MENTAL HEALTH AND THE ELDERLY

JOINT HEARING

BEFORE THE

SUBCOMMITTEE ON LONG-TERM CARE

AND THE

SUBCOMMITTEE ON HEALTH OF THE ELDERLY

OF THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

NINETY-FOURTH CONGRESS

FIRST SESSION

WASHINGTON, D.C.

SEPTEMBER 29, 1975

Printed for the use of the Special Committee on Aging

U.S. GOVERNMENT PRINTING OFFICE
63-476 WASHINGTON : 1976

For sale by the Superintendent of Documents, U.S. Government Printing Office
Washington, D.C. 20402 - Price $2.10

SPECIAL COMMITTEE ON AGING

FRANK CHURCH, Idaho, *Chairman*

HARRISON A. WILLIAMS, Jr., New Jersey
JENNINGS RANDOLPH, West Virginia
EDMUND S. MUSKIE, Maine
FRANK E. MOSS, Utah
EDWARD M. KENNEDY, Massachusetts
WALTER F. MONDALE, Minnesota
VANCE HARTKE, Indiana
CLAIBORNE PELL, Rhode Island
THOMAS F. EAGLETON, Missouri
JOHN V. TUNNEY, California
LAWTON CHILES, Florida
DICK CLARK, Iowa
JOHN A. DURKIN, New Hampshire

HIRAM L. FONG, Hawaii
CLIFFORD P. HANSEN, Wyoming
EDWARD W. BROOKE, Massachusetts
CHARLES H. PERCY, Illinois
ROBERT T. STAFFORD, Vermont
J. GLENN BEALL, Jr., Maryland
PETE V. DOMENICI, New Mexico
BILL BROCK, Tennessee
DEWEY F. BARTLETT, Oklahoma

William E. Oriol, *Staff Director*
David A. Affeldt, *Chief Counsel*
Val J. Halamandaris, *Associate Counsel*
John Guy Miller, *Minority Staff Director*
Patricia G. Oriol, *Chief Clerk*

Subcommittee on Long-Term Care

FRANK E. MOSS, Utah, *Chairman*

HARRISON A. WILLIAMS, Jr., New Jersey
FRANK CHURCH, Idaho
EDMUND S. MUSKIE, Maine
EDWARD M. KENNEDY, Massachusetts
CLAIBORNE PELL, Rhode Island
THOMAS F. EAGLETON, Missouri
JOHN V. TUNNEY, California
WALTER F. MONDALE, Minnesota
LAWTON CHILES, Florida
DICK CLARK, Iowa

CHARLES H. PERCY, Illinois
HIRAM L. FONG, Hawaii
EDWARD W. BROOKE, Massachusetts
J. GLENN BEALL, Jr., Maryland
PETE V. DOMENICI, New Mexico
BILL BROCK, Tennessee
DEWEY F. BARTLETT, Oklahoma

Subcommittee on Health of the Elderly

EDMUND S. MUSKIE, Maine, *Chairman*

FRANK E. MOSS, Utah
HARRISON A. WILLIAMS, Jr., New Jersey
EDWARD M. KENNEDY, Massachusetts
WALTER F. MONDALE, Minnesota
VANCE HARTKE, Indiana
CLAIBORNE PELL, Rhode Island
THOMAS F. EAGLETON, Missouri
JOHN V. TUNNEY, California
LAWTON CHILES, Florida
DICK CLARK, Iowa
JOHN A. DURKIN, New Hampshire

PETE V. DOMENICI, New Mexico
CLIFFORD P. HANSEN, Wyoming
EDWARD W. BROOKE, Massachusetts
CHARLES H. PERCY, Illinois
ROBERT T. STAFFORD, Vermont
J. GLENN BEALL, Jr., Maryland
DEWEY F. BARTLETT, Oklahoma

CONTENTS

CHRONOLOGICAL LIST OF WITNESSES

APPENDIXES

MENTAL HEALTH AND THE ELDERLY

MONDAY, SEPTEMBER 29, 1975

U.S. SENATE,
SUBCOMMITTEE ON LONG-TERM CARE AND THE
SUBCOMMITTEE ON HEALTH OF THE ELDERLY
OF THE SPECIAL COMMITTEE ON AGING,
Washington, D.C.

The subcommittees met, pursuant to notice, at 9:30 a.m. in room 6202, Dirksen Office Building, Senator Frank E. Moss presiding.

Present: Senators Moss, Muskie, and Domenici.

Also present: William E. Oriol, staff director; Val J. Halamandaris, associate counsel; William A. Recktenwald, investigator; John Guy Miller, minority staff director; Margaret S. Fayé, minority professional staff member; Patricia G. Oriol, chief clerk; Eugene R. Cummings, printing assistant; and Dona Daniel and Trina Hopper, clerks.

OPENING STATEMENT BY SENATOR FRANK E. MOSS, PRESIDING

Senator Moss. The subcommittee will now come to order.

It is a pleasure to welcome you here this morning to this joint hearing between my Subcommittee on Long-Term Care and the Subcommittee on Health of the Elderly, chaired by Senator Muskie. We are here to survey the mental health needs of the elderly and to assess the impact of the Supreme Court's landmark decision in *Donaldson* v. *O'Connor*.

For years, thousands of individuals have languished in U.S. mental institutions, the victims of involuntary commitment proceedings. Our citizens, especially the elderly, could be placed in such institutions with comparative ease. Generally, all that was involved was the affidavit of a family member and that of a physician. Once housed in an institution, the constitutional rights under the 5th, 8th, 13th, and 14th amendments evaporated. Generally, no treatment was forthcoming, and release was out of the question.

Thankfully, the Supreme Court has helped clarify this problem. In the *Donaldson* case, the Court emphasized that individuals who are involuntarily committed must be given treatment or released. While the gains inherent in this decision are obvious, some experts are afraid of a backlash. The fear is that the present trend to dump mental patients out of State hospitals into boardinghomes will intensify.

SHARP DROP IN NUMBER OF INPATIENTS

I would like to take this occasion to release the results of a study by the staff of my subcommittee. It reports that the number of inpatients in State mental hospitals dropped 44 percent between 1969 and 1974—from 427,799 to 237,692. At the same time, the number of elderly was reduced by an even sharper margin. Whereas there were 135,322 elderly inpatients in 1969, there were 59,685 at the end of 1974, for a drop of 56 percent. States like Wisconsin, Illinois, and California led the parade.

Complete details can be found in the following State-by-State table.

