from our Division of Medical Services, which means that we can do it if we are able to get through the - if we're just able to put it together. It's a difficult process. So we're working on our own six-bed facility.

MR. WALSH: I think the summary is that of the 45 patients, there are few of them that at this point we feel that we could develop an outside placement for.

SEN. GAUVREAU: Peter, of the 45 patients, we have also a summary of the Probate Judge's report, Judge Mitchell. Are these the same individuals -

MR. WALSH: Yes.

SEN. GAUVREAU: Because they came from his court?

MR. WALSH: Yes.

SEN. GAUVREAU: What I was just trying to get at before, I see a pattern of some concern. Many of these people seem to be, or

at least the allegation is they're being overmedicated, and that's what Judge Mitchell's summary seems to indicate. What I was concerned about was whether the department feels that - do you have concerns that perhaps patient care at AMHI in many of these cases is so inappropriate as to justify changing - taking a person out of the hospital and to another provider?

MR. WALSH: That was one of the concerns that we had when we looked at a number of the patients, was the medication, and that was one of the specific things that we asked the medical and psychiatrist to look at.

MR. BANCROFT: The questions that we raised initially were based, again, on educated lay people reviewing the records and raising questions, and we saw instances of - with the heat over there, psychotropic medication or medication which addresses the mental health difficulties, psychosis, with the heat it seems to interact so that there were some cases that we noted in the record, which were very adequately documented, that there were cases of orthostatic hypotension is the word, which basically is the person becoming groggy and sometimes passing out as a result of the medication and the heat and not enough water and so forth, and the blood pressure drops, as I understand it, and a person is liable to just pass out. So we were concerned about those with our public wards and we noted those and we made - and there were other instances where it just appeared that a person was receiving a high dosage of psychotropic medication, just out of context with the behavior as we saw it, and we referred

these to two psychiatrist. We had one psychiatrist originally who, just because he was too busy, only evaluated - came in and evaluated one person for us, and then we had another psychiatrist, quite a reputable psychiatrist who has little to do with AMHI, although I don't think there's a psychiatrist in Maine that doesn't have something to do with AMHI, he came in and reviewed, I believe it was 16 of our concerns, specific concerns, and reviewed those records at our request thoroughly and met with all 16 of the wards. This was two months after our initial assessment. In the meantime, a MD had been in there reviewing many of those same 16 for medical problems which were associated, and he had noted some concerns about medication issues when he was in there a month previously. But then when the psychiatrist went in specifically to look at these issues only recently, they seemed, most of them, to have been pretty adequately dealt with and in most cases it was adequate to begin with. Some of the high dosages, for instances, seemed to be appropriate for the age and weight and psychosis of the patient. So some of them were unfounded to begin with and many of them seemed to have been dealt with by other - by our involvement we've made some changes.

SEN. GAUVREAU: Does that mean that the dosage levels in some cases was reduced based upon your focusing on the degree of medication?

MR. BANCROFT: That's correct, in some cases.

MR. WALSH: In fact, there have been many - as a result of our individual - you know, work with the individual patients, from

the time we started in June there have been many changes that have occurred. One of our patients was incontinent and was in a - placed in a room that was too far from the bathroom and was blocked in. That was something that was taken care of right away. We made sure the fire marshal got in to take a look at the room. So as we were going along, we have been sharing the information in terms of things that we thought needed happening right away with staff in the department and at AMHI. So there have been changes that have been taking place from the time that we began the review. In other words, we didn't just wait until this whole thing was completed and then get over there.

MR. BANCROFT: The important point that we might miss here is that we act as guardian on behalf of the individual, so they can't give medication unless we authorize it, and they can't give any levels other than what we authorize, and most of the treatment is supposed to be collaboration with us, and I think that after our involvement there, we have become much more active with them in reviewing it, and so it's kind of a two-way street in that respect. We act as the patient and they act as the treater, and so - but in some respects we requested that they be lowered, in other respects, they suggested that they might try it on a lower level for a while and we agreed.

MR. WALSH: But we did note, and one of the recommendations I made was that the system for notifying guardians was one that we believed needed to be changed and we have to take some of the responsibility, because we have - we've had one caseworker with

a large caseload over there. As this program - as I talked about, the program has grown, our knowledge about what our role is has changed as we've gone along, and we have discovered and found out that we just have to be much more pro-active and much more of an advocate, much more involved in the individual case plans, which is why we're hiring additional people right now, so that we will know more than we have in the past when a patient's need changes in their medication, when they need to go the hospital, we just have to know a lot more about the individual situations than we have in the past. And that's going to take additional staff and it's going to take additional systems in terms of notifying us when there are problems because we don't have people living over there, so there have to be clear lines of relationship in terms of us knowing when there is something happening.

SEN. GAUVREAU: Representative Boutilier.

EXAMINATION BY REP. BOUTILIER

Q. I have just two quick questions. I didn't want to spend a lot of time on the one case you mentioned about Massachusetts, but it seems to me that there's an inherent conflict of interest to have an out-of-state firm assess a patient to their own facility. Didn't you find any conflict of interest in that regard?

MR. BANCROFT: No, because his behavior makes him - he's not a candidate due - because of his behavior in the five facilities that I mentioned. The refusal was that we needed to get those officially in writing in order to justify our going to Medicaid with

such an exorbitant request. They were not - we approached them originally and they were screened out immediately.

MR. WALSH: Every facility is going to do an evaluation of whether or not the patient fits their particular program. That happens with children and with adults as well.

Q. Maybe there was a miscommunication and I didn't understand. You said that you felt that this patient would be properly placed in that out-of-state facility. They then assessed the patient to find out whether that was the case?

MR. BANCROFT: No, we originally evaluated the five facilities that - the three in Maine, certainly, first, and it was determined right away that he couldn't be adequately served at those, and then we got - we went further and further afield until we found this New Medico system which said that they thought they could deal with this type of individual and they came up and did an assessment and said they could.

MR. WALSH: In other words, what we will try to do is look at the ward's needs and then try to identify a program that says they work with those types of needs, and then they will do an assessment. We'll start in Maine.

Q. But you understand my concern --

MR. WALSH: Absolutely, right. In many cases it's not so much a question of having a pure evaluation saying this is the place to go to, but actually, and it's the same with children services, of actually - you know, there might only be one program in the

country that says that they will work with that type of a problem.

Q. And the second question, and it's a reiteration of what Paul was saying, and I guess we're all concerned about it. If you got to the point where you made a major decision to assess all the public wards, you've talked about the long term of establishing better communication because you don't want DHS people living there, what are you doing now though in the short term? How far apart are your current assessments? For instance, in terms of medication you said that your involvement did cause changes in care. Well, obviously we want that to continue. What's the distance between your assessments on an ongoing basis?

MR. BANCROFT: We have - the commissioner, in fact, has directed us to continue this process twice yearly with our - in other words, there's going to be a case review system set up for our public wards in the institutes.

MR. WALSH: A complete assessment, as we did -

MR. BANCROFT: Which would be similar to this assessment process where - in other words, some of us from outside the facility will come in and review the caseworkers and AMHI's work. We're going to review it from outside.

Q. So during that process you would also see the notes, see whether the reduction that originally occurred because of your involvement had continued through the time and between the next time of the assessment?

MR. WALSH: Yes, that's correct.

MR. BANCROFT: And at this time right now, partially through the

Judge's involvement, we are reviewing 12 of the more - what the Judge considered to be the more serious situations monthly, we're doing those monthly right now. In fact, we just had our first monthly report on those 12, which is very similar to the original assessment, only it's an ongoing - the original question is what we've done this month and what we plan to do next month, and so it's an ongoing process.

MR. WALSH: And we're also involved, really, on a day-to-day basis. We don't have somebody who lives there, but we have somebody who is there most of the -

MR. BANCROFT: We have someone there daily.

MS. SALDIVAR: But we also have a caseworker who, when we hire the project line, will no longer have 80 cases, she'll have 40, which means the caseworker can attend the team treatment meetings, can participate and be more of the advocate.

Q. Better awareness of each case?

MS. SALDIVAR: Absolutely, yes.

MR. BANCROFT: We were in a situation where the facility more or less had to tell us what was happening, and then we either agreed with it or not, and what we need to do is to become more active in seeking treatment that we feel is appropriate.

SEN. GAUVREAU: Representative Rolde.

EXAMINATION BY REP. ROLDE

Q. Peter, when you were talking about plans for some sort of a group home that you were working on, and then you sort of intimated that the Department of Mental Health was also doing that,

it led me to think, what type of coordination is there between the two departments? It's always been historical around here that they haven't gotten along together too well. Do you work closely with them?

MR. WALSH: Yes, we do. We work closely with them on a case-by-case basis in terms of our people being involved with the treatment teams at the patient level, in terms of communications with the managers at the institutes, and in terms of sharing of information from that level and the commissioner's to the other department.

Q. For example, are you going to be planning group homes, are they going to be planning group homes? Do you have an overlap, is there going to be -

MR. WALSH: We're working on just one specific group home. They have all the other funds that were allocated by the legislature to develop community-based alternatives. Again, our responsibility isn't just the people who are at AMHI but to other wards as well, so we are constantly trying to look for ways of expanding community-based programs, not only for the people at AMHI but for our other wards as well in the community.

Q. But in this type of planning you work together?

A. Yes, we work closely with all levels of the department over there, yes.

Q. Okay, my other question is, presumably you've had wards at AMHI for a long time. Why has this problem just suddenly exploded?

MR. WALSH: Well, as I spoke -

Q. I may have missed that.

MR. WALSH: Most of the people who are wards have lived at AMHI, some of them for very long periods of time. The program has grown from one in which we had no state wards - four state wards, to one where we now have 450. We have had - we first became involved with AMHI in, I think, '83, '84 or '85, where we went from zero to 50 wards. We did an initial assessment when those people came into our guardianship program and we've had staff over there. But as I said, we've been learning as the program has grown, and it was a result of a number of different things that started coming together, actually, in the late spring, early summer, that caused us to begin to do a much more intensive review of what was happening over there.

SEN. GAUVREAU: Representative Burke.

EXAMINATION BY REP. BURKE

Q. Can you go over your chronology just a little bit for me? You told AMHI what you were going to investigate?

MR. WALSH: Yes. We told them that we were going to be doing an assessment of all of our wards.

Q. And then how long was it before you then actually got in there and did it?

MR. BANCROFT: Two weeks.

Q. Two weeks. So you gave them fair warning that you were coming, what you were going to look at. Did you find it at all surprising that when you got there there were still deficiencies?

MR. BANCROFT: No. They apparently didn't treat us any differently. I think there were - some of the things we heard

were that they were used to having groups of people come through. I think they were just extremely busy and overcrowded and understaffed and were trying to keep up, and I don't think they - my opinion is, they didn't have time to do any scurrying around.

