Mentally Ill.
Maine.

L.D. 1528

"An Act to Establish and Protect the Rights of Recipients of Mental Health Services"

Why it is needed

What it will provide

ine Citizens' Commission on Human Rights ; May 1979

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Commission on Human Rights
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Sponsored by Association of Scientologists for Reform

L. D. No. 1528

AN ACT to Establish and Protect the Rights of Recipients of Mental Health Services

WHY IT'S NEEDED IN MAINE

INTRODUCTION

LD 1528 is a comprehensive bill to establish and protect the rights of recipients of mental health services, meaning, specifically, those people who suffer from mental illnesses, as separate from those whose plight is mental retardation. Maine already has a fine Bill of Rights for the mentally retarded, and it was that bill, in part, which led to the conception of this bill: as those with mental illnesses were not afforded the same rights by law as the mentally retarded.

A brief view of the history of the treatment of mental illness reveals vast changes occurring in the last century; in treatment methods, in education, in planning. In the past ten years, there has been a rise in the interest in what the rights and responsibilities of mental patients are, and how these should be delegated and exercised. Society as a whole has gone beyond the idea that all "crazy people" should be locked away forever. The emphasis now is on reinvolvement and reentry to normal productive life. This bill was written with this in mind - to secure the rights of recipients of mental health services so that they will have the option to exercise these rights and become more self-determined and able to handle their own lives. This should be the goal of psychiatric treatment, and this is exactly the goal of this piece of legislation.

There are other factors that prompted the origination of this bill. The Citizens Commission on Human Rights, which is an advocacy group for the rights of recipients of mental health services, began extensive research in February of 1978 into the condition of mental health recipients here in Maine. We toured many of the pcyhiatric units at the state's general hospitals, as well as the two state institutions. We found conditions in these different units to vary considerably; although we are fortunately past the days of "snakepit" and "back wards". The subject we found most commonly lacking and inconsistent was the conception of what mental patients' rights are and how these should and could be used. With this data, we then investigated what other states and countries had done about the problem, and found that in the last six years, eight states had passed legislation that guaranteed the emancipation of mental patients rights to a greater or lesser degree. At that point, in speaking with ex-mental patients, doctors, lawyers, legislators, mental health professionals, and friends, we found that there was broad support for some kind of Bill of Rights for mental patients. Using other state statutes, guidelines, laws from other states, the Constitution of the United States, the Universal Declaration of Human Rights adopted by the United Nations Assembly, and the Nuremberg Code, we set forth to compose this legislation for Maine.

Current Maine statutes concerning the rights of mental patients provides only the right to humane care and treatment, a section on mechanical restraints and seclusion, the right to communication and visits, general rights and the right to Habeas Corpus. We feel that the state needs to address itself more fully on the subject of rights

for recipients. Each section of the bill was written because of a specific need for change in that area. We have found abuses occuring which would have been prevented, had there been a law to protect these rights. Our information comes from those who have suffered these indignities, those who observed them, and from books and articles published on the rights of people in institutional settings. To protect the confidentiality of those who told us their experiences, no names will be used; however, what is described did actually occur and is documented.

To make the need for this bill most clear and understandable, each separate section will be stated, followed by the reason for it's necessity, as well as specific examples of how these rights have been violated.

Express written and informed consent.

Be it enacted by the People of the State of Maine, as follows:

Sec. 1. 34 MRSA § 2251, sub-§§ 9 and 10 are enacted to read:

9. Express, written and informed consent for treatment. "Express, written and informed consent for treatment" means that a person knowingly, clearly and explicitly manifests voluntary acceptance or allowance of the planned or proposed treatment in writing to the treatment staff. If the person is illiterate, or does not understand English, or is blind, deaf or otherwise unable to communicate, appropriate measures shall be taken to supply the information necessary to make an express, written and informed consent.

This definition of express written and informed consent related to an idea which has existed in medicine for over two hundred years, but which has achieved an especially marked interest and concern within the past thirty years.

One factor which has created this marked interest is the increase in medical practice of innovative and, at time, hazardous treatment wherein the risk to the health of the patient has sometimes been greater than the intended benefits.

At issue here is a moral question: Does the medical professional have the right to make a treatment choice involving potential harm to his patient? Does he have the right to deny his patient sufficient knowledge of the procedure and it's potential hazards, and in the face of this information, should the patient have the right to consent or refuse to consent to the proposed treatment?

In light of the fact that some psychiatric treatments are potentially intrusive to a recipient's life in ways that he himself may not desire, it then becomes only correct to provide that the recipient understands and consents to the treatment with full knowledge of possible risks, side effects, and benefits.

If the medical professional goes ahead and administers a potentially hazardous treatment without the recipient's express written and informed consent and the treatment results in harm to the recipient, the professional leaves himself open to innumerable moral, ethical, and legal problems. This definition is stated to protect the professional as well as the recipient from unnecessary and unpleasant consequences.

> "The primary reason most mental patients should have the right to refuse treatment is very simple: most mental patients have not been found legally incompetent by a court after a proper judicial hearing; therefore, they should have the same right as anyone else to pick and choose the treatment they will accept."
>
> The Rights of Mental Patients by Bruce Ennis and Richard Emery; A.C.L.U. Avon Books; New York; 1978; p. 132

RECIPIENT OF MENTAL HEALTH SERVICES

10. Recipient of mental health services. "Recipient of mental health services" hereinafter referred to as "recipient" means an individual who is receiving mental health treatment from an agency or facility licensed or funded by the Bureau of Mental Health or the Department of Human Services to provide mental health services.

The term mental patient conjures up all types of pictures in many of us - crazy, psychotic, depressed, screaming, unhappy people caught up in their own madness, without hope of <u>really</u> changing. Today, in mental health, the emphasis is on getting people back into the mainstream of life, living productive lives. To refer to all the people who are receiving mental health services, in this day and age, as mental patients is an erroneous and stigmatizing label. Each person receiving mental health services is an individual, with individual needs and problems; to refer to all of them as "mental patients" only adds to their problems. The title of recipients of mental health services greatly lessens this stigmatization - it creates less of a bad feeling for those who are recipients, for thier families and friends. In using this term, we are not attempting to make light of the reasons that a person seeks mental health services; we are merely putting it into a more modern and proper perspective. If people are to get well and handle their own lives, they can at least be afforded the dignity of a more respectable title while they are in the

process of doing so. This section also clarifies who is a recipient of mental health services and to whom the rights listed in this bill apply. People who are receiving mental health services from mental health centers, state institutions, and the psychiatric units of private and general hospitals are all recipients of mental health services.