NUMBER OF INPATIENTS IN STATE MENTAL HOSPITALS, 1969, 1973, AND 1974, AND NUMBER OVER AGE 65 BY STATE

State	Total inpatients			Percentage of decrease (or increase)		Total inpatients over age 65		
	1969	1973	1974	1969–74	1973–74	1969	1973	1974
Alabama	7, 601	3, 810	3, 067	—60	—20. 0	2, 646	1, 197	639
Alaska	674	831	148	—78	—83. 0	27	11	0
Arizona	1, 141	659	655	—43	—1. 0	384	179	116
Arkansas	1, 460	1, 247	474	—68	—62. 0	311	416	491
California	16, 116	7, 011	6, 476	—60	—8. 0	4, 129	997	573
Colorado	10, 317	11, 952	5, 652	—45	—53. 0	1, 250	1, 379	614
Connecticut	6, 068	3, 892	3, 597	—41	—8. 0	1, 611	601	568
Delaware	1, 140	944	966	—15	+2. 3	408	380	410
District of Columbia	5, 111	2, 994	2, 708	—47	—10. 0	2, 058	1, 161	1, 077
Florida	9, 562	8, 170	6, 385	—33	—22. 0	3, 952	3, 241	1, 966
Georgia	7, 653	6, 480	7, 446	—3	+15. 0	2, 207	1, 678	1, 040
Hawaii	581	250	297	—49	+18. 0	182	52	92
Idaho	527	232	207	—61	—11. 0	300	100	46
Illinois	28, 233	15, 703	14, 179	—50	—10. 0	7, 263	2, 065	1, 744
Indiana	16, 703	12, 866	7, 735	—54	—40. 0	4, 209	2, 783	1, 248
Iowa	2, 230	2, 954	991	—56	—66. 0	1, 742	431	132
Kansas	5, 592	5, 961	1, 298	—77	—78. 0	1, 175	982	114
Kentucky	3, 479	1, 199	1, 956	—44	+63. 0	873	412	390
Louisiana	4, 676	3, 327	2, 851	—39	—14. 0	553	349	255
Maine	2, 726	1, 249	1, 480	—46	+18. 0	1, 072	463	442
Maryland	7, 161	5, 950	4, 968	—31	—17. 0	2, 387	1, 983	1, 469
Massachusetts	21, 000	7, 500	11, 688	—44	+55. 0	8, 000	2, 300	1, 050
Michigan	12, 293	6, 865	5, 922	—52	—14. 0	2, 890	1, 358	1, 119
Minnesota	3, 792	2, 710	5, 584	+47	+106. 0	785	574	478
Mississippi	5, 955	5, 627	4, 107	—31	—27. 0	2, 567	2, 272	865
Missouri	7, 496	5, 210	4, 054	—46	—22. 0	2, 587	1, 439	807
Montana	1, 376	1, 104	1, 057	—23	—4. 0	500	453	139
Nebraska	1, 685	765	2, 815	+67	+267. 0	382	70	208
Nevada	439	367	264	—40	—28. 0	78	77	19
New Hampshire	2, 074	1, 446	1, 306	—37	—10. 0	966	672	472
New Jersey	22, 857	21, 616	10, 695	—53	—51. 0	6, 563	4, 981	3, 680
New Mexico	700	400	337	—52	—16. 0	168	61	86
New York	70, 765	44, 042	39, 770	—44	—10. 0	28, 400	19, 642	17, 681
North Carolina	22, 507	20, 010	4, 829	—79	—76. 0	3, 824	4, 188	1, 347
North Dakota	1, 208	644	642	—47	—. 5	360	200	146
Ohio	16, 934	16, 726	9, 793	—42	—42. 0	4, 752	3, 155	2, 850
Oklahoma	3, 854	2, 702	2, 281	—41	—16. 0	713	552	507
Oregon	3, 360	3, 340	3, 491	+4	+4. 5	710	730	219
Pennsylvania	27, 536	18, 235	16, 307	—41	—11. 0	8, 360	5, 811	5, 597
Puerto Rico	(1)	1, 154	995	(1)	—14. 0	(1)	129	166
Rhode Island	1, 881	1, 845	3, 456	+84	+87. 0	610	687	660
South Carolina	5, 805	5, 484	4, 330	—25	—20. 0	1, 872	2, 161	1, 224
South Dakota	1, 229	860	690	—44	—20. 0	711	425	194
Tennessee	6, 713	4, 584	4, 562	—32	—. 5	1, 807	1, 353	1, 357
Texas	14, 253	9, 048	8, 588	—40	—5. 0	5, 464	2, 876	1, 447
Utah	1, 284	823	897	—30	+9. 0	209	80	96
Vermont	1, 079	582	475	—56	—18. 0	455	182	110
Virginia	11, 338	7, 740	6, 072	—46	—22. 0	4, 100	2, 700	2, 614
Washington	4, 252	3, 738	4, 286	+1	+14. 5	722	430	349
West Virginia	3, 950	3, 507	2, 869	—27	—18. 0	1, 194	1, 206	782
Wisconsin	10, 908	7, 574	1, 691	—84	—78. 0	4, 616	3, 222	96
Wyoming	453	304	303	—33		160	95	60
Total	427, 799	304, 233	237, 691			135, 322	84, 959	59, 685

---

[1] 1969 figures for Puerto Rico not available.

Source: Committee questionnaire.

Part of the reason for this massive dumping effort has been humanitarian reasons. Mental institutions are historically poor therapeutic environments. A second reason is the effect of recent Court decisions such as *Donaldson* and its predecessors in lower courts. A third reason is cost and the advent of the supplementary security income program. In Washington, D.C., it costs an average of $24,000 a year to care for a patient in a mental hospital, while the same individual can be placed in a boardinghome for $157 a month in SSI funds. Obviously, the pressures are intense.

But the real tragedy is that there is little, if any, screening to determine who are proper candidates for discharge.

Year	Total in patients	Percentage of reduction		Total over age 65	Percentage of reduction		Percentage of inpatients over age 65
		1969 base	1973–74		1969 base	1973–74	
1969	427,799			135,322			32
1973	304,233	29		84,959	37		28
1974	237,692	44	22	59,685	56	30	25

There is no followup in most States to insure the patient is appropriately placed.

No psychiatric services are available.

There are few, if any, recreational services provided.

In some cases, the physical environment provided by a boardinghome may be unsafe or undesirable.

In short, cost has become the overriding factor, and the rights and needs of individuals are given low priority. Large doses of tranquilizers take the place of competent trained personnel. In many States, we have created psychiatric or geriatric ghettos by dumping thousands of former mental patients into one area of the city under the rationale that they are being "returned to the community."

These are some of my concerns this morning. Obviously, several questions are raised by my remarks.

With respect to the aged, what is the difference between senility and mental illness or are these simply meaningless labels? Where should individuals with these problems be housed? What kinds of services should they be provided? What can be done to insure the release of all patients unnecessarily committed to State mental hospitals? What precautions can be taken to insure that appropriate discharges are made and that therapeutic and recreational services are provided? I hope that we can develop these and other questions relating to the rights of mental patients at today's hearing.

As I have indicated, this is a joint hearing with Senator Muskie, chairman of one of the subcommittees, and unfortunately Senator Muskie is tied up this morning on matters that are going to the floor, and he will not be here until later.

He would like to have his opening statement inserted in the record, and I will read it.

[The statement of Senator Muskie follows:]

STATEMENT BY SENATOR EDMUND S. MUSKIE

Senator Moss [reading]: "It is appropriate and timely for the two subcommittees represented here this morning to focus once again on mental health issues related to older Americans.

"Since publication 3 years ago of the Aging Committee's report on mental health care of the elderly, no firm policy regarding this vital health issue has yet been adopted. During that time, a majority of the 3 million elderly Americans in need of mental health services have not been reached, and programs designed to help them—such as medicare, medicaid, and community mental health centers—have failed to provide the kind of treatment that is essential to their health and well-being.

"Federal courts have attempted to define the rights of institutionalized patients to treatment. More recently, the Supreme Court has handed down a new ruling on the constitutional rights of mental patients.

QUESTION OF RIGHTS AND SECURITY'S INTEREST

"It is therefore significant to explore the impact of this case, for it leads us to the difficult question of where we must strike a balance between an individual's rights and society's interests.

"Basically, the decision reaffirms that a mentally ill person cannot be confined to an institution unwillingly if he or she is capable of surviving safely in freedom, even if it is asserted that the confinement is for the person's physical good.

"To the Senate Committee on Aging, this principle is of special importance. It is no secret that a disproportionate number of patients in mental hospitals were old when admitted or have grown old during confinement.

"No free society can let any of its citizens be forgotten simply because they are helpless and apparently without hope or self-direction. We cannot put people out of our minds simply because they are out of our sight: in this case, people who are deep within a shunned institution.

"This is one side of the coin.

"On the other side is an equally troubling issue. I'm referring to the so-called dumping process under which long-term patients in State hospitals are 'returned to the community.' In principle, this is desirable. In practice, the actual procedure often results in inappropriate placement in nursing homes, boarding homes, or appalling apartments or welfare hotels. The name of the game, I'm sorry to say, is the replacement of State dollars with Federal dollars, with little consideration of individuals' needs.

"I have sought since 1972 for the establishment of a Presidential Commission on Mental Health and the Elderly to explore the issues I have already mentioned, as well as others. That goal is not yet achieved, but I'm happy to report that in overriding the veto on S. 66—the Public Health Services Act—the Congress also saved a modified version of this proposal. Under terms of that act, the Secretary of

Health, Education, and Welfare will appoint a Committee on Mental Health and Illness of the Elderly. I will welcome the suggestions of our witnesses—particularly Dr. Butler, who was so helpful in the development and support of my legislation—as to the best possible course of action that the new committee can and will take."

