DEINSTITUTIONALIZATION IN MAINE

Prepared by:

Council #74
American Federation of State, County
and Municipal Employees - AFL-CIO

June 2, 1975

The purpose of this report is to examine the implications of a nationally popular policy that has led to the depopulation of many state institutions, and in particular to assess the impact of the implementation of this policy in the State of Maine.

First, it will be helpful to review the development of this policy, usually known as "deinstitutionalization." As we all know, fads in psychiatry are notorious. At one time, institutions were thought to be the only settings in which rehabilitation and treatment of mental illness was possible. However, rather than being a great cornerstone of great reform in mental health care, the institutions became huge warehouses providing little more than custodial care. As a result, there was growing public indignation about the plight of those citizens who were confined to institutions, ostensibly for treatment, and the mood was set for a drastic change in public policy relative to the care of the nation's mentally ill and mentally retarded.

In the early 1960's, federal legislation was passed that promoted the concept of community care, which could provide an alternative to institutionalization, the only other public mental health service.

The real purpose of the legislation was to demonstrate to the states and communities, the need for preventive care outside the institutions. Since mental health care was traditionally the financial responsibility of the states, the legislation provided for gradual withdrawal of federal funds which were to be supplanted by state/local appropriations. (In Maine, there has been steady growth in the community mental health programs, but with the threat of declining federal support, their future is in question).

With the advent of the new federal policy to promote community-based care and the growing public concern about the quality of care in the institutions, the stage was set to transfer large numbers of people from the institutions to "the community." This report represents an effort to uncover the story behind the depopulation of this state's institutions and the circumstances of those citizens once served by them.

The three largest state institutions most directly affected by this policy are Pineland Training Center, a residential treatment center for the mentally retarded; and the two mental health institutions at Augusta and Bangor. At Pineland Training Center, the population of the institution has been reduced from 1400 to 493. At Bangor Mental Health Institute (BMHI) the resident census has been reduced from 930 to 344, and at Augusta Mental Health Institute (AMHI) there are 417 residents, reduced from 1529. Since it is certain these

hundreds of residents were not all treated and "cured" before their discharge, one might reasonably inquire about the care of these displaced people and whether appropriate programs were planned to serve them upon their re-entry into "the community."

Of course, the deinstitutionalization process was to include a determination of needed services for those who were to be discharged, and subsequent to that, the development of community resources to maintain the client in non-institutional settings. In other words, before large scale movements of patients from the institutions into "the community" were initiated, there should have been an alternative plan to deliver the necessary supportive/maintenance/developmental services to them. In Maine, this comprehensive planning was not done. The net result of this policy is that the state Department of Mental Health and Corrections transferred its financial burden of providing custodial care from its budget to the federal government and Maine's Department of Health and Welfare. Unfortunately, the transfer of responsibility did little to improve the mental health and care of the former residents. Many moved to nursing homes, boarding homes, and foster homes, none of which were adequately prepared or trained to care for mentally ill or mentally retarded people. These mini-institutions lack rehabilitation or recreation programs, certainly do not provide a therapeutic setting, and in general provide another type of inadequate custodial care.

While patients were moved from the institutions in large numbers, there was little planning to provide for a treatment program for the discharged patient. The primary, and in some cases, the only requirement necessary to move a patient from an institution, was that shelter in "the community" had been located. Eventually, some after-care programs developed, the purpose of which was to create a network of supportive social services for the discharged patient. The service delivery was fragmented at best, since each of the mental health clinics and each of the regional offices of the Department of Health and Welfare were allowed to develop their own regional version of after-care services, in the absence of a state mental health plan to deliver services to deinstitutionalized clients. Since services to deinstitutionalized clients were a high priority to some agencies and a low priority to others, there exist great gaps in service in some parts of the state. For many patients, the result is that they no longer have access to the institution, and have no meaningful access to community services in the few places where they exist.

First, let's examine the implication of the policy which seeks to promote discharge and drastically restrict admission to the institution; and secondly, let's briefly review some of the reasons why "the community" has been unable to provide the necessary care and services to the discharged patients.

The institutions, quite simply, are no longer accessible to many

ex-patients who have either failed to make a successful adjustment in a less restritive community setting, or who have been discharged to totally inadequate and/or inappropriate community programs. The motivation for this seems to be a desire to put pressure on the community to develop appropriate alternatives to the institution, but, unfortunately, the patient is the victim of this maneuvering. Rather than use patients as a pawn in forcing social change, the state Department of Mental Health and Corrections should be providing leadership in planning mental health services throughout the state. Former Commissioner William F. Kearns, in issuing the policy which prompted the mass movement from the state institutions to the private homes, stated "The state hospitals have been used inappropriately as nursing homes to solve the economic problems of the elderly poor, as a means of solving the social incompatiability of certain unwanted people, and as a way of providing temporary resolution of crises which do not involve mental illness. They have been used for acute medical care of certain patients who present problems in acceptability which exclude them from care in their local general hospitals."