RESTRAINT AND SECLUSION

Present statute in Maine law concerning mechanical restraint and seclusion states:

> Section 2253. Mechanical Restraint and Seclusion
>
> Restraint, including any mechanical means of restricting movement, and seclusion, including isolation by means of doors which cannot be opened by the patient, shall not be applied to a patient unless it is determined by the head of the hospital or his designee to be required by the medical needs of the patient. Every use of mechanical restraint or seclusion and the reasons thereof shall be recorded and available for inspection. The limitation of the use of seclusion by this section shall not be applied to maximum security installations.

What we feel is necessary to add to that statement is the following:

> **Sec. 2. 34 MRSA § 2253** is amended by inserting at the end the following new paragraphs:
>
> **Seclusion and restraint are forms of management and treatment of acute behavorial disturbances, ordered by licensed health personnel when a recipient presents a threat to himself or others. The danger must be clear and immediate. As forms of treatment, seclusion and restraint are subject to the same quality assurance standards and monitoring of effectiveness as are other treatment methods. Thus, use of seclusion and restraint shall have the purpose and intended effect of treatment. Inappropriate use of seclusion and restraint as a threat or form of punishment constitute mistreatment within the intent of this section.**
>
> **Safety precautions shall be followed to prevent injuries to the recipient in the seclusion room. Seclusion rooms shall be adequately lighted and heated. Regular meals and toilet privileges shall be offered at appropriate times and intervals. The recipient in the seclusion room shall be observed at least every 15 minutes by qualified personnel.**

The latter statement further emphasises that restraint and seclusion are to be used with great discretion, when that person is posing a threat to himself and others, and the danger of this must be

clear and immediate. In other words, a recipient cannot be put in a seclusion room or in restraints at a whim, for no justifiable reasons.

A number of people who have had the experience of being in a seclusion room or in restraints told us that the most humiliating aspect of this procedure was the fact that they were not allowed normal functions, like going to the bathroom, having a drink of water when they were parched, and bing stripped naked in a bare and cold room. We feel that if these measures must be taken to prevent harm to the recipients or others, then they must be done in a manner that is not dehumanizing. Having qualified personnel checking on the person in restraint and seclusion every fifteen minutes ensures the safety of the recipient.

Section 2481. Legislative Intent

CHAPTER 194

RIGHTS OF RECIPIENTS OF MENTAL HEALTH SERVICES

§ 2481. Legislative intent

It is the intent of the Legislature to articulate the rights of recipients of mental health services so that these rights may be exercised and protected. No recipient of services shall be deprived of any rights, benefits or privileges guaranteed by law, the Constitution of Maine or the Constitution of the United States solely on account of the receipt of mental health services or a diagnosis of mental illness. It is the clear, unequivocal intent of this chapter to guarantee individual dignity, liberty, pursuit of happiness and the protection of the civil and legal rights of recipients of mental health services.

This section expresses a clear-cut statement of the intent to provide a new, heightened awareness of recipients' rights in this state. It is entirely in keeping for Maine, a state that has a reputation for self-determinism to put forth this resolution for

those who receive mental health services.

Other states that have passed legislation concerning the rights of recipients of mental health services in the past six years are:

California
Connecticut
Florida
Illinois
Louisiana
Massachusetts
Oregon
West Virginia

There may be more by this time. The fact that these states have these laws points out the growing concern with this area. With the provisions of this bill, it will be possible for Maine to deal with its mental health recipients in an enlightened and more responsible way.

Section 2482. Rights and Basic Protections of Recipients

§ 2482. Rights and basic protection of recipients

No recipient shall be presumed incompetent nor shall the person be held incompetent except as determined by a court. The determination shall be separate from a judicial proceeding held to determine whether a person is subject to involuntary admission or meets the standard for judicial admission.

This section was written to clarify the status of a person receiving mental health services. In our research, and in talking to a number of people, we found that many assumed that if a person was in a mental health hospital or receiving some kind of counseling, they were incompetent, meaning they were unfit to handle any important decision. This is definitely not the case: simply, every recipient in a psychiatric unit is not incompetent, and can not be assumed so until it is decided by a court with sufficient evidence to warrant it.

In keeping with an individual's dignity, we want to make it

perfectly clear that many recipients of mental health services are indeed competent, and should not be assumed incompetent only because they are receiving mental health services.

Section 2483. Humane Care

Current statute (Title 34, Section 2252) states:

> Right to humane care and treatment
>
> Every patient shall be entitled to humane care and treatment and to the extent that facilities, equipment and personnel are available, to medical care and treatment in accordance with the highest standards accepted in medical practice.

We find this statement to be only minimally adequate in that it does not provide for the recipient's maximum involvment in his treatment. We proposed to expand the statement as follows:

> **§ 2483. Humane care**
>
> **A recipient shall be provided with adequate and humane care and services in the least restrictive and appropriate environment pursuant to an active, individualized treatment plan monitored by qualified personnel.**
>
> **The recipient has the right to maximum feasible involvement in the planning and implementation of the treatment plan, including the right to attend and have input into treatment planning, ongoing staffings and discharge planning. Further, the intent of the recipient's involvement in the treatment planning and implementation is to achieve a treatment process agreeable to the treatment staff and the recipient. The recipient has the right to include disagreements and clarifications into the record and the right to sign or not to sign the treatment plan. Upon discharge, the recipient has the right to receive a copy of the discharge summary and treatment record, if so desired, after reviewing these with qualified personnel.**

Again, in talking to people who have received mental health services, we found that a common complaint was that the recipients did not have that much to do with their own treatment, in terms of making

decisions, or in knowing how their progress was going. If the goal of mental health is to reinvolve a person with self-determination in life, a lack of consideration in treatment that is to accomplish that reinvolvement would be detrimental to the attainment of that goal.