That is a statement by Senator Muskie.

Senator Domenici, do you have an opening statement?

STATEMENT BY SENATOR PETE V. DOMENICI

Senator DOMENICI. I have an opening statement; however, I do believe we are going to be seriously pressed for time, and I would ask it be made a part of the record.

I do want to confirm that one of the very serious problems, even in a State like mine, with only 1 million people in the entire State, the problem of dumping is a serious one.

That even occurred prior to the decision by the U.S. Supreme Court. In that instance, it began to occur as a money-saving experiment, and people who had been in the one institution for years were, all of a sudden, found to no longer be welcome at the institution. There was no place for them to go. As a result of previous hearings by this committee and others in board-and-room-type facilities that were being used by that kind of individual, many serious problems have come to our attention. I look forward to the in-depth look now at the constitutional issues, and, certainly, I look forward to seeking some reasonable solutions to the problem that it brings.

It is a very honest, forthright, and simple decision. It is almost so simplistic—that you should not have someone in an institution, called a mental institution, and just release those people with nowhere to go. But the facts that surrounded that case—regardless of precedent, regardless of history, that case did come about. I just ask that my statement be made a part of the record, and we will try to work with you and others on this serious problem.

Thank you.

Senator MOSS. Thank you very much, Senator, and your full statement will be placed in the record at this point.

[The prepared statement of Senator Domenici follows:]

PREPARED STATEMENT BY SENATOR PETE V. DOMENICI

Mr. Chairman, I congratulate the committee for conducting these hearings today on this important issue. There is no question that the care of the mentally ill today is far different from earlier times. In early colonial America, no community care whatsoever was available for those deemed "mad." If they had no family to care for them, the mentally disabled faced a life of beggary and continuing public humiliation. Only gradually did the notion that the community as a whole has some responsibility to care for the mentally disabled come to the fore, and even then the institutions created were more often to protect the public than to cure or try to cure the mentally ill.

Today, we all accept the idea that, to some degree at least, the care of the mentally ill is a public responsibility. With modern advances in phychiatry and psychology, we accept further the proposition that the mentally ill can be treated and, in many cases, cured. Because of that, we like to think that when we commit a person diagnosed as mentally ill to a mental hospital, the purpose is humane and therapeutic.

In many cases, no doubt, this is so. Many people have benefited from a period of hospitalization. Yet today we will hear from a man who should give us a fuller sense of the realities of the situation. For 15 years Kenneth Donaldson was confined in a mental hospital. For 15 years he asked the public authorities either to give him back his freedom or to provide him the treatment necessary to cure him. He received neither, until he filed suit in 1971 contending that the hospital officials were violating his constitutional right to treatment. Then, without explanation, he was freed.

HISTORIC RULING BY SUPREME COURT

On June 26 of this year, the Supreme Court unanimously bore witness to the rightfulness of Mr. Donaldson's cause. In a historic ruling, the Court in *O'Connor* v. *Donaldson* stated the public responsibility to care for the mentally ill does not extend to denying persons such as Mr. Donaldson the simple right to be free if they so choose. In the Court's word:

> "a State cannot constitutionally confine without more a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends." *O'Connor* v. *Donaldson*, 43 LW at 4933.

In other words, the Court found that Donaldson was dangerous neither to himself nor to others; he could support himself outside the hospital; the hospital provided him no treatment. Consequently, there was no legitimate basis for confining him in the hospital for all those years: *he should have been free.*

This is a startlingly simple conclusion, so simple, in fact, that it moves one to marvel that not until this summer was this principle embodied in the law of the land. Indeed, the fact that this case was even necessary moves one to wonder whether we have been blinded by the apparent benevolence of our motives in institutionalizing the mentally ill to the realities of life in those institutions. Have we overlooked, or tried not to see, those realities?

I think it is fair to say that Mr. Donaldson is not unique. There are many—no one knows how many—like him in mental hospitals all across this land. For them the Court's decision kindles new hope that the most basic right of Americans—the right of liberty itself—will soon be theirs.

But it must also be said that the Court's decision leaves unanswered more questions than it answers. The Court said that the State cannot confine and give no more than custodial care to nondangerous mentally-ill persons who could support themselves outside the hospital. What about the mentally ill who are dangerous, either to themselves or others? What is the State's responsibility, and the limit of that responsibility, in that case? Or what if the State provided more than custodial care to persons such as Mr. Donaldson? Would it then be constitutionally permissible to keep him confined against his will in a mental hospital? Or what about those who, like Mr. Donaldson, are not dangerous but who, unlike Mr. Donaldson, cannot live safely in freedom? What is the nature of the public responsibility for them? Is custodial care for them constitutionally sufficient?

ELDERLY PATIENTS "LITERALLY DUMPED"

In my own State of New Mexico, for example, many elderly patients were literally dumped out of the mental institutions in a money-saving effort. These people had lived most of their lives in the institutions and were, of course, extremely vulnerable.

At the same time the institutions were emptied, many boarding homes were initiated in the communities surrounding the mental hospitals. Many of these homes were operated by loving, patient individuals. Other homes were run by individuals who were most interested in taking the supplemental security income allotment of the elderly in return for deterioriating rooms and scanty food.

When this happened, New Mexico only had one State inspector of boarding homes. After a report issued by this committee, the State trained more. But this cannot be the entire remedy. It is my hope and anticipation, Mr. Chairman, that these hearings will shed some light on these questions. The problems of those confined in our mental hospitals are far more than mental, and many, in fact, may be created by outdated laws. We must respond to those problems to the best of our ability.

I want to join you, Mr. Chairman, in welcoming to this hearing the distinguished witnesses from whom we will be receiving testimony today. In particular, I want to welcome Mr. Kenneth Donaldson to our witness table. It is in no small measure due to his courage and persistence that mental patients across this land can look to the future with new hope. I welcome this opportunity to hear him.

Senator Moss. We will proceed now.

Our first witnesses will be made up of a panel at this time: Mr. Kenneth Donaldson, a former patient; Ms. Patricia Wald, litigation director, The Mental Health Law Project, Washington, D.C., accompanied by Benjamin W. Heineman, Jr., Esq., law firm of Williams, Connolly & Califano, Washington, D.C.; and Ms. Gail Marker, M.S.W.

We are pleased to have all of you before the subcommittees, and I look forward to hearing your testimony.

Mr. Donaldson, I think you should go first, and then in whatever order after that that you want to proceed.

You may proceed, Mr. Donaldson.

STATEMENT OF KENNETH DONALDSON, FORMER MENTAL PATIENT

Mr. Donaldson. Gentlemen, it gives me a great deal of pleasure to be here. After my experience of 15 years, just being alive is something, and I think it is the most important statement that I will make, to just be sitting here this morning.

I lost hundreds of friends who died from abuse. My experience is unique, only in the fact that I lived to tell the story, and largely, that is because of my belief in Christian Science, medication was not forced on me.

Medication that they gave in these hospitals, at least in the hospital I was in, tears a person up, and I had hundreds of friends that died there—that did not live through the experience.

The treatment consists almost entirely of tranquilizer drugs. They usually will give two of them, and the two together is even worse than just double.

An average doctor's call will last less than 2 minutes. The doctor will ask three questions. He will ask what ward you are on; do you take any medication; are you working anyplace. And that will be all—the end of the interview.

Some patients went as much as 4 years, that I know of, without seeing a doctor, and some of them were on medication all that time.

My experience over the years is that most of those locked up with me—there were 6,800 in the hospital when I went there, there were 1,300 of us under one doctor for a period of 2 years.

There was one doctor for 1,300 men. He was licensed by the State of Florida only as an obstetrician.