Q. And you made sure that the staff that was on the wards that you were looking at belonged on those wards and hadn't been pulled from other wards to beef up the charts or anything like that?

MR. WALSH: We made a number of recommendations regarding staffing patterns, regarding - we looked at records. We looked at records going back 50 years. We have one ward who has been there for years. Some of the investigations that our protective services people are involved with were alleged incidents in 1984, so we really did a fairly complete review.

MR. BANCROFT: Those incidents, for instance, the 46 public wards that we have there are well-known - there's public knowledge there, it can be determined who they are from public records, but when we went over, we assumed that we were gonig to find certain things and one of the things that we thought we might find was abuse and neglect, you know, with overcrowing, those conditions do occur, and we did, and we made referrals immediately to our protective division, our protective program within our division, and those were - those investigations then were not told to AMHI. In other words, we went over and we said we're going to do an overall assessment of all 46, and when we found things like referrals to our protective division, we did not

tell them who they were or what they were, and the protective people came over and did their investigations without informing them in advance.

Q. Will we get a copy of the adult protective findings?

MR. WALSH: Yes. We can certainly give you the results.

MS. SALDIVAR: Those are just being completed right now, and we need to follow the confidentiality standard --

MR. WALSH: They can't share with this committee the individual records but -

Q. No, no, I understand that. And in terms of the specific findings that were referred to physicians and psychiatrists and things like that, the things that Judge Mitchell had requested, could we also see a copy of those types of things, again not violating anyone's confidentiality but -

MR. WALSH: We can certainly do a summary, as we have done with the other information.

Q. In a shorter amount of time than six months?

MR. WALSH: Oh, yes. We could put this together in the next month.

Q. Okay.

MS. SALDIVAR: I'd just like to add that during the interim, while we're getting these followup reports, we've been having scheduled meetings with the AMHI staff in particular, so that we have been sharing what these results are and what the recommendations are so that they, as the caretakers, can, in fact, move and act on these reports that we are getting. So it is a

process that we're involved in. We're just going step by step.

Q. Two quick questions then. One, do you feel that now because of your focus on these particular 45 or 47 patients, that they will then be receiving a little more attention, needless to say, more attention than they had been receiving prior to your visit, but also more attention than some of the others who are not then state wards, causing abuse and neglect of non-state wards?

MR. BANCROFT: My personal feeling is that that probably won't be the case. We are concerned, by statute, with our public wards, naturally, and we decline to - by statute, again, we didn't have the statutory authority to investigate the rest, but I don't think from my involvement over there that anybody felt - I didn't get a feeling from any of the staff or administration over there that that might be the case. And that, surely, I don't think would cause neglect of the others.

Q. Did you do any kind of comparison with a chart? You walk onto the ward, you say I want to look at the charts of Mr. Smith, Ms. Jones, so on down the line, these are the state wards. Did you pick up another chart to see if, in fact, your charts had been beefed up?

MR. BANCROFT: Those other charts would be confidential to me, too.

Q. So there's no comparison then, really, you don't know whether or not giving them that two weeks allowed them to beef up the charts that you would be looking at?

MR. BANCROFT: I don't know that for certain.

REP. BURKE: Okay, thank you.

SEN. GAUVREAU: Representative Cathcart.

EXAMINATION BY REP. CATHCART

Q. Sorry if I missed this, but now that you've done this assessment and will soon have the full report, with the new staff how often are you going to be able to check on these same patients in the future?

MR. WALSH: We're planning to do a full-scale review twice a year with a team, where we will go in and have the team look at the whole thing.

MS. SALDIVAR: Using the outside consultants again.

MR. WALSH: Right, with our staff. Our staff is over there now, even the person that has a lot of cases is over there very often, and when we hire new staff, they will be there even more often. We're hiring an additional person to work with the guardianship cases, and we're hiring an additional person to do investigations of patient to patient abuse, staff to patient abuse, whatever it may be. So we will have - they will be - I've been saying that they will be staffed in our regional office in Augusta, but they will be spending most of their time at the facility visiting with the patients. It really will be on a daily basis that we will be working in terms of developing the treatment plans, checking to see that they're being kept up to date, getting the second opinions when we feel they're necessary, and then we will be doing the more formal review at least twice a year, and on some patients we're going to be doing formal reviews that will be

sent to the Judge, I think, every three weeks for the next year, as he's asked us - once a month.

Q. I wish there were some way we could have such thorough checking up on all the patients at AMHI instead of just your wards there. I'm concerned about the fact that they knew two weeks ahead also that you were coming, and there's still the glaring problems, such as overmedication and the incontinence and they never considered that maybe the person wanted to drink a lot of water because of the overmedication and that was why they always had to go to the bathroom and which is way down the hall. I'm just sort of distressed, that it seems to me that DHS is having to hire new people to check up on the other department on things that just should be routinely checked on and taken care of at AMHI. That's the way it sounds to me, is that your advocates are going in and yet AMHI only has one advocate for all of those patients there.

MR. WALSH: Again, our statutory responsibility is as a substitute decision-maker for the person over there, and for other mentally ill people, they're involved with the treatment planning. We're not - one of our functions is advocacy, certainly, but we have to put ourselves in the role of the patient.

MS. SALDIVAR: The informed consent issues, for example.

Q. I understand that. But would you agree with me that what you found in doing this assessment was that the patients were getting woefully inadequate treatment?

MR. WALSH: I don't think we found - we found some cases where

there was woefully inadequate treatment. What we found was - were individual situations, many of which, again, have been corrected, and some of which our outside consultants said, well, it looked like this was too much medication, but when we looked at it again it seemed appropriate at the time. Many of these problems - we were in there, again, at the same time that the legislature was beginning to look at the overcrowding issues and many of those other issues, so we were in there at the same time this public expression of what the problems were over there was going on, so I don't think we were tremendously surprised in terms of looking at the individual cases. And then we were pleased with the legislature's allocation of the funds it had allocated there, because we think that that's going to help a lot in terms of the problems that we have discovered, and, in fact, has already begun to take hold. And certainly when the community-based - you know, when you have an institution that is overcrowded, the best answer - I have caseworkers in children and adult services who have too many cases, and the best answer is to have fewer cases. And when you have an institution that's overcrowded, the first thing is to stop the overcrowding, and the way we're going to do that is through the development of alternative placements and then having additional staff. So what I'm saying is, my point is that the issues that we discovered were the same issues that we were - that the legislature, we think, saw in the - when they addressed the problem in the fall. So we weren't greatly surprised at - Tom, I don't know, you were with

the people over there - in terms of doing the reviews. There were some situations that we felt needed rectifying right away, and we met with the mental health officials over there and made sure that those situations were rectified.

Q. I've just been so concerned, because what I read in this report is that there is a lot of dehumanizing of these people in that hospital, and if that was found in a number of cases when they knew two weeks in advance that you were coming to assess them, I just fear for the other patients.

MR. WALSH: I really don't think that two weeks in advance - I wasn't over there during those two weeks, but the kinds of issues that we found, the policies and procedures that needed correcting, for instance, we found that there is no policy on sexual assaults, on dealing with sexuality of patients. Here you have an institute that has adults over there. Adults have sexual urges, and we found, and that's some of our recommendations, that there be developed policies on sexual assaults, policies on what happens with sexual issues because they're going to come up in an institution like that. I don't think that a two-week - knowlege that we were coming in within two weeks was going to make much difference in terms of the issues that we discovered.

Q. Just one question about BMHI. You said you're just beginning your assessment there. Have you gotten any reports at all back? How many patients do you have that are your wards there?

MR. WALSH: We have about 50 -

MS. SALDIVAR: It's 62, I think.

Q. Have you got any preliminary findings? Can you just -

MR. BANCROFT: We're more than half through our initial assessment, which then remains to be written up. So I guess we're half through. We have assessed close to two thirds of the population up there that we need to assess, but we have not written up all those so that - you know, we're only about half through.

MR. WALSH: What's your general impression?

Q. Yeah, I want to just -

MR. BANCROFT: Well, the general impression is that it's kind of early to say, but the overcrowding, it's not the same type of problem, I don't think.

Q. So you're finding it markedly different? And if so, better than AMHI or can you make that statement?

MR. BANCROFT: I'd have to say it's markedly different.

Q. Are you finding the same kinds of problems in general, the overmedication and the improper use of seclusion and restraint and such?

MR. BANCROFT: The ones that I've been personally involved with, I have not seen those same problems.

Q. And you think it will be maybe six months before you have -

MR. WALSH: No, I'm talking about six months before our total overall report. These assessments, we will finish the team's and then we have to write it all up, and then we have to bring in the outside, so that's what I'm saying in terms of getting the whole report finalized, it just going to take more time.

REP. CATHCART: Thank you.

EXAMINATION BY REP. CLARK

Q. Peter, I guess I've got questions that fall into three kinds of categories. One is, I'm still having trouble with the relationship of your department to the Office of Advocacy. For instance, it occurred to me as you were talking about the fact that you didn't have access to other records to compare, could you have gone to one of the advocates and had them do that? I don't know that, it's just -

MR. WALSH: We operate under specific statutes. If we get a specific complaint of abuse or neglect or exploitation of an adult, then we would open that as a protective case. If a person gets referred to us as being incapacitated or dependent, we would open - we would assess that case for guardianship. Other than that, we do not have any reason, and I don't think we should have, to go looking other people's records.

Q. Okay. But what relationship do you have with that Office of Advocacy?

MR. WALSH: We have a very close relationship with the Office of Advocacy. We have clearly spelled out memoranda of agreements. We've had - in fact, we've had an agreement that the Office of Advocacy would do the investigations, the protective investigations, at AMHI for the past three years, so we have had a close relationship. They have access to our records. This confidential report, the statute allows them, and they have a copy of our report. They will get copies of our findings. They basically get everything that we have.

Q. Did I hear you say that your goal is to have a staff to patient ratio of one to forty in terms of your wards at AMHI?
MS. SALDIVAR: That's what will occur based on getting a project line for this particular caseload, but we've recently completed some standards for caseload sizes, and the ideal, if you're to do the work with the clients and on their behalf and the advocacy role, the ideal would be no more than 25 cases per worker.
MR. WALSH: We have some additional people coming on - we've requested from the legislature some additional staff in adult services. But the guardianship program is continuing to grow and I don't think that the end is in sight. I think that the more litigation there is regarding consent issues, regarding people in nursing homes, I mean if every nursing home in the state came to us and said we want you to come in and assume this role, which some of them have done, it's a problem.
Q. Based on your staffing assessment around DHS wards, if we were going to make a recommendation to the Department of Mental Health about the number of advocates that they needed in each of these institutions, what kind of staff ratio should we - staff to patient ratio should we be looking at? I mean, I hear one to eighty, I hear one to forty, I hear one to twenty five.
MS. SALDIVAR: Let me see if I can separate. The mental health advocates who are in the institute are with the Department of Mental Health and Mental Retardation.
Q. That's correct, I understand that, but if we're going to make a recommendation about how many more of them they need, it

seems to me that your experience at staffing with DHS wards might be helpful to us. But I'm hearing enough different numbers here that I don't know which one of those experiences ought to be helpful, is what I'm trying to say.