This section provides a number of ways that a recipient may have a maximum possible involvement in the planning and implementation of his treatment.

By allowing for this involvement, the intention is to ensure that the recipient is allowed a greater responsibility in his own stabilization and recovery. It would seem necessary to have a person's agreement on what is being done for him in order for that process to work to its fullest potential.

Our research has further shown that a person's psychiatric record often may contain statements that are inaccurate, misleading and, in some cases, false. The result of this type of misrepresentation can have far reaching consequences for the person's continuing health care. Inaccurate and ambiguous statements which become a part of a permanent medical record often give a picture of the person which is far from correct, and could lead to improper treatment in some cases. Currently, because there is not an overall recognition of the need for the recipient's agreement, disagreements and corrections, many cases exist where a person has been destructively and wrongfully stigmatized. The passage of this bill would go far to prevent this type of abuse from continuing.

Section 2484. Practice of Religion

Currently in Maine statute, there is no clear cut statement of a recipient's right to freedom in the practice of religion. L. D. 1528 provides the following:

> **§ 2484. Practice of religion**
>
> **Recipients have the right to religious freedom and practice. Maximum effort shall be made to facilitate the recipient's freedom to exercise religious practice and to protect other recipients' freedom to their own choice of religious practice.**

As this right is one of the long held and long respected rights of the U. S. Constitution, it is our feeling that inclusion of it in this bill is a necessity.

A situation occurred in this state within the last three years in which a chronically ill recipient was refused help in becoming a member of a major church on the basis that the person didn't know what he was doing, and couldn't really understand religion anyway. This is one example of a person's religious freedom and practice being refused on totally specious grounds.

To assume that medical decisions are senior to religious decisions is to tread thin ice, even when life threatening situations occur. To legislate that medicine or good clinical practice can obviate the need for respect of conscientious and fully considered religious belief is to enter into an area which could be fought with legal and moral difficulties, which even now are being argued in many camps.

This section states simply what had been available and understood for over two hundred years, and is a principle upon which this country is founded, and which, in good conscience, cannot be at all mitigated in regard to the recipient of mental health services.

Section 2485. Communication

Maine statute does contain a section on recipient rights to communication and visitation, as follows:

Section 2254, Right to Communication and Visitation

Every patient shall be entitled:

1. Mail - to communicate by sealed envelopes with the department, clergyman or his attorney and with the court, if any, which ordered his hospitalization, and to communicate by mail in accordance with the regulations of the hospital
2. Visitors - to receive visitors unless definitely contraindicated by his medical condition; except that he may be visited by his clergyman or his attorney at any reasonable time.

We feel that the above is not adequate to allow for enough privacy and access in communication and propose the following in L.D. 1528:

§ 2485. Communication

Recipients shall have full rights to unimpeded, private and uncensored communication by mail, telephone and visitation, unless specifically restricted in the individual treatment plan for stated cause.

1. Mail. Each recipient shall be allowed to receive, send and mail sealed, unopened correspondence. No staff member employed by a hospital shall hold or censor any incoming or outgoing correspondence without the consent of the recipient or his legal guardian. The inpatient or residential facilities shall provide pens, paper, envelopes and postage in reasonable amounts to recipients who are otherwise unable to procure them.

2. Telephone. Recipients may make and receive a reasonable number of telephone calls per day at reasonable hours and in privacy. Staff assistance shall be provided as needed. Telephone funds or access thereto shall be provided by the inpatient or residential facility in reasonable amounts to recipients who are otherwise unable to procure these resources.

3. Visitors. Recipients shall have an unrestricted right to receive or refuse a reasonable number of visitors during reasonable hours. Nothing in this subsection shall be construed to permit infringement upon other recipients' rights. Recipients may receive their personal therapist, attorney, a representative of the Office of Advocacy or their clergy at any reasonable time.

Recipients in a mental health facility are vulnerable in that closed society that they temporarily or more permanently exist in. The provisions in this bill allow a recipient to reach the outside

world more easily, and gives them privacy in their personal letters and phone calls. Several of our correspondents told us of letters mailed but not received by relatives, and the frustration this caused. Another related how he was denied the use of the phone when he was trying to finalize discharge arrangements with his family. And another told of the pain she experienced when letters she had written were ridiculed publicly by staff - letters she had sent but never left the ward.

To accomplish the goal of greater independence, we felt that recipients must be allowed the freedom and privacy to communicate, receive visitors (or choose not to) and to make life arrangements.

Section 2486. Work

§ 2486. Work

Recipients engaged in work programs which require compliance with state and federal wage and hour laws shall be provided with fair compensation for labor in compliance with state and federal statutes and regulations. Wages earned by a recipient shall be considered remuneration to which he is entitled and these wages shall be paid at least every 2 weeks. Activities which are considered normal in open community life and which relate to activities of daily living shall not be considered remunerable in the intent of this section.

This proposal is based on existing federal and state laws and regulations. It is inserted here to present this information clearly to recipients, and to reinforce that if a person works in any type of program as applicable, they are entitled to fair remuneration. More than one of our correspondents stated that at one time many residents of mental health facilities were forced to work long hours, and were not paid for this. Federal law prohibits such practices now. The last sentence of this section delineates the recipient's responsibility

to take care of their own area.

The 13th Amendment of the U. S. Constitution:

> "Neither slavery nor involuntary servitude, except as punishment for crime whereof the party shall have been duly convicted, shall exist within the United States . . ."

Section 2487. Personal Finances

Present statute does not cover this area. We propose the following:

§ 2487. Personal finances

A recipient may use his own finances as he chooses, within reason, unless this right is limited by guardianship or conservatorship. A recipient may deposit or cause to be deposited funds in his own name with the inpatient or residential facility or a financial institution. Funds deposited with the hospital shall not be retained by the hospital. Any earnings attributable to a recipient's funds shall accrue to him.