Confinement Deteriorates Young and Old

The saddest thing is seeing people die in front of your eyes—not only old men, but old men of course go quicker than the younger ones. They would give up hope after about 2 years. People deteriorate physically when they are in confinement—even the young people. But many of the older people just gave up, and they were not fit really to return to society.

There are not any words in my vocabulary—I have written a whole thick book about it, which will be out next year—but there are not any words I can tell you that will accurately describe what it is to live in such a setting.

What do we want now for these older people? Most of us in those institutions, who have come out, do not want to see Federal money perpetuate such a thing.

Many professional people, psychiatrists, psychologists, social workers, say we need an entirely new profession to handle the problems of the elderly, that the medical profession today does not understand, and does not care about them.

As an illustration of what can be done, in my home State of Pennsylvania, Harrisburg State Hospital, there is a small pilot program which is self-financed. They have a sheltered workshop on the grounds, and they contract small clerical jobs with some of the neighboring manufacturers. They are able to give work in the hospital to people who have been locked up for 20 or 30 years, and build up their self-respect, and then when they find a place in the community for them, even if they do not work in the community, they have their self-respect back, and they are able to go out of the hospital.

Something like that has to be done for these people. The Government is getting so big—as you all know, or maybe you do not see it here in Washington—that to keep up with all of the things that people need, you are going to have to have volunteer services of many of our citizens.

ADVISORY GROUP MADE UP OF SENIOR CITIZENS

My suggestion is that you use the vast, untapped reservoir of senior citizens. The Federal Government could pay the office expenses, mimeograph expenses, phone and mail, and let groups of senior citizens in each community handle the problems of the old people.

They could regulate the living conditions; they could advise them; and another group of senior citizens could go up to the State hospitals and talk to these people, find out what they want, and work out ways for them to get out of the hospital.

Everything that has been done so far is so small in proportion that it is going to take some vast movement like that.

There are still probably 100,000 or 200,000 old people in these State hospitals.

Another thing I would like to see is that each individual who is getting money from the Federal Government could have the final say on how his money is to be spent. As it is now, even when they come out of the hospital and are able to live in the community, someone else will decide how their money will be handled.

Unless a man is not able to tell the difference between his right hand and his left hand, it is very demeaning to have somebody else spend his money for him and leave him with nothing in his pocket. Working through the courts, while we welcome these new court decisions, and while it is quite important to see these advances, it is going to be very slow.

I see in the news and I hear from a few people in Pennsylvania: as far as they know, no one else has been released because of my own court success.

It will take lawyers all over the country; it will take public-spirited groups to finance these cases, and each, patient by patient, will have to put his case in court.

For that reason, this is a problem for the legislative branch of the Government. Uncle Sam controls the money, and he can make the rules. I think that is the way the thing has to be solved.

Thank you.

Senator Moss. Well, thank you very much, Mr. Donaldson. We appreciate your appearance and your testimony. We have a more complete written statement that you have prepared, which will be placed in the record. I will have some questions that I would like to ask you but I think I will have the other witnesses who are seated at the table testify first, and then we can ask questions of all four of you at the same time. Thank you.

[The prepared statement of Mr. Donaldson follows:]

PREPARED STATEMENT OF KENNETH DONALDSON

Gentlemen, as a senior citizen, I welcome the opportunity to give you my observations on the treatment of senior citizens in one large State hospital, which is funded partly by the Federal Government.

I was incarcerated nearly 15 years (from 1957 to 1971) as an involuntary patient at Florida State Hospital, in Chattahoochee, which is 44 miles west of Tallahassee. There was nothing wrong with me mentally, morally, physically, financially, or legally. There was no legitimate reason for my being there even 1 day. Yet for 15 years the doctors said that I was so ill I could not even be released to the custody of a halfway house where residents had access to psychiatrists. As proof of my illness, the doctors pointed to my plans to return north, get a job, and write a book on my case. And that is exactly what I did, when the hospital finally released me. The book is entitled "Insanity Inside Out." It will be published by Crown Publishers early next year. For more details, I have appended hereto my recent article in *Harper's Weekly*.

I did not just sit there waiting for this farce to end. Among other things, I petitioned the courts. Both alone and with the help of Morton Birnbaum, of Brooklyn, who is both a medical doctor and a lawyer, I petitioned the several State and Federal courts a total of 19 times, including four approaches to the Supreme Court in Washington. But not one time during those 15 years did I have a personal hearing in court, although Florida law guaranteed me that right. Then on our 20th round of appeals, the Federal District Court in Tallahassee set a date for my personal appearance on a petition for writ of habeas corpus. About 10 days before I was to appear, the hospital released me as "miraculously cured," as attorney Bruce Ennis said. After my release, with the help of the Mental Health Law Project, Washington, D.C., we won a damage suit against two of the hospital doctors. Carried up to the Supreme Court in Washington, this resulted in a landmark decision (9–0) on June 26 this year that so-called mentally-ill people who are not dangerous and who can provide for themselves in the free world cannot be held in a mental facility against their will. The question of the monetary damages has been remanded to the lower courts for further hearing.

WHAT IS HOSPITAL LIFE LIKE WITHOUT TREATMENT?

So that you might better understand what the senior citizen/mental patient gets for the Federal dollars, here are some of the things that passed for treatment in Chattahoochie. Reports from other patients around the country show that there are similar conditions in most States.

First of all, few of the doctors are certified physicians. A large number are not even licensed to practice medicine in the State. Some have a poor grasp of English and of the mores of our country. My doctor for 10 years, who for a 2-year period was the only doctor for 1,300 men, was licensed by the State only as an obstetrician.

A typical interview consisted of the doctor asking three questions:

"What ward are you on?

"Are you taking medication?

"Are you working anyplace?

"That'll be all."

Medication was given indiscriminately by doctors to patients who sometimes were not seen by a doctor for months, even years. Some attendants were able, without a doctor's orders, to give medicines to keep quiet on the wards. Some patients too were able to get handfuls of most any medicine.

There was physical abuse of old men. Arms were broken (which were reported as "fall in shower"), teeth knocked out, ears bloodied. Sometimes these things were done by sadistic attendants without provocation, other times for some slight infraction of the rules. In Chattahoochee, brutal criminals (who made up a third of the ward population on my ward) did the beating of old men. Some few times it was done by some brutal noncriminal.

I lived on at least 11 wards (including one open ward) with from 60 to 240 beds, some of them touching. There was the same mix of patients on all the closed wards—screamers, senile, epileptics, retarded, juvenile delinquents, catatonic, plus about one-third "charge patients" (those charged with a crime, petty to vicious, or those transferred from the State prison). Most wards were noisy, with some patients and attendants teasing other patients.

That is the environment, gentlemen, that Federal dollars are helping to provide for our elderly.

It is my experience that many of the doctors and other staff members do not know the difference between those who are mentally ill and who are not. And some of the staff couldn't care less. Many professionals working in this field have said the same thing. A wire-service dispatch in the *Miami Herald*, August 6, 1971, said: "Dr. Butler Johns of the Lincoln School of Psychiatry, said, 'It may be necessary for us to create a brandnew profession, to finally admit that psychiatry and medicine are not really interested in the problems of old people.'"

DETERIORATION OF SKILLS OF AGED

One of the saddest things was seeing elderly men lose their fight, right before your eyes. Some literally lie down and die. After 2 years of confinement, everyone at any age noticeably deteriorates. The shoulders stoop, the muscles go flabby. With each added year, there is a little more fear of and a little less desire for the give-and-take of outside life. Even the rare stubborn man, whose mind doesn't go flabby in this setting, loses that fierce sharpness seen in healthy bodies of our aged in the free world.

I am a student of Christian Science. I give Christian Science credit for my survival. But I do not like to see Christian Science (or strong faith in some other religion) as the only salvation for senior citizens in State institutions.