MS. SALDIVAR: The numbers and ratios I've referred to are the casework ratios.

Q. Okay but which one of those three ought this committee to be recommending or funding for the Department of Mental Health? What's your recommendation?

MS. SALDIVAR: I think it's apples and oranges. I think what we do in casework is not what the mental health advocate does in an institute. I think it really is quite a different role.

MR. WALSH: One of the things that I have found - I probably shouldn't be saying this, in foster care because there are problems - we are one of the few states in the country that have passed a federal foster care review at three different levels of compliance, first 65%, then 80, then 90% compliance, and I attribute that in great measure to the fact that we have a case review system. Every six months the case is reviewed by a person who works for me, or who has line authority from my office. They do not work for the regional offices, and they review every case. There's a team meeting, basically. If the child is old enough, the child participates. They have a checklist that they go down and those reviews are scheduled on a regular basis. That is an institutionalized way. I know that if I'm not here tomorrow or if the regional manager isn't there, that child

is going to be seen an outside - it's outside in terms of the fact that it's not in the line authority. That doesn't solve all the problems, of course, but it does in terms of know that the child has a case plan, knowing that we're working towards it, knowing that somebody outside of the caseworker is looking at that on a regular basis. I'm firm advocate of that kind of a system, not so much that we need all kinds of new advocate. To me, a whole set of new advocates tells me a lot of things that I basically already know that I've got to fix up, but certainly a case review that has that independent perspective and is looked in a very helpful way. Our supervisors look at it as a chance for them to come in with difficult problems and have some outside - we have volunteers now who sit in on those panels that we recruit and train, and we have community members, and they get to learn a lot about the system. So if you ask me about whether you should have a lot more people who are doing advocacy or more of something that's actually involved in helping in the treatment, I would actually push in that direction.

Q. Okay, that's consistent with the notes I made to myself earlier. Do you have a backlog of referrals to adult protective services at any of the institutions or at all of the institutions, and what numbers are involved in that?

MS. SALDIVAR: We have a backlog of guardianship study requests but not adult protective referrals, and they really are quite separate in what we are being asked to do.

Q. What's the numbers in terms of the guardianship?

MR. BANCROFT: It's not so much with the numbers as it is the length of time that we've been not able to deal with them. We have some that are overdue a year.

Q. Would you check on that more specifically both in terms of numbers and time waiting for assessment?

MR. WALSH: We can probably get to that today.

MR. BANCROFT: Sure, we can get that.

Q. You know, are we talking about 50 or are we talking about 150 or are we talking about -

MR. BANCROFT: Less than 50.

Q. Okay. There were rumors that it was considerably higher than that.

MR. BANCROFT: You mean that are awaiting studies or to assume guardianship?

Q. Hm-mm.

MR. BANCROFT: No, it's less than 50.

Q. Okay. My final question is somewhat unrelated, and that is that the Committee on Aging handed me a copy of this booklet this morning, which I have to say has not come to my attention up until now. What recommendations that are in here related to this population have you been able to act on, and what is in the pipeline?

MR. WALSH: Some of it has to do with additional staff that we've already talked about. Some of it has to do with changes in policies and procedures, better coordination between the departments. Those are the areas that we've been working on.

Q. And specifically I noticed Recommendation 1, I recall here, is that we're now going to have an IDC for adults.

MR. WALSH: We haven't brought together an interdepartmental committee for adults, but we have initiated formalized discussions between the department and the Department of Mental Health and Mental Retardation regarding services to adults. We haven't moved to the full point of bringing in other departments. We thought we would start there first and first sort out issues that relate to our two departments and move on from there.

One of the - it wasn't mentioned in that report, but one of the things that we will be recommending to the legislature is transferring the adult services program from the Bureau of Social Services, you will be getting a bill on this, to the Committee on - to the Bureau of Maine's Elderly. Ninety percent - 95% of what the Bureau of Social Services deals with are child and family service issues. Over 75% of the people who are seen in the adult services program are 60 and over, and the ones - the other 25% are younger people with chronic problems that are going to be lifelong problems. So we are recommending - we'll be recommending that the adult services program be transferred within the department to the Bureau of Maine's Elderly. That means that the elderly legislation will have to be changed to enable them to serve some people who are not 60 years of age, and I personally believe - that was something I've been pushing, that it will strengthen both the children's programs in the bureau, as well as the adult programs.

Q. My sense is that we probably - that this has been the year of the child, let me put it that way, and that probably many of these adults, whether they're senior citizens or not, have gotten lost in the shuffle as we've - the publicity around some children's issues, so I would certainly support some things that would keep that in perspective, at least.

MR. WALSH: In some ways that's the way our system works, that things get to a crisis point and then we deal with them. I've been watching the Savings and Loans, and I thought President Bush hit the nail on the head when somebody said who's to blame for this, and he said, well, there's enough blame to go around for everybody and it's time to move on with the positive solutions. I feel the same way, really, about this particular situation. I'm sure you've heard it, you've been listening to it, that we certainly can do more and are planning to do more. I think that it's a type of situation where we really - AMHI is going to exist, BMHI is going to exist, and people need it and we need it and the state needs it and we've got to do everything we can to fix up the conditions that are there.

REP. CLARK: Thank you.

EXAMINATION BY REP. MANNING

Q. Let's go back to the housing situation. I don't think you hit on it as much as I wanted that Neil brought out. You had indicated that you were working on a six-bed facility. What - who is going to go in that six-bed facility?

MR. BANCROFT: The Department of Human Services' public wards.

Q. And what would be the reason they would go in there? Would it be mental illness?

MR. BANCROFT: The majority of cases we had contemplated would be.

Q. Has there been any talk at all with the Department of Mental Health on this particular project?

MR. BANCROFT: We told them we were doing it.

Q. What was their reaction?

MR. BANCROFT: I don't recall one.

MR. WALSH: And this is something that we - in the adult services program -

Q. Yeah, but this is a pot of gold that we all have, whether it's in mental health or human services, and I'm just trying to figure out, you know, who is doing what out there.

MR. BANCROFT: We have not found it to be that way, Representative Manning.

Q. Well, we have to look at it that way, we as the ones who are the appropriators of the funds have to look at it that way, and I'm just wondering whether the right foot knows what the left foot is doing in this case.

MR. WALSH: We are certainly aware of their plans and their funding of community programs. Those programs, when they get started, will be of benefit to the people that we are serving. Our people will be able to use those programs and they will be available. This other program was something that we started. Our caseworkers spend 75% of their time, at least, trying to find placements for people in the protective services program and

in the guardianship program. That's constantly what they're doing, looking for adult boarding homes, looking for -

Q. Peter, in two days of testimony with the Commissioner, and bringing back the bureau director of mental health, there was never any indication that the Department of Human Services was also starting a program to have the six-bed facility. We asked him to outline the community area. There was never - I mean, if we didn't have you back here today, we would have not known that there was going to be a six-bed boarding home out there somewhere.

MR. WALSH: We started developing this program two years ago. We started looking at where we could get funds. We started looking at where we could get funds. We started working with Medicaid. This was something that really we have been working on and -

Q. Well, let me tell you - let me go back six months, when I sat in the Commissioner's office and said, let's take $2 million and go out there and buy homes throughout the whole state before the price of homes go right off the market so that we have homes out there, and they said, no, we're working with the Maine Housing Authority. Never did they say they also had six beds also on line, coming on line with the Department of Human Services.

MR. WALSH: I have to say this is something that started in our office. We started looking at the need for that. We started putting together the pieces in terms of a funding plan.

Q. I think Neil hit it right on the head. This has been going on

for nine years and I thought we had calmed it down when we put the, I think, interdepartmental council together, but it hasn't. We don't know what is going on because one isn't telling the other completely.

MS. SALDIVAR: May I respond just briefly to that? The work group between the two departments that has just recently been initiated as a result of the ID - task force. In fact, I think there are meetings this afternoon. We are going to be meeting, and we've had a couple of meetings to set this up so that we can talk with my Bureau, the Bureau of Maine's Elderly, the Bureau of Health and the Bureau of Mental Regardation, and today's meeting was to bring in the community piece of what they will be doing. But we decided the first agenda item was going to be public guardianships, because BMR has a public guardianship program, as well as we do, so that BMR and us, and bringing in Mental Health, I do think this small work group at my level will begin to understand what's going on and coordinating.

Q. Well six months ago they were going to start doing community stuff with housing and all that stuff, and all I hear is meetings, meetings, meetings. I mean, we're in a crisis over there, and if it takes meetings today and meetings tomorrow and meetings next week, something has got to be done. If you can get people out of there, and you say you can get six people out of there, then we ought to be doing something about it. I mean, it's funny that your department can get all kinds of money, and that department up on the fourth floor can't get any money. I mean,

you talked about I'm going to get an advocate, Peter, you're talking about a person who is going to go one to forty ratio. The advocates here yesterday said they put in their budget for another advocate over there and got shot down by the Department of Mental Health, or got shot down by the Governor's office, I don't know, but I'll find out whether it was the department saying or whether - yet, you can get one to forty and they can't get another advocate over there. You know, when you talk about what your people do, it's basically the same thing. A caseworker and an advocate do almost the same thing. I can't imagine that there is many other different things, but I'm shocked to sit here and hear you say, well, it's in my budget and it's in Part II, right?

MR. WALSH: Yes, we have a request for additional staff in the adult services program.

Q. So it got all the way through the Governor's office?

MR. WALSH: We've been requesting it as -

Q. So Human Services gets -

MR. WALSH: I said we had not had any additional staff since 1985.

Q. Yeah, but Human Services got the cut, but Mental Health did not get the cut. Mental Health did not get a cut when it came to the advocate?

MR. WALSH: All I can talk about, Representative Manning, is that we presented out needs. Many of our needs were cut as well, many of our requests were cut, the adult services request has been cut.

Q. But, Peter, when you look at a one to forty ratio, and you look at what the rest of the advocates over there are trying to do and are getting burned out in doing it, when one state employee starts looking at a one to forty ratio and he's getting burned out because he's got all these problems over there and one department can get funded to have a one to forty ratio and the other department can't get funded to have another advocate, what does that do to personnel? And forget whether they work in that department across the street or this department upstairs -

SEN. GAUVREAU: Can I break in? I think Peter will be saved by the bell. We received a phone call from the Speaker urging our immediate attendance at the Joint Convention, so why don't we recess. We'll reconvene at 1:15 p.m. The members, after we finish here, will catch up with the southern-central Maine tour.

RECESSED AT 10:55 a.m.