In other words, even though it was clear that many patients were poor and not wanted in "the community," the Commissioner used these very patients in an effort to force the community into accepting its responsibility for them. Unfortunately, the Commissioner was right about the "incompatibility of certain unwanted people": Evidence indicates that many ex-patients parade in and out of one foster/

boarding home after another. According to Rachel Rhalen, Supervisor of Adult Protective Services of the Health and Welfare Department in Bangor, it is not uncommon for many of the chronically mentally ill patients to move in and out of half a dozen homes in a two-month period. Even though the adjustment to the community and adjustment of the community has failed, the state institution is no longer a resource so the patients are forced to relocate in a series of homes.

One obligation of the institution is to protect people who might do harm to themselves or others, yet it is clear that implementation of this policy is lax. There are countless examples of patients -- former, current and potential -- who have harmed themselves (and at times killed themselves) by slashing their wrists, overdosing, drowning, hanging, shooting, and some patients have even lost or taken their lives while on "ground privileges." There are other examples of discharged patients who have harmed others or destroyed property. The question is: Who should be held responsible for the behavior of patients who have been discharged before they were ready for independent living, or who have been discharged to living situations that could only be conducive to such behavior? One of the unfortunate side effects of the deinstitutionalization policy and subsequent pressure to discharge patients without proper community support and supervision is that some are re-institutionalized, but in our corrections system, rather than in a health care facility. Is prison or one of our infamous county jails, a place we want to send adults with the mental or emotional

maturity of children?

Finally, it is incumbent on the new Commissioner of Mental Health and Corrections to re-examine the implementation of the restrictive admission policy and the liberal discharge policy at the state institutions. We have uncovered situations where records were falsified in order to find an accepting foster home for an AMHI patient. In another situation, an uncooperative boarding home operator was threatened, not with removal of the ex-Pineland residents, but with total discharge of the residents from the institution to her complete care. (The operator was going to be given more responsibility to care for the residents since discharge means supportive services of Pineland would no longer be as accessible). Also, due to lack of cooperation between general hospital and state institutions there is evidence that general hospital staff send mentally ill people home without even trying to commit some patients who are obviously in need of care and protection.

Furthermore, it appears that there have been changes in certain policies to accomodate acceleration of the discharges at Pineland. For example, while it was once a policy to discharge residents only to an area close to relatives, a new procedure established last March encourages community placement outside the resident's "priority area," to eliminate extension of the resident's term at Pineland while awaiting placement.

Another inter-departmental memo indicates that other Pineland residents who are waiting for community placements will be placed in inappropriate community settings on a temporary basis, the only purpose being removal of residents from Pineland. To sum it up, a resident's plan for community placement might call for an opening in an individual or small group living arrangement in York County, but in order to transfer the resident from Pineland to the community, the actual placement might be in Knox County in a large boarding home where there happened to be a vacancy. There is such intense feeling about minimizing the population at the state institutions that overzealous staff can effectively deny proper care, treatment, and in some cases, protection to a significant number of vulnerable Maine citizens.

In order to illustrate the problem more concretely, some personal situations which have been brought to our attention are listed below. Since it serves no purpose to relate all the instances of neglect or bureaucratic indifference reported to us, it should be noted the incidents described below represent a cross-section of cases which seem to indicate a definite pattern rather than an isolated circumstance. Generally speaking, these examples illustrate the inaccessibility of the institutions for those requesting care and those requiring protection.

EXAMPLE 1

A woman who had been a patient for many years at AMHI was discharged

to a foster home. The patient had attempted suicide several times, both before her admission to AMHI and while she was a patient at the institution. She also had a history of coronary problems, however, when the patient was taken to the foster home, her accompanying record indicated there had been no suicidal gestures in the past, no medical problems, and no medication needed. The patient had a short stay in the foster home. One month after placement, she had a coronary and died. A large quantity of medication was found in her belongings.