Despite the deterioration, it is my observation that the ability to live in the free world, like that to ride a bicycle, is not wholly destroyed by flabbiness. And last year, I had the heart-warming experience of seeing a project at one State hospital, which is rescuing some of these people who have been cruelly incarcerated for 5, 10, or 20 years. It is a small project at Harrisburg State Hospital in my home State of Pennsylvania. It is giving these human wrecks the ability to exist again as whole individuals in the free world. It is a self-funded project, supported by contract jobs which these patients do in a sheltered workshop in the hospital. Its scope is limited by the short supply of suitable contract work in the community. I have appended several pages from a chapter which could not be included in my book because of size limitations.

In Chattahoochee, I saw innumerable instances where the mere application of commonsense and kindness were sufficient to stop the downslide of an old-timer. This is what has been carried on a step further at Harrisburg. Also, there were hundreds of men there as stubborn as I, who could have made the changeover to the free world as easily as I. Sadly, most of them died while I was there, weakened by the powerful medicines. Here again I was fortunate, in that my belief in Christian Science was respected (except for a 10-day period during my 10th year) and I was not forced to take medication. Otherwise, gentlemen, I assure you that I would not be addressing you today.

AN EXAMPLE OF A STEP IN THE RIGHT DIRECTION

I am witnessing, in my home city of York, a successful beginning of a joint State/county program to get the patients out of the big State institutions and back into boarding homes in the community. Most of these patients returning to the boarding homes are elderly and without family. The program is limited by two factors: the inability of the community to absorb more old people who have not been rehabilitated for reentry into free society, and the inability of government at all levels to finance adequate living standards for these returned people. In York, most of these expatients get only $160 a month from social security. The best homes take $144, leaving only pin money for the expatient. Poorer homes take the whole $160. It is left up to the local volunteer mental health association to police those homes to see that each expatient gets minimal food and shelter. And the association has to provide such other things as transportation, recreation, and clothes—even letter-writing, for these people are unprepared to operate as normal people.

What I would like to see is: a three-part program to be initiated over the next 7 years:

(1) Giving back freedom of choice to the individual;
(2) Redirecting Federal funding of State mental hospitals;
(3) Tapping the reservoir of senior citizens' skills.

INTRODUCTION

As my friend Doctor Birnbaum insists, it doesn't do much good to take a person out of a State hospital and put him in a building without locks on the outside doors (where there are muggings in the halls and where women are afraid to go to the hall toilet at night and have to urinate in the wash basin in their room). In places like New York City, these rooming houses for expatients are often on streets where one prowl car with two policemen won't drive alone but only together with another prowl car with two policemen in it. Such streets are where some senior citizens are being sent today from the State institutions. So something better has to be worked out.

Also, Doctor Birnbaum has been pointing out that the legislature rather than the judiciary seems the proper instrumentality to establish a realistic program. "Only the legislature has the means to set up a comprehensive scheme and to coordinate it with necessary legislative appropriations," he says.

With those two thoughts in mind, let us look at a program that, in my opinion, would accomplish what it is going to take the courts many, many years—considering the number of volunteer lawyers available for the job; the length of time to get each case through the crowded courts; the opposition of State hospital doctors to freeing many patients.

1. This is the only time in the history of the world that we locked up people for their own good. It is my observation over 15 years that such people knew when they were so-called mentally ill and that they would ask for help. If they know that, they should be allowed to direct their lives. And unless they are so far gone that they can't tell the difference between their right hand and their left, they should be allowed to have control over the handling of whatever Federal money is allotted to them. No longer should someone else have arbitrary authority to run the patient's (or expatient's) life but should respect the latter's wishes.

The Congress of the United States, by controlling the purse strings to a large extent for these patients and expatients, can give back the freedom of choice to these individuals.

2. Lawyer talks to lawyer and doctor to doctor about improvements being made in the handling of the segment of senior citizens labeled as mentally ill (whether rightly or wrongly so labeled); but senior citizens continue to be beaten up, overmedicated, and unjustly restrained in the back wards of State hospitals all over the country. To be sure, hospital officials say that these medieval conditions no longer exist, but the continuing line of reports from patients tells otherwise.

Under the present setup of inefficient State hospitals, the States (taking Pennsylvania as an example) are unable to finance the return of patients to their local communities plus operating their outmoded hospitals. The dilemma is that the hospital staff is so fouled up in the interlacing demands of workers' unions and professional groups that there is no way out financially. Only the Federal

Government has the taxing capacity to swing the change. It is my personal feeling that more than enough Federal funds are going into our State hospitals at present to fund adequate local community living for every senior citizen who opts to leave the State hospital. Furthermore, today some of the States (as did Florida when I was incarcerated there) put their HEW payments for senior citizens into the State's general fund instead of into a treatment program.

Experts say that only 5 percent of those in State mental hospitals belong locked up. As only one-fourth or one-third of the total population of these hospitals are senior citizens, the total percentage of patients needing to be supported by the States behind bars is so tiny that they could well afford to do so without the help of Federal funds. The way to start is to announce a cut-off date within 7 years of Federal funds to State hospitals for the benefit of senior citizens.

3. It is increasingly evident that we are going to have to use the talents of our citizens in broadening our public social structure: Big Brother can't supply all our needs. And one almost untapped reservoir of talent is that of our senior citizens.

With the backing of the Federal Government to pay for the expenses of office rental, phone, mail, transportation, mimeographing, and such, committees of volunteer senior citizens could be organized to work on two levels: in the communities and in the State hospitals.

In the communities, these committees would work with the expatient to see that his wishes were respected concerning residence. These committees could also serve to advise the Congress on legislation to benefit these expatients.

In the State hospitals, these committees would acquaint the patient of his rights to leave under the Supreme Court ruling in the *Donaldson* case and would assist the patient if he chose to leave.

Each committee would be composed of volunteer workers only. They would be governed by their own rules. Each committee would determine its own size. Members would be drawn from all walks of life, but with not more than two members from any one profession, trade, or other category.

It is fine to have new laws to benefit the senior citizens who are labeled as mentally ill. It is fine to have landmark court decisions to benefit all people. The main problem remaining for senior citizens is finding a way to see that the laws are followed and to make the court decisions effective. For this we will need the eternal vigilance of watch-dog committees. As a fellow senior citizen I have the feeling that senior citizens would pitch in gladly and make this transformation to a humane system a reality.

Thank you, gentlemen.

Senator Moss. Our next witnesses are Mr. Benjamin W. Heineman, Jr., Patricia M. Wald, and Gail R. Marker.

Ms. Wald, you may proceed.

Ms. Wald. Mr. Chairman, Mr. Heineman will be the next witness.

STATEMENT OF BENJAMIN W. HEINEMAN, JR., ATTORNEY, WASHINGTON, D.C.

Mr. Heineman. Good morning Mr. Chairman. Until recently I was a lawyer at the Center for Law and Social Policy, and was cocounsel for Kenneth Donaldson in his case before the Supreme Court and am also active in litigation on behalf of the mentally disabled. Patricia M. Wald, a staff attorney at the mental health law project, has also been active in right to treatment and right to education litigation on behalf of the mentally disabled as well as handicapped children and juvenile delinquents. Gail R. Marker, M.S.W., is a social worker on the staff of the mental health law project who has worked in mental hospitals and has studied alternatives to the large mental hospital. Both the Center for Law and Social Policy and the mental health law project are foundation funded public interest law firms concerned with protecting and advancing the rights of mentally ill citizens. We are grateful for the opportunity to appear before you this morning.

MANY INVOLUNTARILY CONFINED PATIENTS

In order to aid the subcommittee in its legislative oversight functions, we will attempt to provide an overview of the postconfinement constitutional rights of the involuntarily committed mentally ill which courts have established in the last decade and which Mr. Donaldson's case dramatically illustrates. It should be emphasized that the constitutional rights attach because individuals are involuntarily confined in hospitals due to mental illness—that is, they are deprived of their constitutional right to liberty because they suffer from a disability. And, as the subcommittees well know, many of those persons involuntarily confined in Government hospitals are elderly citizens. For example, at St. Elizabeths Hospital here in Washington, approximately 60 percent of the present patient population are persons over 55 years of age. And a great many of these persons were involuntarily confined pursuant to civil commitment processes.