X

STATE OF MAINE

HUMAN RESOURCES COMMITTEE

HEARING ON AUGUSTA MENTAL HEALTH INSTITUTE ISSUES HELD ON FEBRUARY 7, 1989, IN ROOM 113 OF THE STATE OFFICE BUILDING, AUGUSTA, MAINE.

Maralee Kaler

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Augusta, Maine
February 7, 1989
2:35 P.M.

SENATOR GAUVREAU - Back on the record. We are renewing questioning with the Department of Human Services related to the Department's survey of the wards in its custody at AMHI. When we broke off this morning, Representative Manning was - had certain questions to Peter Walsh and we'll begin at that point.

EXAMINATION OF MR. WALSH, MR. BANCROFT AND MS. SALDIVAR

BY REPRESENTATIVE MANNING

Q. Now that I've had dinner, I don't know if my blood pressure's come down.

MR. WALSH - Well, I don't want to do anything to raise it back again, Representative.

Q. You can see the irony of the fact that the advocates yesterday were indicating that they have not had the ability to get more advocates; and yet in Part 2 of your budget you have got more people just to deal with strictly AMHI. There is some irony in that situation.

MR. WALSH - I don't know if I misspoke. We are in the process right now of hiring four new staff; two of those persons will be in our protective services program and will have as their primary responsibility responding to abuse/neglect complaints from the institutes - BMHI and AMHI. Two of them will be added to our public guardianship program. One of them will be stationed with most of their clients at AMHI - not stationed at AMHI, but will have clients at AMHI and one of them at BMHI. In the Part 2

budget we had a general request - this was put together last spring and over the summer - for additional caseworker staff because of the numbers that I was talking about in the general public guardianship program and the protective program; and there's only three additional caseworkers in that request. So, - and I also think that the - I just can't comment on the - whether or not the advocates have or should have more staff. That's something that's in another department.

Q. We sat here and unfortunately maybe you probably should have been here yesterday for the whole day. I didn't think of inviting you; but now that - now looking at it from what the advocates told us I think it probably would have been beneficial for you people to be here because they told us a much more graphic description of what is going on over there compared to what we had heard by two previous people who spoke, both Commissioner and Bill Daumueller. So, it bothers me that a department like yours where - and I'm not saying that ought not to have it, but if this administration recognizes the fact that the guardianship program is growing and they do have a number of individuals under their guardianship program at the two institutions, that two of those people's primary responsibility is to watch out for those 60 at Bangor and 45 at AMHI, you're talking, you know, roughly 100 people for two staff persons primary job; and yet the advocates yesterday who have to cover all the other people plus yours - if memory serves me right you had indicated that they had the ability to do a number of

things under an agreement signed three years ago. Those are the things that disturb me. The administration on one hand says yeah you can have this and on the other hand the advocates - it's no wonder we get people burned out.

MR. WALSH - Without again commenting on the number of advocates, I think that the job of the advocate and the caseworker are two significantly different jobs. The caseworker has ongoing responsibility for actually participating in the care and treatment for those 45 wards for whom - that they're representing. The advocate has - I think has a different job in terms of overall monitoring of conditions, investigating individual issues. So, I think the jobs are different jobs. Again, that's not to say that you don't need more advocates. But, I know that we need more caseworkers to do the job that we have to do now. That's what I do know. And really, I have to leave the number of advocates up to the Department of Mental Health.

Q. I know you get what you can get. We know how that works. Peter, you talked about, and it disturbed me to hear you say that this was a normal procedure that you were starting to look at what happened - the guardians at AMHI. It was a normal procedure. I think if memory serves me right, maybe, Tom, you had said that you had because of maybe people over there you thought it was time to start taking a look at those people. This is how that investigation started, right?

MR. WALSH - I think when we first started doing - getting involved

on a higher level than we had been before, we had not contemplated doing a full scale assessment of all of our wards. When we first started thinking about this we responded to some issues that were brought to our attention about particular individuals and we went from the particular individuals to a decision after we reviewed those that we had to do the full-scale assessment.

Q. Where were those - when were those particular incidents happening? What was the time frame of that?

MR. WALSH - June and July, right. We first started responding - during the month of July -

Q. Let me ask you this. That's what I'm trying to get. You're saying in June and July. As somebody who's responsible for the guardian - being guardians over the State wards, weren't you - didn't a major red flag go up when AMHI lost decertification?

MR. WALSH - Yes.

Q. That's what I want to hear you say. Let me put it this way. If I'm in your position and I read in the morning paper in the KJ that the certification at AMHI - that Medicare just decertified AMHI, maybe those aren't your patients; but if they're happening to some other patients, jeepers, something must be happening to mine.

MR. BANCROFT - I might be able to give you a little more detail, Representative Manning. The Medicare decertification was, I believe, in the spring. I think it was in May. And, we were concerned, as you said; and it was only a couple of weeks later

June 13th that Judge Mitchell in Probate Court in Kennebec County - we were seeking a guardianship of an individual at AMHI on June 13 in court and he expressed his concern at that time about our plan which has to be filed at the time we seek guardianship. In other words, what we're going to do to offer treatment on behalf of the proposed ward. And, he said he wanted an amended plan from us due to the Medicare decertification announced previously and he wanted to certify adequacy at AMHI. This was sort of a major departure for the judge who had originally granted guardianship for individuals at AMHI because AMHI was certified, AMHI was JCAH accredited, AMHI was seen as an adequate treatment facility. After that decertification he became more concerned and he expressed that concern to us in one of his orders on June 13th for a specific ward that we were seeking guardianship of.

Q. But I mean when that red flag came up, would it have taken the Judge of Probate for you people to start something?

MR. BANCROFT - Well, that was one of the areas.

Q. Granted, you're both under the same administration; but you do have under the State laws responsibility for people. Wouldn't somehow somebody say maybe we ought to get a team over there and find out how our people are doing in May? I forget what day it was in May that we lost the certification, but it would -

REPRESENTATIVE BOUTILIER - April 29th.

REPRESENTATIVE MANNING - April 29th.

REPRESENTATIVE BOUTILIER - May 29th. Extended from April 29th.

REPRESENTATIVE MANNING - I'm just - that's a concern I have 'cause at first I thought I heard you say, you know, you didn't hear - and I don't think anybody in this room is talking about just the Medicare patients. But, if Medicare decertified a segment of that institution, then the - it would seem to me that the rest of the people over there might be in as much of a particular problem as the rest of AMHI. That's - I'm concerned that it took Judge what do you call it - Judge Mitchell to make you people take a second look at that.

MR. BANCROFT - He was one of the reasons.

MR. WALSH - We did not at the time of the Medicare decertification - at that time we just did not see a need to do a full-scale, full-fledged review.

Q. Let me put it this way. When Susan Parker called me on a conference call to inform me that we lost certification, we were decertified, I was quite frankly shocked. And me as a lay person and as a legislator, if I was shocked, people who have your ability and your capacity under the State Laws of the State of Maine should have been saying hey, let's get a team in there tomorrow.

MR. BANCROFT - Again, Representative Manning, I'm speaking for myself and I most usually act as guardian, I can most definitely say that we took it very seriously and that I was personally upset to the point that within - well, from May29th to the time that we were in there in July beginning our assessments and then the full-fledged team came in early September, it

seemed as though we were responding as rapidly as we could at the time. There was a lot of things that happened in between with the wards. We heard from -

Q. Let me ask you this question. Hypothetical question. If in December you learn that you lose JCAHO, is it gonna take two months to reassess what's going on; or are we gonna have somebody in there and say okay, another plan of action for these 45 state wards has got to come up.

MR. WALSH - We would have to see what the impact of the loss of that would be on the wards.

Q. Ten million dollars in Medicaid I think we were told during the course of the hearings.

REPRESENTATIVE BOUTILIER - It wouldn't be December; it would be June.

REPRESENTATIVE MANNING - Well, whenever. Peter, I'm just telling you I would hope that we - your department can react a little faster than that in the future. I understand you run under a lot of workload and believe me this Committee will be the first one to be supporting your positions, probably, for caseworkers. We've never not supported additional caseworkers and additional people that your department has asked for. I just think that - I'm wondering whether or not if Judge Mitchell had said nothing, would we have had a Department of Human Services record.

MR. WALSH - Yes we would have. And, I can say that because Tom

and Joyce's concern was heightened. The concern of our case-workers was heightened. We had never done a - as I said before in my testimony, we have had a tremendous number of wards in the last five years. This is - we might be one of the states with the highest per capita program in public guardianships. It's a new service that is being provided by states to the extent that we're providing it. So, we have learned that we have to be more assertive as a result of all of these situations and that being more assertive means that we are going to be instituting regular reviews. We are going to be putting more staff over there. We are going to be training our staff in terms of being more assertive and taking - so what I'm saying is we have learned a lot by this situation as well. If in hindsight the day that they lost Medicare certification - I don't think that we probably would have had a team in there much before when we had it anyway. So, I think we moved as fast as the circumstances at that time would allow.

Q. With the additional personnel you're asking for in the Part 2 budget, are you - how are they gonna interact with the advocates over there? Can you take us through - I mean, it sounds - and I have no qualms whatsoever you getting these people. Believe me. But, I don't want to see - we heard yesterday a lot of non-cooperation of state employees with the advocates. Can you take us through how this is gonna work, Tom?

MR. BANCROFT - The guardianship program - I think we can say that

we cooperate quite well with the advocates because we - the guardianship program is a little different thrust than the protective program, for instance, where they're going in and investigating abuse and neglect. In the guardianship program we are - we see ourselves as consumers of services at AMHI. We represent the patient. So that the advocate also represents the patient in a different way by trying to effect systems change. It's difficult for us as bureaucrats to effect a systems change but sometimes it's necessary on behalf of our wards. We see ourselves cooperating - we have cooperated very well with the advocates in the past.

Q. So if you had a problem over there with a guardian knowing that you are a bureaucrat, and there's nothing against bureaucrats.

MR. WALSH - Professional bureaucrat.

Q. Professional bureaucrat. And there's nothing against them, believe me. Representative Rolde was once a professional bureaucrat. He did a good job at it in his other life. Would you tend to see yourself going more to the advocates to see something change for your clients rather than going through the chain of command through the departments?

MR. BANCROFT - We've done it both ways, Representative Manning. The advocates - in fact it was only a couple weeks after the 13th when Judge Mitchell gave us our first letter that we met with - on June 29th we had a regular meeting at AMHI with the casework supervisor, myself, program specialist, Rick Hanley who was the Deputy Superintendent, and Tom Ward who was the

patient advocate at that time and now is an advocate elsewhere. And, Tom Ward at that time told us that we had two wards in danger. He felt we had two wards in danger. This was basically what really alerted us. And, he named names; he named a couple of names. And, we were in there within a week assessing. That was what we considered to be the beginning of our assessment process right there - it was from the patient advocate over there. The administration was also present at the time, but it was the advocates that gave us the information and caused us to act.