EXAMPLE 2

A middle-aged woman was discharged from BMHI approximately nine years ago, and had attempted suicide many times since her discharge. The woman's mother who had been caring for her subsequently became ill and could no longer care for her daughter, so the daughter moved into her own apartment. She became increasingly depressed, fearful of being alone, and had no supervision in taking her medication. She began to have dizzy spells and would pass out. The mother was aware of the problem and turned to BMHI for assistance, since they had been the primary caretaker in the past. For two weeks, the mother tried to negotiate her way into the mental health system to obtain some assistance for her daughter. Finally, she was referred to the Health and Welfare Department by an "after-care" worker from the Counseling Center, the local mental health agency, because the "after-care" worker said they did not accept jurisdiction for servicing clients who had been discharged such a long time ago.

Despite the client's history and persisting problem, she was referred to the Health and Welfare Department for a shelter placement. Even though the Health and Welfare staff thought it was an inappropriate referral, it was clear someone had to intervene. To assist the woman, they decided to accept the referral, but it was too late. The woman slashed her wrists the previous night and was taken to the Eastern Maine Medical Center. The day this incident was reported to us, the Social Worker received a call from the Hospital with a message that "they almost lost the woman the night before."

EXAMPLE 3

A city welfare worker was asked to intervene to assist a woman who had locked herself in her apartment for days and wouldn't let anyone in. Her mail, including two month's social security checks, had been building up in the mailbox. After coaxing, for over two hours, the welfare worker was admitted to the apartment. The woman had not been eating (she thought the stove was contaminated), she had stuffed towels down the toilet so jars of urine were abundant throughout the apartment, she exhibited paranoia about neighbors "being after her", and she had been hallucinating. She was taken to the medical center for examination, but when she decided not to accept a voluntary admission, the doctor sent her home. The following week, the welfare worker and then the police intervened to assist this woman. She was examined again, refused voluntary admission, and was returned home to her apartment. The doctor explained the patient's

rights had to be protected. No one knows what became of her.

EXAMPLE 4

On another occasion, when a Social Worker could find no shelter for a particular client (ex-BMHI patient) who had been in and out of 15 to 20 foster and boarding homes, the client responded by swallowing a bottle full of pills. The Worker called the Medical Center first to determine whether the ingestion of that many pills was dangerous - which it was - but the Worker was referred to the state institution to obtain treatment for the client. After calling the state institution to find they wouldn't admit the client either, the Worker returned to her office to find the client missing. The Worker and police searched the vicinity, found the client passed out on the ground, took him to the medical facility where he was treated for three days and discharged. Apparently an unsuccessful effort was made to have the client admitted to BMHI, but during the client's third day at the Medical Center an ambulance from the client's hometown coincidentally brought someone to the Medical Center. The client was then discharged and given a free ride home to his trailer in Washington County.

EXAMPLE 5

One 18-year old boy discharged from AMHI went on a spree of violent behavior. He seriously abused his 15-year old wife, devastated two apartments city welfare had secured for him, and finally was conficted on larceny and arson charges after setting fire to a public building. The boy was sentenced to the County jail.

EXAMPLE 6

One young man was recently sentenced to a minimum of one year at Thomaston Prison after going through plea bargaining. This ex-Pineland resident had been through a succession of community placements, and subsequently found his own living quarters where he received no guidance or supervision. From the time of his arrest to his subsequent sentencing, a period of five months, he was not visited by a Social Worker.

EXAMPLE 7

Still another young man from Pineland was returned home to live with an abusive and alcoholic father. Predictably, a confrontation occurred; the father was injured and the son was charged with aggravated assult and battery. Should this young man be held responsible for his behavior, when the real error was placement in an unsuitable home?

While there are many examples of patients discharged before they are ready for independent living, the push to allow personal freedom to patients has also resulted in a lax policy in the issuance of "ground privileges." While some of the following incidents have already been reported in the press, they are outlined in the context of this paper to identify a trend in the policies of the mental health institutes.

There are, of course, reports of several people committing suicide while residing at the Mental Health Institutes. One man hung himself in the cemetary opposite AMHI.

A badly beaten female patient was found dead outside the institution.

Another patient, a mentally retarded young man, was allowed to go to a ball game with some other patients. He became separated from the group and was later found dead in a cornfield. He died from exposure.

Another patient was given ground privileges, jumped off a high bridge and subsequently died.

Then, of course, there is the well-publicized case of the woman who drowned her three children, was admitted and discharged, whereupon she drowned three more children, was re-admitted to the hospital, then given ground privileges, and she drowned herself.

There are other examples, like the completely disoriented man who was given ground privileges, wandered off alone into a field, fell, and died of exposure, but the list need not drag on. Suffice it to say that it is past time for the Department of Mental Health and Corrections to review its policies with greater understanding of the vulnerable people it should be serving and protecting.