Establishing the constitutional rights of our mentally disabled citizens is critically important because those mentally ill persons subjected to the States' involuntary, civil commitment processes are one of the most vulnerable segments of society—usually destitute, often without families and generally powerless to resist the arbitrary exercise of State authority affecting their most basic personal liberties. The mentally ill are particularly vulnerable after they have been hospitalized involuntarily pursuant to court order, since, historically, both case and statutory law have focused primarily on commitment procedures rather than on substantive postconfinement rights. To safeguard the constitutional rights of mental patients, courts have begun to scrutinize the often appalling conditions of involuntary confinement. The most critical of the postconfinement rights—the constitutional right to be restored to liberty either by treatment or by release—has been recognized by medical experts, legal commentators, by the Justice Department, by the lower Federal courts and, in the case of Mr. Donaldson, by the U.S. Supreme Court.

PHASED TREATMENT FACILITIES NEEDED

The underlying theme of the postconfinement, constitutional litigation may be simply stated: For mentally ill patients who require confinement under Government control pursuant to statute, a continuum of phased treatment facilities should be available so that those patients may be returned as soon as possible and insofar as possible to full, productive and autonomous lives in the community, given their needs and capacities. Implementation of this principle—restoration of liberty as soon as and insofar as possible—requires high quality facilities that serve as less restrictive alternatives to a 24-hour psychiatric hospital. Such facilities include nursing homes, foster homes, personal care homes, halfway houses.

Implementation of this principle avoids two evils that often afflict statutory systems of confinement for the mentally ill: warehousing and dumping. Warehousing occurs when mentally ill persons are retained, for protracted periods beyond the time medically required, in 24-hour hospitals—"total" institutions characterized by mass wards, bureaucratic routine and debilitating effects on those very persons whom the hospital is supposed to help. Dumping occurs when, in a precipitous attempt to cut costs by simply emptying psychiatric hospitals, governments discharge patients to the streets or to substandard alernative facilities—often characterized by scandalous conditions—that do even greater harm than overlong retention in the mental hospitals.

In the fifties and sixties, public attention was focused on the dangers of warehousing patients in large mental institutions. In the seventies, public attention has focused on the enormous shortcomings of many existing alternatives to such institutions, especially nursing homes. Yet, both evils must be kept in view as legislatures and courts seek to insure, as a matter of statutory or constitutional right, that the involuntarily confined mentally ill have available to them a phased system of institutions in which both the large mental hospital and residential alternatives play an appropriate role and benefit rather than harm patients. Indeed, despite the recent attention given to the dangers of "dumping," "warehousing" remains a significant problem. At St. Elizabeths Hospital, nearly 45 percent of the present inpatient population does not, according to the estimates of the hospital's own clinical staff, need to be retained in a 24-hour psychiatric facility. Yet they are warehoused nonetheless because there are no suitable alternatives to St. Elizabeths.

THE DONALDSON CASE: THE RIGHT TO LIBERTY*

Placed in this context, the decision handed down by the Supreme Court last June in the case of *O'Connor* v. *Donaldson* was historic. It was the first case to reach the High Court which involved the post-confinement rights of a patient who was involuntarily confined solely through the civil process. And the Court ruled that involuntarily confined mental patients have a constitutional right to liberty. It ruled further that mere custodial care, without treatment, could not jusify the abridgment of constitutional liberty entailed by civil commitment to a mental hospital, when a mentally ill individual is dangerous neither to himself nor to others and is "capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends."

Although Mr. Donaldson's case is of signal importance, it was a relatively narrow decision based on the stark facts of the case—the totally unnecessary confinement of Mr. Donaldson for 15 years. The Supreme Court stated that it did not have to decide whether an involuntarily confined mentally ill person dangerous to self or to others has a right to treatment.

But there are a number of ancillary holdings in the case that are significant, and which point the way toward ultimate Supreme Court recognition of the right to treatment.

First, the Supreme Court made clear that, since an individual's due process right to liberty is infringed by involuntary civil commitment, such infringement requires constitutionally acceptable justification by the State.

---

*See the Mental Health Law Project publication, appendix 1, p. 69.

Second, the Court invited scrutiny by the Federal judiciary of the postconfinement rights of the involuntarily confined mentally ill, for it stated that even if Mr. Donaldson's involuntary confinement was "initially permissible, it could not constitutionally continue after that basis no longer existed." The constitutional rights of involuntarily confined patients are not to be left solely to the unfettered discretion of State doctors or other public health officials.

Third, the Supreme Court held that the adequacy or suitability of the treatment being provided to an involuntarily confined person was a "justiciable" question that could appropriately be explored by the courts. And, the Court ruled that the nature and duration of confinement must bear a reasonable relation to the purpose of that involuntary confinement. As the Court stated: "Where 'treatment' is the sole asserted ground for depriving a person of liberty it is plainly unacceptable to suggest that the courts are powerless to determine whether the asserted ground is present."

Fourth, the Court hinted that patients' liberty should only be infringed in the least restrictive manner possible given the goals of their involuntary confinement.

Finally, the Court suggested that the standard of "dangerous to self or to others"—which, in most States, must be met in order to commit an individual to a psychiatric hospital—should be construed strictly. It thus suggested, albeit tangentially, that the net used to sweep individuals into the State's involuntary mental health system should not be cast too widely.

Mr. Donaldson's case was an individual action for damages. Following sound judicial practice, the Supreme Court decided the case on the narrow set of facts before it and expressly left open other, broader issues involving the postconfinement rights of the involuntarily confined mentally ill. But we believe that the Supreme Court's decision, properly read, is a signal to the lower courts to continue their careful adjudication which has led to recognition of more expensive substantive rights for the mentally ill.

THE LOWER COURT PRECEDENT: THE RIGHT TO TREATMENT

Indeed, the lower Federal courts and some State courts have firmly established that involuntarily confined mental patients have a constitutionally based right to treatment while they are in governmental mental hospitals. Establishment of this right has come in class action suits which seek prospective injunctive relief aimed at upgrading conditions at State hospitals so that minimal standards, mandated by the constitution, are established. The most famous case is *Wyatt* v. *Stickney*, now *Wyatt* v. *Aderholt*, a class action brought against the State of Alabama to alter the primitive conditions in that State's hospitals for the mentally ill and the mentally retarded. And as the Court of Appeals for the Fifth Circuit stated in *Donaldson* v. *O'Connor*, "an enormous range of precedent" supporting the right to treatment exists.

Existing case law and commentary on the constitutional right to treatment demonstrates that broad and sensible guidelines for defining the right have already begun to develop. The fundamental thrust of the precedent and the literature is that, when enforcing the right to treatment, courts will not attempt to prescribe specific forms of treatment for specific patients, but will limit their review to whether some form of treatment recognized by responsible professionals is being provided. In conducting that review, courts will ordinarily look to good faith efforts by State officials to provide treatment that is within the range of accepted professional practice. In reality, the right to treatment suits that have been brought to date have involved State hospital conditions or official acts that are so substandard that there could be virtual unanimity among responsible professionals and professional groups that a reasonable level of treatment was not being provided. The suit aims at provision of minimally humane and decent care and treatment, not optimal care and treatment.

For example, in *Wyatt* v. *Aderholt*, the district court ordered institutionwide relief. The district court held that there were three fundamental conditions which were constitutionally necessary for adequate treatment of the involuntarily confined mentally ill and mentally retarded: First, a humane psychological and physical environment; second, qualified staff in numbers sufficient to administer adequate treatment; and third, individualized treatment plans. After reviewing memoranda submitted by the parties, by leading professional organizations such as the American Psychiatric Association and the American Psychological Association, and by the Justice Department, the court ordered adoption of specific care and treatment standards at the Alabama hospitals in order to establish the requisite constitutional floor which would protect patients. The district court's decision was affirmed by the fifth circuit court of appeals in all significant particulars regarding the right to treatment and the standards implementing that right. And the State decided not to take the case to the Supreme Court. The fifth circuit also reversed the only Federal court to rule that there was not a right to treatment. And just after rendering a decision in the *Donaldson* case, the Supreme Court refused to review that fifth circuit decision, indicating clearly that the court is interested in letting the right to treatment develop further in the lower courts.