MR. WALSH - If I could just also say that again we share our information with the advocates. The report of these assessments that we did went to the advocates for the disabled. That's not to say that there are not - we're in a process right now of negotiating whether or not the advocates should serve - should represent our wards over there. We're doing some negotiations with them about their representing them as attorneys.

Q. When you talk about advocates, Peter, let's talk - what advocates are you talking about?

A. I'm talking about the advocates for the - the formerly ADD advocates for the developmentally disabled which I understand now is advocates for the disabled.

MS. SALDIVAR - Maine Advocacy Services.

MR. WALSH - Maine Advocacy Services, right.

Q. You're not talking about the in-house advocate.

MR. WALSH - As well as the in-house advocate, yes.

Q. What do you mean by negotiation?

MR. WALSH - They have written - the Maine Advocacy Services has written to us requesting to become the legal representative for certain clients - certain wards; and so we're just - we just want to make sure that if we do allow that to happen that we're doing it in accordance with all the statutes. So our attorneys are looking at their request and we've got some correspondence going back and forth.

Q. Are you dealing at all with the in-house advocates?

MR. WALSH - Yes.

MR. BANCROFT - That's what I was referring to.

MR. WALSH - He was talking about the in-house and I was talking about the -

MS. SALDIVAR - In addition, the in-house, the Mental Health Advocate - the resident advocate at AMHI, for example, we are negotiating with them as well to renegotiate our 1985 agreement. I do not know what you heard about noncooperation yesterday or before, but I do know -

Q. It was mostly noncooperation I think amongst members of the staff over there towards the advocates.

A. You mean AMHI's staff.

Q. AMHI's staff.

MS. SALDIVAR - I do know there are problems in terms of establishing a protocol within the institute whereby reports and incidences will come to the mental health advocate in the institute and whereby they will all come to adult protective

as we will be in the protective program as opposed to the guardianship. Assuming responsibility under our law instead of delegating it to the mental health advocate, we'll be assuming responsibility especially for the resident versus resident incidences where harm happens to one resident or both. So that the mental health advocate and us in adult protective have been and continue to work on this in a very cooperative way and we will have this worked out. We will ahve the protocol and we will be working together on certain investigations, others they will do, others we will do.

MR. WALSH - We've had a memorandum of agreement since 1985 with the advocate's office at AMHI and that agreement has been in effect and has been - I actually call it a memorandum to disagreement because you never pull it out 'til you have a disagreement and then you pull it out and you look at it and say what are our roles here and how do we resolve this problem.

Q. Peter, let's go back to housing. It intrigues me about the six-bed unit. Where's the funds coming from?

MR. WALSH - I just want to go back. It surprised us this morning about the six-bed unit. I think a year and a half or two years ago Joyce and Tom came to me with a proposal to start a six-bed - I don't even think they said a six-bed - they said they needed to get a program going for some of our hard to place clients. Public wards.

Q. Public wards that are under what diagnosis?

MR. WALSH - At that time the request to me was hard to place public wards.

Q. Okay. So we could not - are we now hard to place public wards who are diagnosed with mental illness?

MR. BANCROFT - Many of whom would have diagnoses of mental illness. That kind of equates with hard to place.

MR. WALSH - Our public wards, again, live in various places. In fact I had a breakdown of some of them are in institutions, some of them are in nursing homes, some of them live in their own home and some of them live in boarding homes or other places. And our staff spends a great deal of time trying to find placements for the incapacitated adult. And, many of them are at - at one point they might be at AMHI, then they're out again. So, we have had a chronic shortage - difficulty in terms of placement of some of these people and some of them are even harder to place than others. So, at that particular point I have to say that for the Adult Services Program we have no federal funds. It's not like our Children's Services Program where we have a lot of social security and other related activities. So, anything we do basically is with State money or if we can access Medicaid and other kinds of things. So at the time we did not have the money. So I said to Joyce of course we'll support it if you can find the money in your budget. So, that's like saying that we don't have it. Of course we put it into our budget request but we didn't get it. So, Joyce is persistent and the next she said well I'll

wait 'til next year. I have a special support account and I'll take the seed out of there and I'll see if we can get Medicaid to help with the funding. So, this was a year ago and Joyce has since then been working with Medicaid. They have agreed to not only seed it, but to fund it. So we are now - we've gone through a process of identifying an agency to run this. The State isn't gonna run it. We're going to contract it out. We had one agency that was ready to start the program and then for some reason they are not able to do it. So, we're back to the starting boards again in terms of finding an agency.

MR. BANCROFT - A provider agency is what the problem is.

MR. WALSH - This was kind of like a separate track that we had started in the bureau. A small program to deal with some of our difficult to place wards. It really had very little to do with any of the other activities that were going on at the time.

Q. I'm concerned that one is doing one thing and one is doing the other and we might be dealing with the same type of individual.

MR. WALSH - Well, one of the reasons why we said we had to try to get something like this going is the Bureau of Mental Retardation has a model - a couple of programs that they have set up for very difficult to place people who are mentally retarded and they have taken some of our clients if they meet the definition. Well, sometimes there's negotiations. But we

basic - we said we need to have that same type of -

Q. In other words, it's still tough to negotiate with the Department of Mental Health and Retardation?

MR. BANCROFT - Yes.

MR. WALSH - Yes. Right.

MR. BANCROFT - Extremely.

Q. Did you hear that Nancy?

MR. WALSH - When we're talking about the six hardest to place people who are in our state custody, we're talking about some people that have some serious problems and that they require a lot of intensive supervision and care. So what we said was we like this model of this facility they have. We need one of those for ourselves and that's when we started to put one together.

Q. Have you talked at all - let's say tomorrow the X, Y, Z non-profit organization decides they will take it, which Tom said that basically is what's holding up the problem. Would you be taking those six patients out of the AMHI situation or would you be using those beds for people who will be coming down the road?

MR. BANCROFT - There are three that we had contemplated removing from AMHI that we thought would be suitable if we could get the right provider. One of those, I understand, has been placed already and we don't know whether that's gonna work. One now we have determined to be terminally ill and probably won't be able to be placed. But, it's an ongoing

process of evaluation. We feel fairly certain that of this - at least a few.

Q. Okay. Okay.

MS. SALDIVAR - There are also some in the community that are not getting what they need in their existing facility and need the structure, need the programming that would come with this type of facility that doesn't exist in, let's say, the boarding home over here on whatever street, so that when you have incapacitated adults, if you can get the special programming, the special structure within the home that we were hoping to develop, it would benefit several very difficult to place public wards for which there are no existing resource.

MR. WALSH - I think if we had some caseworkers in here to talk about the types of problems people have, when they get to the point where they need a public guardian, you are talking about people who cannot be served usually with all of the services that we have out there. If they're in boarding homes they don't stay very long. If they're part of the elderly services network they just can't make it. I'm talking about the people in the streets. Some of them are in nursing homes already. But, we are talking about the people you see on the streets. Those are the public wards and I'm just saying that it's a very difficult problem to find appropriate placement.

Q. I don't think anybody on this Committee is upset with the fact that you're going out and doing it. I think it was - well, my concern is is whether or not we got two departments of State

government trying to go out and do something that maybe one ought to be doing and you ought to be having some slots.

MR. WALSH - Well, we certainly were very pleased to see the community side of the special session because many of those placements that get set up will be set up for some of our people at AMHI and others that will be coming down the road. That certainly is going to help with our problem.

Q. Would you keep this Committee informed on how that process is going. Hopefully on a monthly basis so that if there is need to do anything before we leave here in June that we might want to shape whatever could help you out on it. Following up, Representative Rolde has a question.

EXAMINATION OF PANEL BY REPRESENTATIVE ROLDE

Q. I have a couple. One is the last thing that you said. Have you seen any impact yet? It was last September I guess that we gave the money for the beefing up of community services. Have you seen any impact?

MR. WALSH - I don't believe the facilities are actually up and running. So, no we haven't.

Q. You have not. What would you do with your 45 wards, and presumably you may have more in the future, if you couldn't put them at AMHI? What kind of a situation would that put you in?

MR. WALSH - I don't think there's any place for the majority of these people.

Q. Could you make a determination sometime that the conditions there were so bad that you couldn't keep anybody there?

MS. SALDIVAR - An example of that would be like when a boarding home has been closed because of deplorable conditions that can't be remedied and we have had to move people. I think these are sicker people than what - but it is an analogy.

MR. WALSH - This would be - the hospitals around the state would have to take these people I think. The psychiatric hospitals. Some nursing homes would. It would be difficult.

SENATOR GAUVREAU - Representative Boutilier?

EXAMINATION OF PANEL BY REPRESENTATIVE BOUTILIER

Q. I just wanted to expand a little bit on what can't be remedied. If you don't have an option - the community and the hospitals are not geared to take up those 45 people; if you don't have it as an option, then it's very difficult for you to ever get to the point where you say there isn't a remedy in the current location, correct? When does it become situation where there isn't a remedy? When you close a boarding home it's no longer there, so obviously there's no remedy to that. But, conditions can get quite deplorable and still you can say we can find a remedy.

MR. BANCROFT - When the boarding home - one of the boarding homes that Joyce referred to - closed, we became guardian of I think six individuals at the time because they were not able to enter into placement for themselves. And, at least

I'm not sure of the nubmers - but many of those were placed at AMHI when that boarding home closed. Many of them went back to AMHI. They had been AMHI patients in the past and had been placed in the community and the community placement turned into a worse facility than AMHI ever was and they ended up going back to AMHI.

MR. WALSH - If AMHI were to close, the first thing that would happen to us is that our emergency telephone system would get a call for us to place all 300 or however many patients there are over there and I would think that's what would happen.

Q. I'm acknowledging that that is not one of the remedies because you don't have those choices. What I'm saying is at some point you have to say things are so deplorable, although we could remedy the time lag is too long and we have to make a choice on those DHS wards as to what we do. Now, have you made a determination as to how long you would wait for a remedy to occur before the remedy wouldn't be helpful?

MR. WALSH - We have looked at that on a case-by-case basis and we have had some wards where if some things had not happened we would have removed -

Q. Immediately, two weeks, three weeks?

MR. WALSH - Yes, immediately.

Q. Then you would have removed those people.

MR. WALSH - We would have removed the individuals, yes.

Q. Then you would have come to the conclusion that if it hadn't happened immediately, there would have been no remedy

sufficient to meet your requirements and you would have moved people.

MR. WALSH - Right.

Q. Now, you're gonna be - you're continuing to do the assessments on and on and on.

MR. WALSH - Right.

Q. There are certain things you're gonna see again probably, because of the situation over there. The deficiency is going to reoccur. How often would the same deficiency that you originally wanted to be changed immediately was, but was temporary. How many times would that occur before you'd say the remedy is not possible and we're gonna remove people?