Finally, it might be well to give an example of a situation which resulted in a positive decision for a Pineland resident, but at the same time illustrates the pressure to discharge as many residents as possible. An elderly blind woman, in her late 70's who had lived at Pineland most of her life, was presented at a team meeting for evaluation for possible community placement. This woman had been "in camisole" for close to twenty years; out of it, she would tear out her hair, fight, rip her dress, and while she is able to negotiate her way around the ward, she strikes out at anyone or anything that crosses her path. Several Social Workers recommended community placement for this woman and there appeared to be unanimous sentiment by the team to "deinstitutionalize" this woman. Finally, the team doctor asked a long overdue question. "Show me how this woman would benefit leaving Pineland Center?" Unable to explain any benefits, the team reversed its decision and agreed to allow the resident to remain at Pineland.

While evidence suggests that, by design, the institutions are no longer a viable resource for many chronic mentally ill or mentally retarded Maine citizens, "the community" is also ill-prepared to fill the gap in service. Inadequate and poor planning has resulted in clients being denied proper care, either because of (1) the paucity of community services, (2) inappropriate community placement of (3) administrative problems and "buck passing."

There are two state agencies, the Department of Health and Welfare, and the Department of Mental Health and Corrections that have responsibilities to plan, develop, and deliver human services, but federal funds subsidize in whole, or in part, a large percentage of human services in Maine. These funds are administered by various federal agencies, each with conflicting administrative requirements, and since state statutes and regulations are often tailored to meet federal requirements, we have a situation whereby the State automatically inherits the lack of coordination demonstrated by federal agencies. In testimony presented to the Maine Human Services Council, the problem was stated quite well: "The concept that a person or family can have a range of problems needing a coordinated, flexible approach has not been embodied in the highest levels of authorization, administration, and funding of human service programs. This leaves Maine with the critical paradox of human service needs un-met, yet scores of agencies, commissions, and advisory boards dealing with the problem."

State human service agencies in Maine have to share in the responsibility for failing to provide a comprehensive service delivery system. To begin with, the State Departments of Mental Health and Corrections and Health and Welfare have different planning districts, and as mentioned earlier, each regional Health and Welfare office or local mental health clinic was allowed to develop its own regional priorities. While regional offices and clinics should have a certain amount of administrative flexibility, there should be a state-wide

coordinated, consistent human service delivery system. If a patient is discharged to Brunswick, he should be offered no less service than the client discharged to Augusta, or Portland. Some examples of how this fragmented system can work to the disadvantage of discharged patients follows:

EXAMPLE 8

A man discharged from AMHI eighteen months ago has moved in and out of several boarding homes. At his last placement, he threatened the boarding home operator with a knife and was, inevitably, no longer welcome at the home. A request to locate a new placement was made to the Department of Health and Welfare in Portland. The client comes from Brunswick. Since the Portland office of Health and Welfare services all of Cumberland County, they had a responsibility to try and assist the client. However, that office contracts out "after-care" services for discharged AMHI patients to Community Health Services in Portland. The contract agency has responsibility to recruit and develop shelter facilities for discharged patients, but services a different geographic area than the Health and Welfare regional office. In this particular situation, the contract agency had no responsibility to develop shelter facilities in the Brunswick area which is outside their catchment area, and since the mental health agency in Bath-Brunswick has no "after-care" program, there has been no development of shelter facilities in that part of the state.

EXAMPLE 9

A young girl who had been a state ward under Health and Welfare jurisdiction was in need of intensive psychiatric services due to severe emotional problems. Despite the fact the girl had reached legal majority, the Department continued to assume responsibility for the girl's care until she was able to function more independently. She was first treated at BMHI, then transferred to a more appropriate setting at Sweetser's Children's Home. When the client was ready to leave the program, no alternative treatment plan "in the community" could be developed for her. As a result, her health deteriorated until she was transferred to an in-patient unit at Webber Hospital in Biddeford. After a few weeks on the in-patient ward, pressure to relocate the girl was renewed. Since more resources were available in Portland, the plan was to secure shelter and a treatment plan for her there. However, because she was going to Portland, the "after-care" program in York County thought it more appropriate for the Cumberland County after-care program to assume responsibility for these services. Since the client did not live in their jurisdiction, the Cumberland County after-care program felt the responsibility rested with the York County group. An attempt was also made to have the girl transferred to Shalom House, a "half-way house" for emotionally disturbed adults, but their evaluation of her concluded she needed stabilization and a structured environment. Despite these needs, AMHI was dismissed as a resource because it was considered unlikely that they would accept the girl.