When a recipient is discharged from an inpatient or residential facility, all his assets, including funds, interest and personal property, shall be returned after notification to the individual or, if unclaimed, these may be disposed of after 180 days or as otherwise specified by statute. Illegal contraband may be impounded and disposed of as otherwise provided by statutes.

The first paragraph was written to prevent any future abuses along financial lines. In the past, there have been many occurrences of people having their money taken away when entering an institution and never seeing it again. This section is present to assure recipients of their right to have money, where it can be deposited, and that they have the right to use it as he chooses, within reason, unless this right is limited by guardianship or conservatorship, where other laws apply. Nothing in this section is intended to promote irresponsible spending of funds; if a person is to be self-sufficient in these matters, he must be allowed this right.

The second paragraph of Section 2487 is also aimed at increas-

ing the recipient's responsibility for his own property. At present, there are no provisions in Maine statutes for the disposal of property left behind at the state institutions. We see no reason why the state must keep all manner of abandoned property for years, which is what happens currently. With this resolution, recipients are made aware that they must claim their possessions or the state has the right to dispose of them.

The last sentence in this section refers to the possession of illegal contraband. In the past year, there have been accounts of the possession of firearms and drugs in the state's institutions. Of course, there was quite an uproar about that, rightly so. Illegal contraband is illegal no matter where it is, and in a mental health facility these items become even more dangerous and potentially destructive. We do not think that this one sentence will prevent all occurrences of this violation. However, it is stated to clearly inform recipients of the illegality of such materials, and it also gives the staff a ready vehicle for removing it from the area.

Section 2488. Personal Property

§ 2488. Personal property

Recipients have the right to control their own personal property. When necessary to protect the recipient or others from imminent injuries, articles may be temporarily taken into custody to be immediately returned when the emergency ends. Recipients may wear their own clothing. If the recipient is unable to provide owned clothing, the mental health institution will provide appropriately sized, seasonably appropriate and contemporary clothing. A reasonable amount of secure personal and central storage shall be available to all inpatient or residential recipients. Recipients shall not be subject to search without good cause.

This section delineates the recipient's control over his own personal property, while giving the staff the right to protect all the recipients from potential harm caused by the use of dangerous objects. It is an abuse of a person's dignity to be deprived of personal belongings that are non-dangerous. One woman told us that her clothes, make-up and comb were taken from her when she entered a mental health facility, and she was not able to get them back. She felt extremely uncomfortable and unattractive as she was forced to go about in a disheveled condition. This may seem a small point. However, it is recognized that a good self-image is a positive aspect of mental health. The segment concerning clothing is also aimed at the concept of a good self-image. Nothing is more undignified and uncomforable than wearing ill-fitting and inappropriate clothing.

The sentence about storage space is placed there to back up something that already exists in the state's psychiatric facilities. We feel it is a good practice and want to ensure it continues.

The last sentence, having to do with searching of recipient's for harmful or possibly stolen items, is stated to guarantee that recipients are not searched unless there is a good, solid reason for doing so. If a good cause does exist, a search should be done for the safety of staff and recipients. However, regular and random unjustified searches have no place in a psychiatric ward, except to create an atmosphere of distrust and fear. Search without good cause could be considered harassment and is a violation of security of personal space as set forth in the U. S. Constitution.

At the recommendation of members of the Governor's Advisory

Council on Mental Health, we have agreed to a further statement on the staff's capacity to restrict from the onset of admission to an acute ward, the possession of dangerous articles; such as razor blades, scissors, ropes, and knives. This makes good sense as even if the recipient holding these is not suicidal or harmful to others, there may be other recipients on the unit who might be feeling such things. Whereupon, the availability of such items could pose a threat to the peace and security of the unit.

Section 2489 General Rights

MRSA Title 34, chapter 191, section 2254 states:

> 3. General Rights. Except to the extent that the head of the hospital determines that it is necessary for the medical welfare of the patient to impose restrictions, and unless a patient has been adjudicated incompetent and has not been restored to legal capacity, and except where specifically restricted by other statute or regulation, but not solely because of the fact of admission to a mental hospital, to exercise all civil rights, including, but not limited to, civil service status, the right to vote, rights relating to the granting, renewal, forfeiture or denial of a license, permit, privilege or benefit pursuant to any law, and the right to enter contractual relationship and to manage his own property.
>
> A. Any limitation imposed by the head of the hospital on the exercise of these rights by the patient and the reasons for such limitation shall be made part of the clinical record of the patient.

We propose this wording in L.D. 1528:

> **§ 2489. General rights**
>
> **All recipients, except those whose rights are legally abridged under provisions of other statutes and regulations, have the right to exercise all civil rights including, but not limited to, civil service status, the right to vote, rights relating to the granting, renewal, forfeiture or denial of a license, permit, privilege or benefit pursuant to any law. Recipients have the right to enter contractual relationships and to manage their own property. No rights shall be abridged solely because of residential status in a mental health facility.**

There are minor differences between the two, however we felt it necessary to clarify the present statute to make it more readable and understandable. The major difference is that in the present statute, the head of the hospital has the right to curtail a recipient's own rights "for the medical welfare of the patient". This gives too much power to one person, and if a recipient is not under guardianship, or criminally committed, then they have the right to exercise these freedoms. We have encountered people who believe that recipients are not able to vote, and this is an erroneous idea. To consider all recipients incompetent, and to treat them as such is clearly an act of discrimination.

Section 2490 Legal Representation

Present statute does not cover this subject. We propose:

§ 2490. Legal representation

Each recipient shall not be denied the right to have access to an attorney, to seek legal advice, to take legal action and each recipient has the right to have priavte interviews with an attorney on any matter. Except as provided otherwise by statute, all recipients shall be responsible for the cost of retaining legal counsel.

This wording does not mandate the Department of Mental Health or Human Services to provide any type of legal representation. It does, however, provide recipients with the right to have access to an attorney. Whenever court proceedings are necessary, and in many other situations, recipients will need

the assistance of lawyers. For example, one does not legally need a lawyer to exercise a writ or Habeas Corpus; but, as law is a complex and specialized field, the whole process would be shortened with a lawyer's aid.