MS. SALDIVAR - I think we would base some of those decisions on safety of our wards.

MR. WALSH - Just for a specific example - I know you reviewed the case of the person who was raped. There absolutely has to be separation of the purpetrator from the ward and if that's not going to happen, we're gonna remove that person.

EXAMINATION OF PANEL BY REPRESENTATIVE ROLDE

Q. I was just gonna ask you to be specific about the kinds of situations where you've said you've got to remedy it right now.

MR. WALSH - That's one.

Q. Are there others without giving any names or anything like that?

MR. WALSH - We're looking at the inappropriate placement - potential inappropriate placement of the head injured fellow in terms of having a better treatment for that person.

Q. I understand that. But, you were saying that there were some that seemed to be in such situations of danger you said you had to make an immediate -

MR. BANCROFT - That rape situation was the best example. I can't think of any others offhand.

EXAMINATION OF PANEL BY REPRESENTATIVE BOUTILIER

Q. But some - you mentioned during the testimony that excessive medication was rampant and that in some cases if there hadn't been any immediate decrease in the medication, the size of dosage, that you would have removed the people. Would that be -

MR. WALSH - We would have tried to.

MR. BANCROFT - I think in a situation like that we can just say that we're not gonna authorize that much medication. We don't have to go so far as to remove them because we're authorizing the medication in the first place.

REPRESENTATIVE BURKE - But, are you there on a day-to-day basis to see what kind of medications they're getting? I mean if there's an order written like Ativan prn, you don't know how often prn is.

MR. BANCROFT - That's true. There might be occasions like that.

MR. WALSH - But again, that's why we've instituted these regular

reviews that we're gonna be doing so we can pick that up. And, we're gonna be continuing to use the second opinion aspect that we've used. I would say that another possible, although we didn't have one, would be if there was a medical emergency and we felt that the person wasn't getting adequate medical attention.

EXAMINATION OF PANEL BY REPRESENTATIVE ROLDE

Q. You had mentioned this boarding home that closed and the six people that were put back at AMHI. Could you give us a little more background? Was something that was under your department or under Mental Health?

MR. WALSH - We've had a number of them over the last years.

MR. BANCROFT - I was talking about Willowcrest in Pittston.

Q. Okay. The reason that I'm asking is that we're being told that community facilities are the answer to AMHI overcrowding and you're telling me that these community facilities are badly run enough so they have to be closed.

MR. WALSH - I think if you have a continuum in just about any field, that we have some excellent facilities, some fair facilities and some poor facilities.

Q. Who was running this particular one?

MS. SALDIVAR - This was quite a few years ago.

MR. WALSH - I was thinking of one in Bangor that we closed in 1981.

MS. SALDIVAR - That was Jefferson Manor.

REPRESENTATIVE MANNING - I might add after the Human Resources Committee.

MR. WALSH - They get licensed by the boarding home program in Human Services and after repeated visits, after repeated citations, the decision was made that they weren't able to provide the type of care that we wanted. In the Jefferson Manor situation, I think we went in and had to develop and found placements for 46 - for 40 people.

REPRESENTATIVE ROLDE - I guess what I'm trying to get at is we're being told that this is a good strategy for solving the overcrowding problem. One, now I'm confused as to which department it's in, because it doesn't seem to be coordinated between the two departments; and, as you said, when it closed six more people went over to AMHI. So, -

MR. WALSH - Right. But the coordination comes in terms of who does the licensing of these facilities. The boarding homes -

Q. You do the licensing.

MR. WALSH - In the Department of Human Services, right.

Q. Who puts up the money for these?

MR. WALSH - There are various sources of funds that are used. Private patients' funding is used. Their Social Security and their SSI payments. The boarding home program provides funding. The original funds to set it up for the new programs were allocated by the Legislature for the new community based programs.

Q. Allocated to which department?

MR. WALSH - To the Department of Mental Health. In the special session. In the last - during the special session there was a -

Q. This last special session?

MR. WALSH - Right.

Q. I'm talking about in the past. I'm still not getting a clear picture of - if you've got a system out there and it seems to me you're doing one part of it and they're doing another part of it. One of these boarding homes closes. More people go up into AMHI. Now we're being told you gotta open more homes so that you can take people out of AMHI. Who's doing it and -

MR. WALSH - If you had - if you looked at a facility out in the State of Maine and you looked at where the funding comes from and where the licensing comes from, you would find that it comes from a lot of different places - the funding. Again, individual patients would be contributing if they had the resources. There would be funds that would probably be supporting some people from Mental Health through funding mechanisms there. So, some of them would be supported by Medicaid most likely. So, there would be a variety of different funding sources, similar to children's facilities.

Q. So in other words, in order to solve this problem of AMHI and its overcrowding, we really need to look at two departments instead of one department, am I correct?

MR. WALSH - We have a significant role, yes.

Q. I wonder just - I guess I have to ask myself out loud is how much you have been involved, how much the two Commissioners have worked together to try and deal with this; and if history is any judge, it's probably not at all.

MR. WALSH - I think that there has been a lot of communication and coordination at the Commissioner level, at my level with people in the department, at Tom's and Joyce's level, communication with the Superintendent, and certainly with our caseworkers who were over there working on a daily basis with the staff at AMHI. We have formal agreements with the departments. We have formal agreements with the advocates. So, there is a lot of communication. Has it solved all the problems? No it hasn't, but there is -

Q. How much are you tied into their three and a half million dollars that we gave them which is to beef up community resources?

MR. WALSH - We will be able to access those facilities for people who have the types of problems that will be served by those facilities.

Q. Have you worked at setting up whatever plan or program -

MR. WALSH - We have discussed it with them. Yes.

SENATOR GAUVREAU - Representative Boutilier?

EXAMINATION OF PANEL BY REPRESENTATIVE BOUTILIER

Q. I don't want to totally get off the track, but I want to change the focus a little bit. That was the question I wanted

to ask earlier, but obviously we broke. The new OBRA regulation. We talked about 25 people possibly being placed in community - inaudible words - we've heard 12, we've heard substantial numbers, all of those different things. The OBRA regulations - the new ones are obviously gonna have a drastic effect as to applicability of placing those people in nursing homes, in community based service areas. Have you begun to address that feasibility if we start spending a lot of money on community resources and find we're not gonna be able to place some of those people in those settings because of the new regulations at OBRA. Do you have a response to that?

MS. SALDIVAR - The Bureau of Medical Services has been setting up joint meetings with multiple groups including mental health and Adult Protective has participated in those meetings because we will be able to do some of the initial assessments in terms of placement; but, we're now going to be the designated representative of the agencies, etc.; but, there's a very - you're right, there's a very real impact not only on new admissions to nursing homes when there's that primary diagnosis of mental illness, but those who are in nursing homes now who will be reviewed and may not be allowed to stay if they do not have the medical backup. So yes, that's an external force that's going to impact on both departments.

Q. It's my understanding - maybe they could explain OBRA for the Committee's purpose. But, my understanding, the OBRA

regulations are much more strict in terms of -

REPRESENTATIVE ROLDE - What is OBRA?

SENATOR GAUVREAU - The Omnibus Reconciliation Act of 1986.

REPRESENTATIVE BOUTILIER - And, they're much more strict in determining an assessment of mental illness and whether that's properly placed and you have to set it in least restrictive areas. So, you can explain a little bit more. I think it's going to have a drastic effect on any kind of placement of AMHI patients that are acute.

MR. BANCROFT - For those nursing home patients.

REPRESENTATIVE BOUTILIER - Yes.

MS. SALDIVAR - And, any dementures other than Alzeheimer's we'll be responsible for our clients to make sure they have neurological exams which is another whole additional - and this is good. We think it's good, but reality - so yes, that does have a big impact. They're just doing the training now so that we're just beginning to udnerstand what an impact this will have on all of our clients in both departments.

EXAMINATION OF PANEL BY SENATOR GAUVREAU

Q. I was intrigued. I reviewed the document which is styled 'Overview of Probate Judge's Report on Guardianship Clients Residing at AMHI' that we have received. This is a summary of the Probate Court's findings. And, I was trying to read that in tandem with your report and then filter into this my perception of the last six days of hearings. I'm mindful that there's a certain degree of hyperbole attendant to any

legislative proceeding and an advocate will always make the best or the worst possible case to dramatize. I understand that. But, I must say that we've received a rather gloomy and dim and even lugubrious picture of the conditions at AMHI and in fact there seems to be a systemic failure of appropriate care, not of an episodic nature, not occasionally, but on the order of the day seems to be inappropriate care rather than the exception. In going over some of these notes - they're cryptic, but they do seem, for example, number 32 - range of problems included unreported assault, complete lack of attention to needs of clients, needs help with basic living skills; and they go on - another one here - down to 93 pounds, no follow up to mental care, inappropriate strip by staff, suspcted abuse and neglect. And, we go on. We have other unreported assaults, suspected abuse and neglect, over-medicated. These seem to be more than simple idle or even moderate concerns. They seem to be very, very profound concerns and what I'm trying to get a flavor of is what is the depth of concern of the Department. Do you feel comfortable with the wards being placed at AMHI now or do you feel that in fact perhaps for safety concerns they ought to be placed in another environment? MR. WALSH - At the present time we do not feel we need to move any but a few that we've talked about earlier. We have serious concerns. We found a number of problems that new staff isn't going to solve. There are some overcrowding problems

and other kinds of things; but we've found a series of other problems for which we have made recommendations and some of which they've already started moving on. Some of the kinds of things that basically have to - any kind of an institution needs to have in place some basic policies and procedural - and I talked earlier about policies regarding sexual issues, policies regarding sexual assault. We found communications problems between staff, interdisciplinary types of problems, problems of one shift coming on with another shift and passing on information. We found problems regarding training. You have a lot of new staff turnover. That seems to be the story in human services these days. It's no stranger to me that we have a lot of turnover. Problems in terms of training. The new staff generally in a lot of cases will end up on the wards with the most difficult patients because the people's seniority. A lot of them want to move on to another place. We found problems in terms of lack of quality assurance. So, we have continuing concerns about some of these issues. We have made recommendations about policy changes, notifications to guardians - I've mentioned that before - that was an issue that we found. That we weren't getting notified - guardians weren't getting notified. We found problems in terms of working with law enforcement. In the rape case the rape took place at 11:45; the Superintendent was notified at eight A.M. and the Superintendent called the patient advocate. The police weren't called until the patient got to the hospital;

the hospital called the police. Yes, we found some serious issues. Coordination of medical issues, transporting clients. So, we have - I'm not - I didn't come over here to say that everything is fine over there. We think that the institution and the Department and the Legislature, through their allocation of new staff and funds and because they've acted on at least some of the recommendations that we have given plus some other things they were doing anyway, that my people tell me that they do not fear for the safety right now of any of our wards over there. Because, that is a question that I ask them on a continuing basis. But, yes there are a lot of issues that still need to be worked through.