Impasse at hand, the client was referred to the Department of Health and Welfare as an adult protective case. Ironically, Health and Welfare (in the Portland region only) contracts out its responsibility to provide adult protection services to the two agencies providing "after-care" which had already refused responsibility. Furthermore, it is important to mention that during this entire experience, the Health and Welfare had discharged the girl from the child custody program because state custody was felt to be more a liability than an asset to her; seemed to be a vehicle for shifting responsibility for the development of a mental health program back to the Department of Health and Welfare, and they did not have the resources to assist the client.

EXAMPLE 10

Another example of such jurisdictional disputes could have had potentially much more serious consequences. A young woman, a patient at BMHI, was committed to the institution for treatment after killing her baby. She was eventually released to her home, but was required to return to the institution every two weeks for an appointment with her therapist. A few weeks ago, she kept her appointment, but appeared to be agitated and distraught. She was nevertheless sent home. The same day, a staff person from BMHI called the Department of Health and Welfare and requested adult protection services for the woman, asking that a Social Worker check on the client to assure her well-being. The Health and Welfare staff person, after consultation with her supervisor,

referred the case back to BMHI. In the meantime, the BMHI staff discovered the woman was living with a couple with a young baby, and they feared the baby might be in danger. At that point, another referral was made to the Department of Health and Welfare -- this time for child protection services for the baby. The Health and Welfare staff again referred the case back to BMHI and after involving supervisors and management at many levels, it finally became clear that BMHI did have responsibility to provide mental health services to their client. Incidentally, because of this jurisdictional dispute, it took four days before anyone was assigned to intervene in the potentially explosive situation.

It is worth noting that these incidents of "passing the buck" serve to illustrate an even greater problem. Workers and Supervisors alike, in both private and public agencies, have themselves indicated that they are unsure about their responsibilities vis-a-vis one another, particularly in the area of servicing incapacitated/disabled adults.

Another symptom of the fragmented system is that of sometimes intense competition between agencies for limited resources, and certainly duplication of effort. For example, in one region, the Department of Health and Welfare contracts out recruitment of foster homes to one agency to develop homes for the mentally retarded client, and to a second agency to develop homes for adults with mental health problems, while it develops homes itself for all other adults in need

of foster care. Since all homes must be approved (i.e., licensed) by the Department of Health and Welfare** the private agency does not control the usage of the foster home, which has created considerable conflict at times.

While it is important for state local/regional offices to determine its priorities based on local needs, and to implement programs with some administrative flexibility, there are certain basic services that should be planned and available to clients consistantly throughout the state. Protection of adults in jeopardy is one of those basic services.

Lack of planning and associated administrative problems created the inadequate system of care we have today. For some deinstitutionalized patients, living in a less restricted environment has meant a definite improvement in their health and well-being. For others, their "freedom" has meant isolation, exploitation, or an unhappy march through countless foster/boarding homes.

It is important to understand where these deinstitutionalized clients

** Note: Apparently two regional offices of Health and Welfare are contracting out the licensing function of foster homes to private agencies which are also engaged in recruiting and placing clients from the institutions. Aside from the questionable legality of contracting out a licensing function, one might reasonably inquire about the desirability of having the licensing function in the same administrative unit as the client placement function.

have gone and the circumstances of their "care" in the community. The program is largely underwritten by the federal government since community-based care in boarding/nursing/foster care entitles the client to a federal subsidy in the form of medical or welfare benefits. This contrasts sharply with the financial burden the state must absorb to finance institutional services, where, at Pineland Center, for example, the state assumes 96% of the cost of maintaining the facility. The federal subsidy to individual clients only provides for basic maintenance, specifically, room and board, so it is still incumbent upon the state to develop and finance treatment and other supportive services to the clients it once cared for in the institution.

At this juncture, it might prove helpful to review the conditions with which some ex-patients must cope, understanding full well that, armed with their government checks, they are a "captive" clientele of the multi-million dollar boarding/nursing home enterprise, since publicly-operated facilities are virtually inaccessible to them.

There are three basic types of shelter provided to most of the discharged patients who are not returned home to their families:

1. Nursing homes
2. Boarding homes
3. Foster homes

Nursing home care in the state has already come under public scrutiny by organized groups of the elderly taking an active interest in the type of service provided in these mini-institutions. It is interesting to note that while the state maintains it is "deinstitutionalizing" its elderly patients and more severely retarded clients, many are merely being transferred to another institution called a nursing home.

In discussions with workers who have first-hand knowledge of conditions in nursing homes, (workers who have been employed in the homes, who license/inspect them, and those who supervise placements of "deinstitutionalized" clients) the most prevalent complaint is that the nursing home staffs were not prepared for the transfer of the patients from the institution; little, if any, staff training has taken place since the mass exodus of patients during the last few years.