A case in point would be that of Kenneth Donaldson who describes in his book, Insanity Inside Out, his 15 year struggle to procure his own release from an asylum. He mentions several times how he had to sneak letters out to lawyers asking for aid, and how he was not allowed to see them when they came. He did eventually win his case, which resulted in a landmark Supreme Court decision, but it took him fifteen years to do it.

We feel that if a recipient desires to consult an attorney, the hospital or institute must give him the right to do so. This right is further stated to be a right granted to all citizens by the U.S. Constitution and the Universal Declaration of Human Rights of the United Nations Assembly.

Section 2491 Therapy

§ 2491. Therapy

Each recipient has the right to be consulted as regards the choice of the recipient's major therapist. Confidences between the recipient and therapist shall be held in trust to facilitate the therapeutic process without fear or reprisals, except in instances where the recipient is in danger of causing harm to himself or others.

We have been made aware through our correspondents that there often exists the uncomfortable situation of a recipient

being assigned to a group leader or other major therapist with whom they have no rapport. This can lead to a lengthier stay and stalled progress in the recipient's case. With this proposition, we hope to give the recipient a choice of the available therapists, if he so desires to choose, so that the stay will be shorter and less costly to the state and the recipient.

The second sentence deals with the subject of trust between the recipient and therapist. Trust is defined as the condition and resulting obligation of having confidence placed in one. We have learned that at times a recipient will confide feelings of anger or upset to a therapist with the intent of sharing and getting help in handling difficult emotions. The recipient often has no intention of manifesting the anger or upset in harmful actions, but needs to communicate the fact that he's feeling a certain way. What has happened is that as a result of sharing these feelings, the recipient may be confined to the unit, or stripped of some personal responsibility, or deprived of positive activities. This is not done as behavior or thought modification, yet, for the recipient, it amounts to reprisal or punishment for having taken the responsibility to share difficult feelings. To be asked in therapy to express oneself, to make the decision to do that (which often takes some courage), and then to be restricted because of it, would certainly make one think twice about making that attempt at sharing feelings in the future. As a practice, this seems contrary to the goals of mental rehabilitation, since it tends to make a recipient guarded and restrained in his communications.

There are situations in which a therapist may be mandated to report the feelings of a client, particularly where these feelings might lead a therapist to be assured that an immediate threat exists to the recipient or another. We do not intend to interfere with such mandates; however, in too many cases, simple communication with the intention of handling difficult emotions results in subtle reprisal which is harmful to the recipient's growth and communication ability. This section of the bill is written with the intent to make more therapists aware that a wrong judgment call can have a devastating effect which essentially can create a groundless constraint upon a person's liberty within an institutional setting.

Section 2492 Review

§ 2492. Review

Reviews and records of recipients' mental health services shall be carried out and documented in accordance with appropriate state and national standards. The staff shall enter into the recipient's review record the response to treatment, current mental status and specific reasons why continued treatment is necessary in the current setting or whether a treatment program is available which is appropriate to physical, mental, social and personal sense of well-being and is less restrictive of the recipient's liberty.

This resolution came into being as a result of several stories we heard. These accounts had to do with people being sent to institutions and remaining there; twenty years later the person had become extremely institutionalized and no one

on the staff really knew who the person was or why they were still there! These are the forgotten people. Fortunately, these incidents appear to have ceased years ago, but we do feel it is necessary to include a provision that states the mental health professionals' responsibility to give the recipient the best care and alternatives available. In this way, progress can be monitored, and advancements made.

Section 2493 Environment

§ 2493. Environment

Each recipient in inpatient or residential settings or facilities shall have the right to healthful, humane and safe physical environment. The environment shall be clean, well-ventilated, well-lit, suitably staffed and shall be comfortably arranged to allow adequate space for each recipient.

The recipient's need for privacy must be respected within constraints of physical environment and treatment needs.

Since the deinstitutionalization process began several years ago, the physical plant conditions of our mental health facilities have certainly improved. There is less crowding and efforts have been made to improve the comfort and livability of the quarters.

This section is written to recognize the minimum standards of what is considered healthful and safe in our living environment. As particularly applicable to the situation in a mental health facility, we have written in that the environment, to be therapeutic, should be suitably staffed to the situation.

Research has shown that the ability to control one's own personal space is an extremely important part of one's healthful and rational functioning in the world. We all know too well the disturbing feeling of the contemporary situations of traffic jams, packed subways and buses. It is one thing to experience these discomforts enroute to somewhere, as we might while travelling. It would be quite another to have to live in such conditions daily and without the power to alter them.

Privacy in a unit that houses a number of people is a very precious commodity. We feel that all recipients should at least have the right to wash, dress, and use the toilet in privacy. Of course, if the recipient is in a crisis where they may harm themselves or others during these times, measures must be taken to accompany him or her to prevent this.

This section was drafted to provide assurance that those qualities of environment which we find most conducive to peace of mind continues to be provided for those of us who either from time to time or more permanently, find ourselves in the mental health facilities of our state.

Section 2494 Physical exercise

§ 2494. Physical exercise

Each recipient shall have the right to appropriate and sufficient physical exercise including the use of available indoor and outdoor facilities and equipment.

It is interesting to note that the recent interest in jogging has produced some data to the effect that physical exercise has a very beneficial effect on a person's sense of mental well-being as well as physical.

Apart from this more strenuous form of exercise, it's no secret that even walking and minimal physical exertion produces a more healthy physical existence.

The phrase "appropriate and sufficient physical exercise" takes several situations into account in stating this most basic human right. The intention is that a recipient be provided the right to take exercise that is appropriate to his physical condition and desire for it, and that is sufficient within bounds of staff and facilities available if he needs to be accompanied to afford him some of the benefits that such activities provide.

The section does not carry any mandate to build new facilities; it simply states that to the extent that any facility is available, even the taken-for-granted facility of a sidewalk, yard or corridor the recipient should have the right to use it pursuant to staff available.

Section 2495 Nutrition

§ 2495. Nutrition

Each recipient in an inpatient or residential facility shall have the right to varied and nutritious food in adequate quantities consistent with health needs. Basic meals shall not be withheld for disciplinary reasons. Dietary requirements and restrictions shall be included in the individual's clinical record and shall be considered in designing treatment plans.