EXTENDING RIGHT TO TREATMENT

Recognizing the widely accepted medical fact that, even under the best of circumstances, many mentally ill persons should not remain in massive 24-hour psychiatric hospitals for any but the shortest possible period of time, patients have brought suits to extend the right to treatment to include treatment in suitable community facilities that are less restrictive alternatives to the large mental hospital. Such suits attempt to avoid the dangers of warehousing, but they are also extremely mindful of the pitfalls of dumping. Thus, such suits seek to establish standards in alternative facilities so that patients who are confined under Government control for mental illness may move swiftly along a continuum of facilities so as to attain the greatest amount of liberty and dignity consistent with their mental disability. In short, whereas cases like *Wyatt* sought establishment of institutionwide standards, the new round of cases seeks to establish systemwide standards, as a matter of constitutional law, in order to vindicate the involuntarily confined mental patients' right to liberty.

We are currently engaged in such a suit. So that the subcommittee may be fully informed about litigation trends, we think it may be helpful, Mr. Chairman, if we briefly describe the lawsuit which represents that next stage in right to treatment developments. But we would note that a motion for summary judgment is currently pending in U.S. District Court for the District of Columbia and we would emphasize that we appear this morning to inform the subcommittees and not to argue the case. The proper forum for such argumentation is, of course, the district court. We will only discuss matters which are already of public record.

One stark fact provides the basis for the litigation, which is called *Dixon et al.* v. *Weinberger et al.* By the hospital's own estimate, literally hundreds of persons presently confined at St. Elizabeths Hospital do not require 24-hour hospitalization but instead, as a matter of sound medical and psychiatric practice, require care and treatment in suitable alternative facilities such as nursing homes, foster homes, personal care homes, and halfway houses. Approximately 1,000 of the 2,250 persons confined as inpatients at the hospital require alternative placement in suitable facilities and no longer need to be retained at the hospital itself. Moreover, the hospital staff estimates that nearly 400 patients, of those presently confined at the hospital, will require alternative placement in the next 12 months.

Accordingly, hundreds of patients are retained longer than is necessary in St. Elizabeths Hospital, at harm to themselves and at unnecessary cost to the taxpayer. There are many reasons for this anomalous state of affairs. Among the most salient reasons, in our view, are the following: Lack of suitable alternative facilities, lack of space in those suitable alternatives which do exist, lack of resources for alternative facilities under current budgetary patterns, and lack of cooperation and coordination between the hospital and the District government.

The litigation in which we are engaged, *Dixon* v. *Weinberger*, attempts to remedy this situation. The case is a class action brought by patients confined under the control of the United States and the District of Columbia government pursuant to the 1964 Hospitalization of the Mentally Ill Act, the District's civil commitment statute. Defendants in the action are officials of both the District and Federal Governments responsible for implementation of the 1964 act and for the administration of mental health care in the District of Columbia.

SUFFICIENT AND ADEQUATE TREATMENT FACILITIES

The suit seeks to compel the defendants to provide the patient plaintiffs with suitable care and treatment, under the least restrictive conditions consistent with the purpose of the 1964 act. Specifically, the action seeks to compel defendants to create, establish, or maintain sufficient and adequate treatment settings or facilities which are less restrictive alternatives to St. Elizabeths Hospital, as it is presently constituted, and promptly to place and treat the plaintiffs in such settings or facilities in order to provide the care and treatment which we maintain is due to the plaintiffs as a matter of both statutory and constitutional right.

Recognizing that the transformation to a meaningful, phased system cannot occur overnight and wishing to avoid the twin evils described above, the immediate relief sought by the suit is to compel the defendants to plan for the swift development of such a phased system. We seek, in other words, expeditious but carefully orchestrated placement of patients in suitable, least restrictive alternatives.

Such a plan, which we believe is an appropriate initial remedy of a long-standing constitutional violation, would recognize that both the legal and medical goal of care and treatment for persons confined as patients pursuant to the 1964 act is to restore them to liberty by returning them to full, productive, and autonomous lives in the community as soon as possible and insofar as possible given their conditions; it would recognize that the mentally ill must be afforded different levels of care in different types of treatment settings as their needs and conditions change; it would recognize that, as patients improve, they should be moved along a continuum of phased treatment settings in order to accomplish the goal of care and treatment while under government control; it would recognize that the prompt placement of hospital in-patients in suitable alternative facilities is of central importance to the success of the treatment process; and it would recognize that many hospitalized patients, including the elderly, have potential that will not be realized without a decent system of care.

Such a plan would be further premised on an awareness that confinement of most persons in a large psychiatric hospital for other than a short time during acute periods of illness imposes its own debilitating harms. As a hospital policy statement observes:

> For many patients whose condition has improved with hospital treatment, the opportunity for community placement and followup care is a further important step in rehabilitation. The alternative of continued institutionalization, . . . ultimately imposes its own burden of added debility.

And the statement goes on to note that the "avoidance of this undesirable alternative" requires alternative placements that are "suitable in both quality and quantity to receive patients whose condition no longer requires full-time, in-patient hospital care." The statement further observes that "protracted institutionalization (in the hospital is) an alternative which has been shown to beget further debility and lessening of individual dignity." The added debility and lessening of dignity attendant on over-long hospitalization has been widely recognized for years: By the Joint Commission on Mental Illness and Health etablished by Congress in the midfifties; in the 1961 and 1963 hearings before the Senate Judiciary Subcommittee on Constitutional Rights that led to the passage of the 1964 Hospitalization of the Mentally Ill Act; and in the professional medical and social science literature.

Finally, such a plan would build on the perception that many existing alternatives to 24-hour hospitalization are alternatives in name only. We need hardly remind the subcommittees of the substandard—some might say subhuman—care in many nursing homes, or worse, welfare hotels.

If we may, Mr. Chairman, we would like to turn now to some of the questions that have arisen from lawsuits seeking to establish the right of involuntarily confined patients to care and treatment in suitable residential facilities that are less restrictive alternatives to the 24-hour mental hospital.

The Problem of the "Voluntary" Patient

Donaldson's constitutional right to liberty and *Dixon's* constitutional right to treatment in the least restrictive alternative setting are pegged on the fact that those patients have been involuntarily committed. A majority of patients in mental hospitals are not there by virtue of civil commitment, however, but are technically "voluntary" or "nonprotesting" admissions. As the mental health system is pushed by professionals and civil libertarians alike to become an almost totally voluntary one, a genuine dilemma arises if in that process, patients lose valuable legal and constitutional rights to treatment. This is especially true because of the wide consensus in the mental health field that once in a residential facility, the differences between volunteer and involuntary patients disappear. Most State codes, for instance, allow a voluntary patient to be detained for several days so that the hospital staff can file an emergency commitment petition. More important, if aged patients try to leave the hospital or nursing home they often have nowhere to go.

One answer, of course, is to rely on statutory rights of adequate care and treatment which apply to voluntary and involuntary patients alike. Such statutory provisions should be written and interpreted to cover rights to adequate care and treatment in community facilities as well as traditional mental hospitals. Statutory rights can, however, be repealed or modified. One court has found an eighth amendment right to "protection from harm" for all persons in State custody, voluntary or involuntary, which embraces not merely a humane and safe living environment, but also the medical and social services that are necessary to protect the individual from deteriorating while he or she is in State custody. Finally, an interesting analogy has sprung up at the other end of the age spectrum—for juvenile patients. Until recently, they were generally assumed to be voluntary—"volunteered" by their parents or guardians.