One social worker cited an experience she had when she was required to supervise placement of an ex-Pineland resident. The worker herself did not feel adequately trained to supervise the placement, nor did she think the nursing home staff completely understood the needs of the severely retarded patient. An effort was made to organize a training program, which would instruct social service field staff, and community medical personnel in the proper care and treatment of the retarded. The program was never implemented. The

social worker finally had her client returned to Pineland since her condition was deteriorating. The client returned malnourished, with a weight loss of 20 pounds, down from 68 to 48 pounds.

Another concern also relates to the inadequacy of staffing in the homes, and the unreasonable, if not illegal, expectations of the unskilled staff. In several nursing homes, employees reported instances where untrained aides were expected to prepare medication and administer it to patients, including intra-muscular injections of drugs, and changes of dressings on patient wounds. While the State of Maine regulations governing the licensing and functioning of nursing homes requires that a licensed registered nurse be on duty or on call at all times, one employee reported that the home in which she worked had no such service available for months at a time. Just recently, there was a strike by nurses' aids at a Biddeford Nursing Home. They charged the home with patient neglect, citing understaffing and inappropriate use of nurses' aides.

EXAMPLE 11

Another incident reported suggests that patients receiving state welfare assistance do not receive the same care and attention as private patients. Specifically, a client receiving welfare assistance complained of pain in her hip and could not bear weight on the affected side. When the doctor was called, he prescribed medication and bed rest. Two weeks later, on a routine visit to the nursing home, the doctor examined the patient, diagnosed a fractured hip, and transferred the client to a hospital.

EXAMPLE 12

Another patient, who had received nursing care for over a year, was finally returned to Pineland after his condition deteriorated considerably. The nursing home staff had described the patient as an "animal" and therefore did not involve him in any program. Dental care was so inadequate while in "the community" that a competent dentist recommended a full mouth extraction. The patient also qualified for $25.00 per month for personal expenses, yet upon his return, he had nothing but the clothes he was wearing.

EXAMPLE 13

Still another resident was returned to Pineland last March in a deteriorated condition. Her weight had dropped from 70 to 41 pounds. After five baths and three shampoos, the bed sores could be treated. Her teeth were encrusted with dark material, her body odor foul, and ears not clean.

EXAMPLE 14

Two staff employees were sent to a community hospital to pick up the body of a resident who had been in a nursing home. When the employees arrived at the hospital, they found the resident laying on a table in feces and urine, her hair filthy, her eyes unclosed because the mucus had dried them open. The nurses on duty said no clothes had come with the patient from the nursing home.

Another former resident died while in community placement; malnutrition was listed as a contributing cause of death.

Several other incidents of negligence in nursing homes have been reported to us, all of which substantiate the fact that the quality of care in some nursing homes is deplorable. In a survey recently completed by the Public Interest Research Group (PIRG) deficiencies were found in a substantial majority of nursing homes in Maine. Of the 101 nursing homes mentioned by respondents in the survey, only 32 were not accused of some form of abuse or violation of the patient's basic rights and dignities. Findings of PIRG also supported the contention that there is widespread misuse of patient's personal spending money. Almost 40% of the people interviewed indicated the patient was not receiving their personal spending money.

The problems in Maine nursing homes have been documented several times, yet little has been done to upgrade the quality of care in them. Most homes lack anything approaching a therapeutic setting, and they lack recreation/socialization programs as well as rehabilitation services. Some preliminary research conducted by the Maine Department of Mental Health and Corrections provides substance to the charge that some patient's health seriously deteriorates upon discharge to private nursing homes. This study should be a precursor to an independent, serious, in-depth analysis of the quality of care provided to discharged patients.

In Maine, two-thirds of all nursing home patients are subsidized by federal and state tax dollars, and therefore clearly establishes the responsibility of our elected officials to investigate and demand proper care for some of our most disadvantaged and powerless citizens.

Many other discharged patients are transferred to a boarding house or foster home. Generally speaking, the most common complaint about these homes is that many are located in a remote area of the state, and usually there is no planned program of activities for the ex-patient. It is evident that most of the boarders spend their day smoking cigarettes, watching television, or just sitting with nothing to do. Again, most of these homes are commercial enterprises and lack any semblance of a therapeutic setting. In a survey of "community placements" completed last year by the Bureau of Mental Retardation, it found that more than 90% of clients who came under their jurisdiction had no opportunity to attend an outside program such as an adult-day activity program or sheltered workshop. Considering the fact that one of the goals of deinstitutionalization is to promote optimal growth and development, it's clear that the Bureau is not meeting its goal.