Q. Now, you told us that you got how many people over at AMHI? Are there two over there now?

MR. WALSH - Staff?

Q. Staff people or assigned.

MR. WALSH - We have two - one of whom has just a couple cases. We have one person, basically.

Q. And you've asked for two new people to work strictly with advocates for wards in the institutions - AMHI and BMHI?

MR. WALSH - Two at each. One for protective services issues. Another thing that we've discovered with the advocates - the advocates were doing investigations of abuse. That was part of our memorandum of agreement. They would sent the results to us and we would review it. We discovered that they felt

there was a conflict of interest on patient-to-patient abuse allegations where one patient has abused another, because they didn't know who the client was. So, we are doing now and will be doing allegations of patient-to-patient abuse which happens in a facility like this. And, so, we need an additional staff person just to be able to pick up on those things. So we will have one additional staff person working on the life activities - the guardianship; and one doing the protective services investigations at each institute.

REPRESENTATIVE MANNING - Everybody, Peter?

MR. WALSH - The allegations of abuse, yes, would be anybody. It's staff abusing clients, allegations of; allegations of staff versus staff. We will be investigating staff versus staff - did I say that? We don't investigate those.

REPRESENTATIVE MANNING - Peter, could you expound on that. I think you hit a lightbulb that I wasn't aware of.

MR. WALSH - Could you get us some advocates?

REPRESENTATIVE MANNING - You're talking about adult protective is gonna start to do -

MR. WALSH - Have started, yes.

REPRESENTATIVE MANNING - Have started and will be starting all abuse over there whether it's your people or Charlie Smith who was brought in by - whose father is a millionaire.

MR. WALSH - Right.

MS. SALDIVAR - What we're saying is that when there is a reported incident of resident versus resident that we will get that report

as well as the mental health advocate; and there will be some cases where we will jointly do some investigations with the mental health advocate, there'll be some where they will investigate - especially those in terms of the union issues that they're very familiar with. We need to learn their process. We need to learn from them and to work together. But, most of the resident versus resident - any resident at AMHI - we will be investigating those reports.

MR. WALSH - And we make referrals to law enforcement if we feel a crime has been committed. That's one of the first things that we do.

MS. SALDIVAR - Which is why we really want to get the protocol for the reporting clear.

MR. WALSH - Now of course law enforcement we don't want to get into how often they can follow up on the referrals that we make in protective services.

SENATOR GAUVREAU - If I understand this, it seems in the past that even when you folks haven't had what you say now is enough intervention in terms of developing individual client plans for your wards, now obviously you're trying to remedy that problem. You're offering your services for these patient to patient conflicts, assaults, whatever. The thought occurred to me earlier this morning we might be ending up setting up a two-tiered system, though, where there'd be an incentive for someone to have their relative named a public ward because

they'd have more direct intervention by you people; whereas the other relative might be living in Jonesboro and have only tangential communication in terms of medications, and really not have any idea whether his or her relative is being over-medicated or whether the treatment plan is really effective. You people - I'm not blaming you because that's your job. You're doing your job. But, people can advocate strongly for your wards, but their neighbor doesn't have that same system.

MR. WALSH - Well, that's -

MR. BANCROFT - This is already happening. Not only in the institute but everywhere in the State that we are supposed to be by statute the guardian of last resort and if family members are available and able and willing - that's what the statute says, if they're able and willing. Unfortunately, for many chronically mentally ill patients, family if they're able aren't willing or vice versa, so we end up being guardians. So that's already happening. And, there are many people who feel inadequate to deal with a complex system such as AMHI.

MR. WALSH - When I first heard this I said you mean they're going to be asking our social workers, some of whom are right out of college - we're going into an institute where the patient may have been there for 45 years - is that the longest?

MR. BANCROFT - I think the record is 65.

MR. WALSH - The record was 65 years. We're coming in now and we're gonna be making decisions about what kinds of treatment. So that's why we have to rely to a great extent on medical opinion, we have to try to put together a picture from the best opinions we can get about what the course of action would be, similar to a family that goes into a hospital and their elderly parent is dying and the hospital wants to know what they want to do. The best you can do to a great extent is get the best opinions you can get.

SENATOR GAUVREAU - Assume I'm Tom Ward, okay, who described to us his frustrations because just of resources. Someone calls him up and says, listen Tom - and I'm the mother of so and so, I'm concerned. Why wouldn't I, being an advocate, say well, you ought to have your son declared a public ward because you can get more direct and more consistent services. I will do what I can for you but realistically I'm only one person and here we have the Department that fortunately has two more staff people working at AMHI and also two others at BMHI. Wouldn't there be an increase in demand?

MR. WALSH - Tom says it's already happened.

MR. BANCROFT - I'm not saying that Tom Ward has given us referrals.

SENATOR GAUVREAU - I'm putting myself in Tom Ward's shoes. But, that would be very logical for Tom Ward to say that because he'd be getting more direct services to his clients.

MR. WALSH - Paul, I'm nervous about the 450 clients. The chart has gone from zero to 450. Where is it gonna end up? The populace is one of the reasons I want to transfer this program to the Bureau of Maine's Elderly.

SENATOR GAUVREAU - Representative Clark?

REPRESENTATIVE CLARK - With all that we've heard in the last two weeks, I'm feeling a considerably high level of anxiety when you say that you're gonna get the reports of patient to patient abuse, assault - whatever word we want to use. What kind of assurances do you actually have that you're getting them now?

MS. SALDIVAR - That's the protocol we're working on; and there are some issues and concerns. There's some reluctance for opening this closed place, and that has to happen.

REPRESENTATIVE CLARK - Is that around confidentiality issues or is it broader than that?

MS. SALDIVAR - Some of it's confidentiality, but there are some broader issues here in terms of past practice. Who used to see the incident reports, who can see them now, who shouldn't be seeing them, how are you gonna make sure nobody gets - and we're really sitting down and talking about all of this. That's part of the article that Peter brought you today.

MR. WALSH - I would really kindly recommend that you read this article. This is the best thing that I've ever read on dealing with patient abuse. It's going to happen in a public

institution.

MS. SALDIVAR - It does happen.

MR. WALSH - And this fellow was extremely realistic about that and said that there has to be the appropriate mind set. That's the first thing he talks about. In terms of the fact that you don't cover up instances of abuse, you give incentives for people to report them and bring them out into the open. Then you have well thought out continuum of discipline from minor abuse to major abuse; and he makes ten recommendations in here regarding ways in which institutions - one of the things he talked about, for instance, he says the very first thing that has to happen is that the Superintendent has to be on the wards every day, has to be known, has to be out there. Don Allen told me that when he was a Superintendent at the Maine Youth Center he said he made it a point every day that he was in Portland - sometimes he was in Augusta - he walked around that institution every single day. He was there. He came down at night. He dropped in. You never knew when he was gonna come. That's what this fellow says here that that's the first thing that has to happen is that there has to be - not only the Superintendent but the managers have to be out there. They have to be giving a sense of respect about the patient. So, really, I highly recommend reviewing this. And that's what I think Joyce is talking about when we say we have to recognize as a society that there are going to be abuse of patients against patients

in spite of - we can't ever have one on one. There are going to be instances of abuse of patients by staff and it will run from minor to major. It's how we respond to that and what the climate is that receives those abuse complaints that's important about what the quality of care at the institution will be.

REPRESENTATIVE CLARK - Obviously, we haven't had a chance to look at the article yet, but certainly one of my concerns as we've listened to all this is that there hasn't seemed to have been any reporting or any accountability and so who knows what, when they know it, that sort of says that for me has been of the most overwhelming things about all this is even when you talk about deaths it's not quite clear to me who knows how many people have died in that institution in the last year. And that - much less that there hasn't been an autopsy. I'm not even sure we know how many bodies there have been over there.

MR. WALSH - You know, I really think that in ways it's a shared responsibility. I'm probably getting off the track here, but as bureaucrats we do sometimes think that we're under seige and if you report something, the first thing is that the finger's gonna be pointed. That's what this fellow says in here in his - he says these approaches to dealing with the problem of patient abuse are more likely to be successful than the - inaudible - mentality that's often ruled the day.

And what he says is that the approach has to be a positive approach. We've been doing - we've got a new institutional abuse team, thanks to the Audit and Program Review Committee and some of the work that we did, that does children's investigations. And, I can tell you at the Maine Youth Center at one point we were not getting referrals. We now get referrals from the Commissioner. He sends them over. He says I want to make sure you get them. So they get reported to him or they come to us and he makes sure that they come over to us and then we get back to him. So, there is a perspective that it is expected and it is recognized that there are gonna be situations. We want to know about them and we want to take the actions necessary to resolve them. Again, it's not gonna solve all the problems, but that atmosphere, that openness I think Joyce was talking about has to be present.

REPRESENTATIVE CLARK - What kind of time line are we talking about to have this kind of program on line?

MS. SALDIVAR - I'm sorry?

REPRESENTATIVE CLARK - You said you needed some valid protocols. Is this gonna be in 18 months we're gonna be able to access these records or is it next week?

MS. SALDIVAR - No, it has to be fairly soon because the mandate we're responsible for -

REPRESENTATIVE CLARK - The federal mandate.

MS. SALDIVAR - No. Ours is the State - the Adult Protective

Act. We do expect that those who are mandated, especially after being informed that they are mandated to report, will do so. And, there is recourse. So, this protocol has to be worked out. If the protocol is worked out in a way that reports come through one person who will then assume some responsibility for working with us on the screening, that's fine. That may be the way to start. But, the institute and the Department itself, or both institutes, will have to help us make that protocol clear, make the directives clear; and that has to happen within the next month.

REPRESENTATIVE CLARK - Thank you.

REPRESENTATIVE DELLERT - I was gonna comment on something that Peter said. Brad and I are on the Nurse Recruitment. I notice one of the things here is have a partner go along; and our nurses have talked about that, you know, having that or having a mentor or something and how well that that would work and that's one of the recommendations.

MR. WALSH - When I read that I said that's my situation. We have a turnover in adult protective and child protective. And, it would be great if we could say three times a year we're gonna bring new staff on board, we're gonna send them to the Criminal Justice Academy or to the Samoset or someplace and we're gonna train them for six weeks and it's gonna be on the job. We don't have the luxury of doing that. We have to fill the gap right away. So that's why I looked at that

and I said that's a great thing and we're doing something about it ourselves.

REPRESENTATIVE DELLERT - I would think that would work very well for the new staff. It's hard to train somebody quickly over at AMHI or anyplace for that matter.

REPRESENTATIVE BURKE - First of all, do you intend to do staff inhouse training on incident reproting?

MS. SALDIVAR - It's already scheduled.

REPRESENTATIVE BURKE - Okay, and how long - how much do you intend to do it? What's the training session consist of?