This clause was drawn up with the intent to provide the most nutritious and varied diet available to recipients. We have been told of inedible and unnourishing foods served at various institutions, and also that at times there was not enough to eat. Due in part to the greater awareness of the role that diet plays in the overall health of an individual, improvements have been made in institutional food. We would like to see these improvements continue with an added emphasis upon the growing awareness of metabolic and nutritional treatment in mental disorder. A great deal of meaningful and successful treatment and research has been accomplished in recent years on the incidence in schizophrenics and those with other mental illnesses of a lack of basic vitamins and amino acids due to the specific metabolism of the individual. Further, food additives have been shown to produce psychological disorders which have disappeared when the additives are removed from the diet. The value of this research cannot be overestimated and should be carefully, yet enthusiastically, investigated and adopted by the mental health field in Maine.

We realize that it is difficult to please everyone's taste when serving mass meals, and we are not saying that every whim of every recipient should be appeased; however, when a recipient has specicific dietary needs (i.e., Kosher, no-salt, vegetarian, etc.) these should be respected as much as possible.

Sec. 2496 Associations

§ 2496. Associations

Taking into consideration each recipient's treatment plan and the peace and security of the ward, each recipient shall have the right to associate freely or not with any person or group. Each recipient has the right to be with others of his own age group, if so desired. Each recipient shall have the right to have suitable opportunities for leisure time activities which include social interaction.

Recognizing that social interaction with others whom one considers his peers is an important aspect of living a full life, we have written this section with the intent to recognize and provide this right. Taken into consideration within the wording is the fact that at times, decidedly antisocial interactions can occur between people and that at such times and conditions, it may be appropriate to limit the complete freedom of association between recipients, but only to the extent that such mitigating circumstances occur.

Also addressed here is the right to be with others of one's own age group, if so desired. It would be well perhaps, to further state "if so desired and feasible" as in small psychiatric units, the age distribution of recipients can vary widely. The point which we are trying to make here is that it has occurred that teenage recipients have been placed on a unit composed mainly of elderly recipients, thus creating a difficult situation for the younger person in that he might have no peer to whom he can easily relate and communicate. The obverse occurrence is equally as possible of the elderly person being placed on

a unit of far younger people. The same difficulty and even potential impossibility of finding another person to talk and share similar viewpoints with occurs in both situations.

Further, we would like to see that opportunities for leisure activity involving social interaction such as dances, for instance or other purely social gatherings are afforded to recipients.

We all need such activities in our lives and to a greater or lesser extent each of us seeks out leisure and social activities in which to relate to others a bit differently than we would at work, in therapy or in the daily habits of living. Again, the broad intention of this bill is to afford the recipient of mental health services a ready means of rehabilitation which parallels life outside of an institution, thereby to better increase his chances for making a positive transition between the two situations.

Section 2497 Consent to treatment

§ 2497. Consent to treatment

Except as otherwise provided, no recipient shall be subjected to electroconvulsive therapy or other convulsive therapies without his express, written and informed consent, unless the recipient has been found to be legally incompetent, in which case, the recipient's guardian must give express, written and informed consent for any of the treatments to be done. In all cases specified in this section, in addition to the opinion of the treating physicians a 2nd qualified opinion in the applicable field must be obtained regarding the proposed procedure. The recipient or his quardian shall be personally informed of the 2 opinions.

This subject has been initially looked at in the first section of this report. It would be well to further elaborate on

this point with regard to the forms of treatment set forth here as being subject to informed consent procedure.

Concerning Electroconvulsive and other convulsive therapies, it might be helpful to explain briefly what these therapies are and how they are assumed to operate. ECT has unfortunately embarrassing beginnings in Italy in the 1930's. Dr. Ugo Cerletti, a Roman psychiatrist, noticed that hogs in the slaughterhouse were stunned and thrown into convulsions by electric shock to the brain before slaughter in order to effect a more humane and painless death. This procedure was being done under pressure from the SPCA. The convulsions were similar in nature to an epileptic coma, and Cerletti decided to experiment further upon dogs to find the amount of electricity necessary to produce death in a dog. To his interest, he found that dogs would rarely die from a 125-volt shock to the brain. It was only when the shock was applied to the body and thus through the heart that death was likely. What he did observe was the dogs going into violent convulsions then lying on their sides for as much as several minutes and finally attempting to rise, many times and finally succeeding. In his own words, "these observations gave me convincing evidence of the harmlessness of a few tenths of a second of application through the head of 125-volt electric current." And at this point, he decided that he was ready to experiment on man.

His first patient was a man who had been picked up by the Roman police for "wandering about" and speaking in "gibberish". Cerletti and his assistants first applied an 80-volt current to the subject's temples for 0.2 seconds. The man's body stiffened but he did not lose consciousness. Cerletti and his assistants debated aloud whether to continue and the subject who had been following the conversation suddenly spoke up quite clearly with no gibberish, "Not another one! It's deadly!" Even though his determination was shaken by this admonition from a man so recently appearing completely out of control of his senses, Cerletti said, "...it was just this fear of yielding to a superstitious notion that caused me to make up my mind. The electrodes were applied again, and a 110-voltage discharge was applied for 0.2 seconds."

Through the years, the basic procedure for administering ECT has remained the same except for the introduction of anesthetics and muscle relaxants in the 1950's to prevent damage to teeth, tongue, and skeletal system, especially the spine, which was frequent before the introduction of the drugs. Today, the administration of ECT is safer to the recipient's body than it was in its early days, but still remains very controversial.

While the methods of administration have significantly been modified, many of the side effects on mental processes continue to remain the same. An article by Dr. Max Fink sums up adequately the various possible risks involved: a fairly low incidence of

death (from 1942-1977 there have been 384 deaths reported and written about in psychiatric literature), brain damage (as determined in part from autopsies of patients who died after treatment and in part from animal experimentation), memory impairment (which varies from reports of temporary loss of memory of events immediately preceding treatment to cases of permanent memory loss of events from many years before treatment), and some evidence of spontaneous appearance of epileptic-like seizures where no epilepsy had existed before treatment.