While there has been no survey of unmet needs of the discharged mental health institute patients (which is interesting in itself), it is clear that one of the reasons placements, particularly for the chronic patients, are short-lived is because there is no activity/treatment program for them. Chemotherapy is the only support many ex-patients

receive once discharged to the community, and there are many problems associated with that which will be addressed later.

The foster home development program has not been particularly successful. Generally speaking, many of the potential foster home operators are interested in caring for a quiet, subdued older person who requires little attention and effort. Obviously, many of the discharged patients from the state institutions do not fall in that category, and for that reason, the foster homes are often not a viable resource for those with responsibilities to locate placements for discharged patients.

It should be pointed out that even some homes where the Social Worker and the foster home operator mutually agree that the possibilities of placement are good, once a client arrives, there are often problems. According to some of the placement workers, it is not uncommon to move chronic mentally ill clients from foster home to boarding home many times in just a few months. This can hardly be a satisfactory experience for the client, the foster home operator, or the Social Worker who has to be a miracle worker to find an appropriate placement.

It is inevitable that the boarding and foster home operators who are running a commercial enterprise are not going to tolerate bizarre or unusual behavior.

EXAMPLE 15

An example, one female client who had been discharged from BMHI had moved from one foster home to another, and in each home would be so disruptive that she would be asked to leave. Behavior could be just unusual - i.e., going outside on the street at dawn in her nightgown to bum cigarettes from passerbys, or it could result in potential danger, i.e., in another foster home, the same client burst into the homeowners bedroom at dawn demanding cigarettes. The homeowner obliged, and a short time later smelled something burning in another room. She found the client smoking in the living room with the carpet burning, apparently unnoticed by the client. The foster home operator insisted the client leave that day. The client was also unable to manage her money (i.e., spent all her cash on perfume), and had been so unsuccessful a candidate for the foster care program, the Social Worker returned the client to BMHI. She spent all day trying to convince a succession of doctors to admit the client. Part of the client's unusual behavior was attributable, in part, to the improper supervision of her drug intake. The client had "made the rounds" from clinics to doctors, each prescribing different medications, which the client was mixing together. Incidentally, the client was voluntarily requesting admission, and finally, at the end of the day, she was offered assistance. Since she has now been at the institute for two months, it's apparent she did need some care and treatment. If it hadn't been for the perseverance of the attendant Social Worker, however, the client would probably be still wandering through one foster home

after another, and going from one doctor to another.

There are countless other examples of ex-patients behaving in a way that is totally unacceptable in the private market place of boarding care.

EXAMPLE 16

One boarding home operator kept calling AMHI asking for help with a patient who was hallucinating, incontinent, and not at all manageable in a boarding home setting. Staff at AMHI kept asking the operator to "hang on" until finally the operator turned elsewhere for advise, and followed it. She drove the client to AMHI and left him at the door.

EXAMPLE 17

Another elderly man, in his 80's, a former BMHI patient, was becoming increasingly unmanageable in his foster home. The client would screech in the middle of the night, shout obsenities, run naked through the house, etc. Suffice to say, without going into detail, that this gentleman had serious problems, but no solution was found until the situation reached a crisis (the man locked himself in his room and threatened violence), and then it took all day and all night (10:30 p.m.) before the client was finally re-admitted to BMHI.

There are many other examples when chronic mentally ill patients are physically, verbally abusive to operators, start fires, become

hysterical and/or unmanageable, don't pay their bills, etc. In general, they are people with problems that are difficult to manage outside the institution, and, in particular, they are people who are impossible to maintain in a stable boarding or foster care environment.

EXAMPLE 18

There have also been other documented cases when clients returned to Pineland from boarding homes, and have exhibited a deteriorated condition. One client who had been discharged for just five months lost 38 pounds (from 125 pounds to 87 pounds) during her boarding home placement. She was returned to Pineland in such poor health that some of the staff went to visit the boarding home since several other Pineland residents continued to board there. The other residents appeared to be in poor health as well, but despite complaints about the home, nothing was done to change the condition there.

Apparently there are still ex-Pineland residents who reside in homes that have not or could not be approved by the Department of Health and Welfare. One situation we found seemed particularly poor. Two women from Pineland were placed in a rooming house several years ago. One woman, in her 60's is capable of doing only rudimentary dressing skills. She sits in a chair all day mumbling. The other woman is capable of being more active and does housework. There are 11 people living in the house, but it has no license because it is listed as an apartment/rooming house. The fire inspector was called to inspect the

premises, and even though he personally thought the home was dangerous, it passed the technical requirements of approval. This homeowner had maintained a similar home in the past that burned to the ground resulting in the death of an elderly man.