MS. SALDIVAR - We felt we'd begin with a series. These are the kind of agreements that we worked out with Rick Hanley, the Deputy Superintendent, so we thought there would be a series of meetings, at least initially, about what is adult protective, what are indicators, and then move into the actual reporting piece.

REPRESENTATIVE BURKE - I anticipate - again, being a nurse - I anticipate that you will meet a lot of resistance from the staff, especially in the psych hospital, that says for God sakes, if we wrote out an incident report every time a patient hit another patient, we'd be here all day. You know, I have a feeling that, hey, you're gonna hit that right on - head on.

MS. SALDIVAR - I think we already have.

REPRESENTATIVE BURKE - Secondly, given that you are currently saying we own part of this problem when patients are abusing patients, when staff abuses patients, when patients abuse staff

this is adult protective service purview. This comes under our purview. Why then when Maine Advocacy Services said to you there's abuse going on hospital-wide, why did you feel that was not under your purview to investigate?

MR. WALSH - We need individual allegations.

MS. SALDIVAR - We were still with our agreement, too, that -

MR. WALSH - That the advocate at the hospital were doing those investigations at that time as per our agreement. But, we also would have to have individual, specific instances reported to us.

REPRESENTATIVE BURKE - Which they were doing; or, which they were willing to do but you said this is not our purview.

MR. WALSH - Their letter said - let me get the language here - said that - asked us to conduct an investigation to the deaths of Mr. Isaacs and Mr. Bolduc and the illness of Mr. Poland. That the Division conduct an investigation of conditions relating to safety and medical care of the remaining residents at AMHI; and that the Division provide protective services as necessary to protect individuals. So, we just felt at that time that we just did not have the authority to go in and do a full-scale review of that without specific allegations being brought to our attention.

REPRESENTATIVE BURKE - Well, did you state it that way in your response to them? Did you state that if you give us specific allegations against specific patients; or did you say we'll

only investigate the ones that are in our - that are our wards?
MR. WALSH - It says in response to the specific requests, the Division of Adult Services will be taking the following action pursuant to Title 22 MRSA 3478, referring the deaths, including Mr. Poland, who died on 8/19, to the Medical Examiner and the office of the Attorney General. Under the mandates of the Adult Protective Services Act and the Probate Code we will focus first on our public wards who are residents of AMHI and BMHI. We will conduct assessments of safety and medical care of the 47 DHS wards at and AMHI and 50 at BMHI. We will determine further actions on completion of these assessments and we will notify Commissioner Parker of our pending assessments and offer cooperative efforts regarding the remaining residents at AMHI.

So actually, when - part of our findings we found some - we did do some protective investigations of some persons who were not our wards that were brought to our attention. So in that summary that I read you earlier where eight were referred to Adult Protective Services, some of those were not State wards.
MS. SALDIVAR - Eight were wards and two were not.
MR. WALSH - Two were not wards.
REPRESENTATIVE BURKE - This is slightly different from what we had been - that we've heard all day, I think. That most of the day's been saying we've just investigated our patients; and had the advocacy services been aware that if they had

provided specific allegations, that you might have investigated each and every one of those, they may have been willing to provide that kind of information.

MR. WALSH - Unless we had specific allegations we would not have had the resources at that time. We had to pull people off of other programs to do the 45 wards.

REPRESENTATIVE BURKE - I understand that, but what I'm saying is that now you've said okay, every time we get a specific allegation we'll investigate it because we are Adult Protective Services. There was a lack of communication, to my mind, between your Department and Maine Advocacy Services because had they understood that if they had provided you with documentation on specific patient allegations, you could have ended up investigating the whole hospital.

MS. SALDIVAR - I think it's the confusion of the two programs as well. We did focus on our guardianship which is a separate program. We didn't get into the adult protective people until after some of the assessments were done. We were still operating with - communicating with the mental health advocates. So, that now we're moving to the adult protective. So even if they had at that time given us 20 names, I don't know that we would have moved in that way then that we would now today.

REPRESENTATIVE BURKE - So now the perceived need is greater. Once you've been there, visited it, saw the conditions, you said -

MS. SALDIVAR - And know that a lot of the incidents were not being reported to anyone.

REPRESENTATIVE BURKE - Yeah, we're very aware of that.

MR. WALSH - And, because of our agreement with the advocates at AMHI.

REPRESENTATIVE BURKE - Internal or external?

MS. SALDIVAR - Internal.

MR. WALSH - Internal. That we will be doing the patient to patient because of their conflict of interest.

REPRESENTATIVE BURKE - Okay. Personally, I'm relieved that you are going to take on the role of protecting them within the institution. My feeling is I wish that when you started the investigation for your guardians that that kind of investigation could have been done for people who were not necessarily your guardians. Again, the perceived response being well, if you're a guardian of the State you have a little more protection here than you do if you're just a payer.

MS. SALDIVAR - We will be offering training for private guardians. Seriously, yes.

REPRESENTATIVE BURKE - Good. That's a good step, too, yes.

MS. SALDIVAR - The Bureau of Maine's Eldery and our bureau are jointly developing the private guardian training.

REPRESENTATIVE BURKE - And this kind of literature will be left at the patient bedside, I assume.

MS. SALDIVAR - Yes. We'll -

SENATOR GAUVREAU - We're almost all set to break.

SENATOR TITCOMB - I just basically had a statement, and I'm sorry that Tom is not here. I personally think that considering the battle that our people from the advocacy office, whether they be in our outside the institute, I think we owe them a great debt of appreciation because very clearly if it had not been for them being so persistent in bringing out some very intolerable situations, it might have been considerably longer before you folks were called in, before we were alerted to the truly significant level of concern there is there. So, I'm sorry Tom isn't here to hear that. I personally feel a great deal of appreciation for their hard work.

REPRESENTATIVE BOUTILIER - Very quickly. You said you were concerned about your 450 cases. Would you say that part of the cause of the increase was your better communications say with Don Allen's ability to say we're gonna send them over there and communication with other groups and that you've got more people coming to you because they feel your program is good and there's better communication throughout the system?

MR. WALSH - Absolutely.

MR. BANCROFT - Definitely.

REPRESENTATIVE BOUTILIER - It's too bad you have so many 'cause you're on the staff; but it's a good thing as to why they're ending up in your -

MR. WALSH - The other reason is this consent to treatment issue

that with our litigous society that we live in, people are afraid to - I'm not blaming you, Senator - people are just afraid of taking actions if they think that somebody cannot consent to treatment.

REPRESENTATIVE BOUTILIER - My last very brief question is in terms of the issues that Christine was raising and Marge raised - that is, whether you get the information. What kind of - I lost the word I want to use - overseen - what kind of authority you have, what kind of ways can you make sure that that's the information you're getting? Is there any penalty for them not providing information in a timely manner without falsifying or fudging the language of the reports and so forth?

MS. SALDIVAR - Yes, but we don't want to start with that.

MR. WALSH - First - as in this article - first, make it a positive thing to report. Recognize that it's going to happen and recognize that if you try to keep this hidden that it's just gonna get worse. Then you don't report things until they're so serious that you can't move on them. So that the fact that these things happen are part of the milieu and have to be taken into account in any good treatment plan. We do have some minor sanctions if we find that people - professionals who are supposed to report abuse do not report it. I don't think we've ever been able to prosecute.

REPRESENTATIVE BOUTILIER - You do have them. They are there. As a last resort - you don't want to use them but they are there.

MR. WALSH - I think the penalty is $500. It's a civil penalty if you do not report - if you suspect - if you're a professional and are mandated to report and do not, I believe there's a $500 fine and a referral to the licensing board.

MS. SALDIVAR - But, our chief AAG and Department of Mental Health and Retardation's AAG have been conversing on exactly this - the protocols, the confidentiality, the law, so we should have a good background to begin with.

REPRESENTATIVE MANNING - Couple quickies. You had said earlier you were working - Representative Rolde asked you of the 6.75 which translates the 3.75 million community money that the Department was given in September, you said that you were working with them to utilize some of that money.

MR. WALSH - We have had discussions with them.

REPRESENTATIVE MANNING - When have they told you to anticipate some of that community money being ready?

MS. SALDIVAR - I couldn't attend the meeting this afternoon which they were -

MR. WALSH - They were laying out the final plans, but we anticipate within the next couple of months some of it will start coming on line.

REPRESENTATIVE MANNING - Okay. 'Cause they're telling us February 1st. The final question - we've got to go - your Department licenses boarding homes, nursing homes, hospitals. To some degree, and some much more than others, the license at the hospital goes along with JCAH, yet we don't do anything

over there - absolutely, unequivocally, the license people in the Department of Human Services does not go in to look at anything.

MR. WALSH - They go into the nursing home over there.

MS. SALDIVAR - The nursing home unit.

REPRESENTATIVE MANNING - To certify it for Medicaid.

MS. SALDIVAR - And the infirmary.

REPRESENTATIVE MANNING - So other than that, there are no licensing people from your Department which go into every other place that this Committee looks at - boarding homes, nursing homes and hospitals. Yet our own people - inaudible.

MR. WALSH - Are you asking me to comment?

REPRESENTATIVE MANNING - I'm just asking you yes or no.

MR. WALSH - That's correct.

REPRESENTATIVE MANNING - I'll let you off. I won't let you editorialize. I want to see you here tomorrow.

MR. WALSH - I have long felt that we should have a set of standards for state institutions that are based on institutions - for private facilities. That's my own personal opinion. Please let the record note that. I think that it just makes sense to have a set of standards and guidelines against which we judge our public institutions as well as our private; and I understand there are some legal problems with that and some other things.

REPRESENTATIVE MANNING - Again, I just want to make sure that

everybody understood that. Okay, thank you, Peter. Peter, for my comment, I appreciate you being available even yesterday which you weren't able to get on and coming over and enlightening us on what you've done in the past. Please keep us informed on those issues we asked you. We do appreciate it.

MR. WALSH - Thank you.

SENATOR GAUVREAU - At this point that will conclude the hearings for today. Some members of the Committee might not be aware that there has been a late breaking development regarding the situation at AMHI; and that is the Department of Mental Health and Retardation has this day forwarded an initiative to the Appropriations Committee to fund additional positions at the institute. And, at this point, rather than close the public hearings, Representative Manning and I will discuss tomorrow whether it would be propitious to invite the Department to return. As you recall, during the course of their presentations the Department indicated a keen desire to work in a collaborative vein with the Committee in fashioning a meaningful response to the problems at AMHI. So, we may well invite the Department back to present to us particulars regarding the new initiative the Department has advanced. So, we will recess rather than adjourn the public hearing at this time and we'll reconvene on Thursday morning at ten o'clock in this same room.

HEARING ADJOURNED AT 4:00 p.m.

XL

STATE OF MAINE

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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Augusta, Maine
February 9, 1989
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 inappropriate 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

I N D E X

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 band-wagon 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

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

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

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.