As to the mechanism of the action of ECT, Lothar Kalinowsky, one of the foremost authorities of ECT in America has this to say, "Many ... theories have been ventilated in the past, but no convincing theory is available. Neither psychological nor organic theories have any basis in clinical or laboratory findings. Therefore we must admit that we are successfully treating conditions of unknown cause with treatments of an equally unknown mode of action."

Other of the convulsive therapies are: insulin coma therapy in which the recipient is administered larger and larger doses of insulin until the desired depth of coma is produced. The large amount of insulin reduces the sugar content of the blood which causes a physiological crisis manifested in the subject by blood pressure, breathing, heart pulse and temperature irregularities, a convulsion (not always); and other severe physical manifestations. In about three hours the subject goes into a deep coma

where brain cell destruction occurs when the blood can no longer provide the sugar essential to the brain's survival. The coma is ended by the administration of carbohydrates, i.e. glucose or sugar.

The adverse effects of insulin coma therapy are similar to those caused by ECT but more severe. Amnesia may be far more extensive, and the more serious and sometimes fatal complication of the treatment is prolonged coma, which occurs when the administration of carbohydrates fails to revive the subject. Further, there is some evidence to suggest that another possible long-term effect might be diabetes.

These and other forms of convulsive therapies were found on the hypothesis made by Cerletti and others that since it was thought that epileptics rarely suffered from schizophrenia, it would then make sense to induce seizures into schizophrenics in order to make them temporarily epileptic and thus not schizophrenic.

It would be illustrative to refer to the case of one Maine resident who has had both these types of therapy. Here in part is her story:

After giving birth to and after having lost her first child, who died suddenly from no known cause, she became depressed and saw a psychiatrist within the next two months. He recommended shock treatments and a brief rest. "The psychiatrist told me that shock treatments were harmless, painless, and helpful and

at that time I believed him." She received 17 insulin shock treatments and 17 or 18 ECT treatments. The ECT was unmodified by muscle relaxants and anesthetics.

She constantly complained of incredible back pain during these treatments which were never treated effectively at the time. "The insulin shock was the most horrible experience of my life, worse than electroshock. I wondered at the time how I could survive it and consequently asked the doctor for the supposedly painless and harmless and helpful ECT treatment."

As a result of these two types of treatment this person feels and has proof that she has suffered fracture of the spine, which still causes severe and constant pain, severe hypoglycemia and disabling diabetes, memory erasure and loss which is permanent for some areas of her life including college education, skill at the piano, many childhood memories. "The stigmatization of this experience has severely effected my functioning in the world both professionally and socially." If informed consent had been in use at this time, this woman told us she would have refused the treatment.

While the likelihood of spinal fracture is less today, the likelihood of memory loss and the stigmatization attached to ECT is not. We have also spoken to other people whose more recent experience of ECT produced major memory loss and dizziness and vocational disabilities, even though the experience included the muscle relaxants and anesthetics. These people also expressed

their belief that if they had been honestly told of the possible side effects, they would have refused.

Although it is said that ECT in this day and age is no longer a very risky procedure and that it is recommended and administered only in extremely rare and specific circumstances, we have found much to indicate its continuing unpredictability and potential liability. Further, it is apparent that controversy continues to exist both within and without the profession of psychiatry as to its use and efficacy.

In all cases, we feel that the potential recipient of ECT must be informed of the risks, benefits foreseen, any alternatives that have not been tried, why the professional is recommending the treatment, what might occur if the treatment is not used, and the division of opinion which exists concerning the treatment. Another condition of informed consent being truly exercised is that the recipient consent voluntarily. For this reason, the section is written with the provision that the recipient can withdraw his consent at any time, prior to or during treatment. We propose that all the necessary information be given as follows in L.D. 1528:

2. Form provided. Except as otherwise provided, any agency performing the procedures specified in this section shall provide a form setting forth clearly and in detail, the following:

A. The reason for treatment, that is, the nature and seriousness of the recipient's illness, disorder or defect;

B. The nature of the procedure to be used in the proposed treatment, including its probable frequency and duration;

C. The probable degree and duration, temporary or permanent, of the improvement or remission expected with and without the treatment;

D. The nature, degree, duration and probability of the side effects and significant risks, commonly known by the medical profession, of the treatment, especially noting the degree and duration of memory loss and its likelihood of irreversibility and the extent to which these side effects may be controlled;

E. That there exists a division of opinion as to the efficacy of the proposed treatment, why and how it works and its commonly known side effects and risks;

F. The reasonable alternative treatments and why the health professional is recommending this particular treatment; and

G. That the recipient has the right to accept or refuse the proposed treatment and if he consents, has the right to revoke his consent at any time prior to or between treatments.

The treating mental health professional shall then present this form to the recipient and orally, clearly and in detail explain all of the information in this section to the recipient. The recipient or his guardian, as applicable, shall sign the form if he is in agreement with receiving the treatment and subsequently it shall be dated and witnessed. A copy of this form shall be placed in the recipient's record.

The treating mental health professional may urge the proposed treatment as the best one but may not use, in an effort to gain consent, any reward or threat, express or implied, nor any other form of inducement or coercion.

A recipient shall not be deemed incapable of informed consent solely by virtue of being diagnosed as a mentally ill or disordered, abnormal or mentally disabled person.

These same conditions also apply to psychosurgery, since psychosurgery is so much more an intrusive form of treatment than ECT. Psychosurgery is the surgical removal or severing of brain tissue with the intent of altering behavior or thought patterns. Some of the commonly known specific procedures of psychosurgery are lobotomy, transorbital leucotomy, and amygdolotomy. The adverse effects are usually more severe than those that result from convulsive treatments. It is a permanent irreversible change in the person's physiology, and as such is extremely intrusive upon a person's liberty. Current estimations of psychosurgical operations performed annually in the United States range from three hundred to one thousand. Psychosurgery is not being done at this time in Maine, yet we feel it is

important to address the subject in this legislation as the popularity of different therapies rises and falls, often according to the availability of funding and research which is granted to them. Psychosurgery is routinely performed in Boston and is highly touted by those doctors who perform the operations. In the event that psychosurgery is reconsidered for use in Maine, this proposal will already be in existence to protect possible subjects. Therefore, L.D. 1528 addresses the subject of psychosurgery in the following manner (the section on informed consent also applies).