There are other examples when ex-Pineland residents were returned in very dirty condition, one with scabies on his body, others just dirty all over. There were several who returned with unusually great weight loss.

There is no doubt that there are probably many former residents of the state institutions who are faring well in boarding and foster care establishments. However, it also appears evident to us that a significant number of them are not adjusting well, are not receiving the proper care and attention, and do not have available critical programs and activities to make the placements successful.

We've examined briefly where patients go and the type of shelter available to them upon their discharge from the state institutions. Concomitant to the discharge of so many patients, there should have been implementation of a statewide network of supportive social/medical services such as adult day activity programs, sheltered workshops, home-maker health-aide services, recreation/socialization programs, training in skills of daily living, etc. Despite the inadequacies of so many of the community shelter services, many placements might have been

more successful if these other services were available. In order to make these services accessible to the discharged patients, there should also be developed an aggressive "after-care" program that could allocate staff to adequately supervise the placements in the private sector, and act as an advocate on behalf of the discharged patient. This "after-care" system should be available to all discharged patients throughout the state, not just in a few select areas. More attention should also be given to the legal status of some of these patients since their mental competence is questioned and, at times when medical attention is needed, it is delayed in search for someone to authorize treatment. And finally, there is a need to investigate the widespread use of chemotherapy as the primary means of community maintenance.

Several instances were reported where patients were discharged on high doses of tranquilizers. One young woman discharged from AMHI was charged with child neglect. The only reason she wasn't caring for her children properly was because she couldn't stay awake with such a high dose of medication.

Another young man was discharged from AMHI receiving an "institutional" dosage of tranquilizers. He continued on the medication for one year while he was drinking heavily. He finally had a breakdown, and after complete detoxification of his system, he had no memory of the time since his discharge.

In summary, the deinstitutionalization policy seems to have been prompted more by political and economic considerations than by the development of a planned treatment strategy for the chronic mentally ill or mentally retarded citizens in this state. The movement of patients from the public institutions to the private boarding and nursing care industry is a means of transferring financial responsibility for health care from the state to the federal government, without enhancing health services in the process. What we need to do is build a comprehensive, integrated mental health system, which recognizes the value of <u>both</u> institutional and community care. Mentally ill and mentally retarded citizens have a right to treatment, whether they're confined in an institutional setting or placed in the community, and this state shoud commit itself to invest the necessary resources to meet that goal.

RECOMMENDATIONS:

1. There should be an immediate moratorium of discharges from state institutions unless it can be demonstrated that community resources exist to meet the full needs of the patient. Furthermore, it is recommended that if any treatment plan is not implemented within 10 days of the community placement, then the patient should be returned to the institution until proper care can be secured.

2. There should be established a special commission authorized by the state legislature to study the practice of deinstitutionalization as applied to the mentally ill and retarded of this state and to determine the adequacy of nursing and boarding home facilities.

3. L.D. 726 should be enacted to staff the Maine Human Services Council so that it can properly carry out its function of establishing overall planning, policy objectives and priorities for all functions and activities relating to human services.

4. The Department of Mental Health and Corrections should immediately undertake the development of a comprehensive state-wide plan to provide needed services to discharged patients.

5. L.D. 1525 should be enacted to provide state funds to community mental health clinics which are threatened with the loss of needed federal funds.

6. Current state expenditures for mental health services that have been eliminated from the Governor's budget should be restored:

    a. Funds for day-treatment services in the community mental health clinics, which were eliminated by administrative action from the Department of Health and Welfare's medical services budget should be restored to the state budget.

    b. The Priority Social Services Program which provides services to the mentally retarded, transportation, homemaker services, and other valuable human services should be restored to the state budget.

    c. Funds necessary to fill all vacancies at the state institutions should be restored to the state budget.

7. L.D. 1326 should be enacted to finance the development of activity programs for mentally retarded residents in boarding, foster, and nursing home clients.

8. L.D. 1135 should be enacted to finance the development of a dental care program that would service discharged Pineland residents.

9. There should be developed a state-wide system of "after-care" services that will effectively monitor all community placements.

One final comment is necessary. Some readers might comfortably put aside this report, dismissint it because a public employee union sponsored it. We are concerned, of course, about our jobs and working conditions, but that does not diminish our concern for our patients/clients. We did not have the time, resources, or expertise to do an in-depth analysis of the mental health system in Maine, but what we have reported is based on facts. We hope that this report will stimulate concern and action by responsible public officials.

##########