> **1. Psychosurgery. Psychosurgery is defined as those operations currently referred to as lobotomy, psychiatric surgery and behavorial surgery, the purpose of which is the modification or control of thoughts, feelings, actions or behavior rather than the treatment of a known and diagnosed physical disease of the brain. Psychosurgery may be performed only if:**
>
> **A. The recipient, a responsible relative of the recipient's choosing and consent and the recipient's guardian, if there is one, gives express, written and informed consent as provided in this section;**
>
> **B. The attending physician adequately documents the reasons for the procedure in the recipient's treatment record, establishes that all other appropriate treatment modalities have been exhausted and that this mode of treatment is definitely indicated and is the least drastic treatment alternative presently available to the recipient; and**
>
> **C. Three physicians, board-certified or eligible in psychiatry or neurosurgery, have personally examined the recipient and unanimously agree with the attending physician's determinations stated in paragraph B and agree that the recipient has the capacity to give informed consent. Record of this agreement shall be documented in the recipient's treatment record and signed by each physician.**
>
> **Under no circumstances shall psychosurgery be performed on a minor.**

On the subject of ECT in Maine, we found that of the hospitals that do the procedure, the type of informed consent used varies a great deal. Some use a very complete procedure, while others do not appear to give enough information to the

recipients. We feel that it is in the best interest of the recipient, their doctors, and for the mental health facility itself to use a complete and in-depth procedure of informed consent as described in this bill. Due to the serious nature of the possible side effects of this procedure, each person must be given the information and the opportunity to consent or refuse.

> **Notwithstanding the absence of express, written and informed consent, emergency medical care may be given to any recipient who has been injured or who is suffering from an acute physical illness or physical condition if, within a high degree of medical certainty, delay in providing the emergency medical care would be life-threatening to the recipient or result in irreversible impairment of normal function.**
>
> **Recipients of any procedures covered by this section have the right to examination to determine their condition and implications of the proposed procedures.**

This next to last paragraph of this section expresses that in cases where emergency medical care ~~and~~ is necessary in situations which are life-threatening due to physical injury or physical disease and delay necessary to obtain informed consent would increase the risk, informed consent may be waived, for that time only. This is written to ensure that recipients who are injured, or become very physically ill, are given the treatments they need to save their lives or the use of their limbs or senses, when they are unable to give their consent.

Section 2498 Medical Treatment

§ 2498. Medical treatment

Each recipient of inpatient or residential services has the right to have a thorough and competent physical examination by a licensed health professional to ensure that his mental condition is definitely not caused by any physical illness, injury or defect and each recipient has the right to seek a 2nd opinion from another licensed health professional of his own choice, if so desired by the recipient. Payment for the 2nd opinion is the responsibility of the recipient.

Each recipient of inpatient or residential services has the right to medical treatment for ordinary physical illnesses. All recipients have a right to access to treatment.

A complete physical examination by a licensed health professional should, and most often is, done when a recipient enters a mental health facility. Often, these examinations will turn up previously undiscovered physical conditions such as tumors, metabolic imbalances, hypoglycemia, etc. At times, these and other conditions can cause symptoms that are similar to those of psychiatric disorders. If these go undetected, then the psychiatric treatment will not be totally effective, as there may be a physical cause to the behavior. Simply, it makes sense to treat the correct condition. We have found that many hospitals in Maine routinely conduct complete physical exams to find just such complications when recipients are admitted to the mental health units. We applaud this practice and state it in this proposed statute to ensure that it continues.

Section 2499 Information

§ 2499. Information

Every recipient shall be informed in writing at the time of admission of the procedures for requesting release from the facility, the availability of counsel, the Office of Advocacy, the rights enumerated in this chapter and rules and regulations applicable to or concerning his conduct while a recipient of services in the facility. If the person is illiterate or does not understand English, or is blind, deaf or otherwise unable to communicate, appropriate measures shall be made to supply this information. A summarized copy in laymen's terms of the rights of recipients of mental health services as enumerated in this chapter shall be prominently displayed in every area where recipients are housed or treated and a copy of these summarized rights shall be given to each recipient.

This section ensures that recipients are made aware of their rights and responsibilities. It provides a vehicle for the communication of these rights and the facility regulations and recipient responsibilities. It also includes provision for communication of this information to non-English speaking recipients and to those whose handicaps would make it difficult or impossible to understand a written explanation. Included here as well is the stipulation that these rights be summarized for publication in laymen's terms so that it might be more readily understandable.

In order to participate as fully as possible in one's own process of treatment in a mental health facility, it is a necessity for each recipient to be well aware of and to feel free to exercise his rights and to understand and agree to his responsibilities.

Conclusion

This report contains a large volume of information on recipients' rights and their experiences with mental health services and facilities. Much more information was not included, as some measure of brevity had to be taken. It is our feeling that the information contained in the report makes plain the need for this legislation to become a part of our statutes. There have been attempts at creating a bill of rights for recipients of mental health services for at least the past two legislative sessions, but for various reasons, these past attempts have not resulted in a statute on the subject. We have been well aware of the reasons that such legislation has not been successful in the past and have incorporated this understanding in the present bill. The bill has been reviewed by many mental health professionals, including some of the outstanding psychiatrists and psychologists in the state as well as the superintendents of the two state institutions, Department of Mental Health personnel and mental health workers, nurses, and perhaps most importantly, former recipients themselves. The Governor's Mental Health Advisory Council voted 9 - 3 at a recent meeting to support the bill with their recommendations which we have expressed in the foregoing report. To those who have reviewed the bill in its various drafts and proposed valuable suggestions and criticisms and to those same people and many others who have stated and shown their support for this legislation, we would like to express our gratitude.

To the Committee we would like to express our deep conviction that this legislation is both strongly needed and strongly desired at a majority of levels of the mental health field in Maine. We hope that this Committee's recommendation will strongly favor this bill's passage.

Thank you.

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