Now the courts have ruled more realistically that they are very often, in truth, involuntary patients who don't want to be in the hospital, and accordingly entitled to due process protections at commitment. If fictional consent can be pierced at the beginning of the process for the young, the same judicial realism should pervade the latter stages of hospitalization to assure adequate treatment for the homeless aged. Whichever legal strategem is used, courts should be urged to acknowledge that mentally distressed persons unable to survive in the community on an outpatient care basis and so driven by their mental or emotional condition to seek treatment are not voluntary patients in any meaningful way, and so are entitled to the same constitutional and statutory rights to adequate treatment as involuntarily committed patients. For if we do not insist on equal treatment of the two patient categories, we will court large-scale manipulations and mislabeling of patients or "volunteers" so as to diminish their legal rights, as well as cause a possible misconcentration of resources into programs and facilities for involuntary patients alone. This, in turn, would encourage a new form of "dumping," for example, exiling of voluntary patients out of the hospital and onto the streets with no transitional community alternatives.

I now turn to Ms. Wald.

STATEMENT OF PATRICIA WALD, LITIGATION DIRECTOR, MENTAL HEALTH LAW PROJECT, WASHINGTON, D.C.

Ms. WALD. Mr. Chairman, subcommittee members, I would like to touch briefly on some of the legal, conceptual and practical problems which we have encountered in trying to place our patients out in suitable community alternatives.

The first is the problem of the voluntary patient. Now, both the *Donaldson* case and the litigation that Mr. Heineman referred to pegged constitutional rights on the fact that there is an involuntary commitment. Nonetheless, the majority of mental patients are not involuntary patients, involuntarily confined.

There are so-called volunteer or nonprotesting admissions, and the question then becomes: Do they have a lesser brand of constitutional or legal rights than those that were involuntarily confined?

We would hope that in the future, both courts and legislature would see to it that the rights of these so-called volunteer patients are just as broad as the rights of the involuntarily confined patients to both treatment, and less restrictive alternatives.

We think this makes sense, because most professionals in the mental health field, and our own experience as well, validates the fact, that once you are in a 24-hour mental hospital, the difference between voluntary and involuntary patients disappears rapidly.

VOLUNTARY ADMISSION—NO OTHER PLACE TO GO

Every State code we know allows a voluntary patient to be retained up to several days in order so that the staff can decide if it wants to file a petition for commitment; moreover, the studies show that a large portion of voluntary patients do not know what they sign, do not know the content of what they have signed, but most important for the aged population, many of them are there because they have no other place to go.

Their relatives will not take them in, their friends will not take them in, yet they are called a voluntary admission. The answer to their legal dilemma must come from both the legislative branch and the court.

We would like to see the statutes themselves give rights to adequate treatment, and especially adequate treatment in the community to volunteer as well as involuntary confined patients.

The District of Columbia does have a statutory right to treatment provision which includes both voluntary and involuntary patients.

There are also some important precedents which we look upon as useful. One is in the *Willowbrook* case; this is a lawsuit on the right to proper conditions, in a home for the retarded, in New York, and the judge there said that to call people involuntarily confined, when in fact they had no other place to go, was a misnomer, but nonetheless such people, voluntary or involuntary, did have a right to protection from harm, and he then defined that protection to be broad enough to include protection from deterioration, mental or physical, while a person is in State custody.

Another relevant case is that of parents volunteering children into mental institutions. All children were formerly looked upon as voluntary patients, whether or not they wanted to be admitted into the institution, because their parents had volunteered them.

Of late, we have had a few cases in which courts said that is plain unrealistic, that the interest of the parent and the child is often in conflict, and accordingly they are given full due process rights at the time of commitment.

We think some of these precedents may prove to be relevant in deciding whether or not the large number of voluntary patients in mental institutions deserve the same kinds of constitutional and legal rights as involuntary ones. We think it is important, an important point, because otherwise we may have a great deal of manipulation and mislabeling of patients as volunteers to diminish their legal rights.

"NO RIGHTS TO TREATMENT"

We were told, and this occurred after Donaldson, that one of the State mental superintendents said, "I don't have to worry about it, because we will tell all of the patients they can now become voluntary, and if they become voluntary, they have no rights to treatment."

There is also a danger of misconcentration of resources in favor of the involuntary patient, who has constitutional rights to bolster his claims. The result would be unjust if rights of access to treatment were not equalized.

The second problem I want to allude to is the relationship between mental health and other social services.

Again, our experience has been that if you go into a ward in a mental hospital, many of the patients, except those that are very severely disturbed, and especially the aged have a combination of mental and physical symptoms, and very often the mental conditions are not the most prominent.

Where they are, whether they are in a mental hospital or a nursing home, is a matter of what alternative resources are available.

Almost any disabled elderly person can satisfy the present mental commitment criteria, which says they are committable if dangerous to themselves if left unaided.

One problem in trying to design legal strategies, which will help the aged, is to find selection criteria to decide who among the multi-disabled elderly persons with both physical and mental problems belong in the mental health bracket, and also when they should leave it.

MENTAL HEALTH SOCIAL SERVICES

The definition of treatment according to most mental professionals is teaching the person to cope with life, teaching him to obtain the social survival skills, how to take the bus, how to bathe and feed himself, how to manage his money; these have become just as important a component of treatment, as the formal psychiatric interview, these are however exactly the same kinds of skills, the same kinds of social services that are needed not just by the mentally ill aged, but by most aged. And so the problem of whether or not you have to put people in the mental health track in order to get needed services, while they are so scarce, and so unfortunately to mislabel them, when perhaps they need not have been in the mental health track at all. The other side of the problem is when you have a patient, such as our patients at St. Elizabeths who do need social services—they are not like Mr. Donaldson, they cannot make it alone in the community—they have to have help, and they need to stay in the mental health track longer than necessary because needed social services do not exist outside. This points to an enormous problem that this subcommittee has; that is the interface between the so-called mental health services and the broad social services that all aged need.

We feel far fewer aged would be in the mental track system if these other social services were up to par.

We are often asked if we can justify our priority in trying to establish constitutional and legal rights to scarce treatment for mental patients, because indeed that may result in the misallocation of scarce social service resources to this segment of the aged, when they all need it.

To begin with we are lawyers concerned with the constitutional and legal rights of client-patients, and fortunately, unlike you, we do not have to legislate and plan in the general welfare area. But I think there are better reasons, and one of those is that the aged elderly, who are put and labeled into the mental health track, have a double burden to bear.

They bear not only the actual physical and mental pangs of old age, but they also bear the stigma of mental illness as well, and many of the best community resources are closed to them.

Model Program for Aged People

Many private home operators just will not take mental patients. Hence we think a little bit of exceptional advocacy on their part is justified. The second justification for our prurity is that we hope some of our lawsuits will develop and create a community-based system, along the lines as I have said before, which will not be exclusively medically and psychiatrically oriented, but will contain all of the kinds of social, recreational, personal care components that will provide a model for all aged people, and not just the mentally ill.

Finally, I just want to touch on some of the very practical problems that we have personally encountered in financing, and monitoring community care for individual patients, and in beginning even a preplanning stage for the development of such a system.

The first point, and obviously a critical one, concerns some of the funding gimmicks in the present State and local systems.

Our experts tell us, for instance, that there are people who are genuinely in need of some physical care who do not belong in nursing homes, and would be better off in a large number of relatively small homes like normal settings; these people do not need specialized medical care, but they do need a lot of extra services, perhaps on a regular, perhaps on an occasional basis, things such as occupational therapy, recreational therapy, transportation to and from social and recreational programs.

We found that the rate of suicides among mental patients is highest for those who spend their time alone, in isolated room and board facilities, who do not have a very normal socialized existence, more or less structured or planned for.

Now, the only place we can find money for those kinds of outside services, training, transportation, even home health services, is in title XXI; this is the kind of money which theoretically would provide for ombudsmen to police the alternative care system, companion assistance, all of these kinds of services. Unfortunately, the furious scramble for title XXI means that in our experience very little is left for this kind of service, and as a result, we feel too many people compete for the few nursing home slots there are who do not really need that level of care, if an adequate program can be found for them in a lesser facility.

REDUCTION OF SSI CHECK

One of the other gimmicks we found is, despite the Supreme Court's emphasis on releasing people like Mr. Donaldson who are capable of surviving in the community with the help of willing friends and family, we have provisions in some of our social security laws that say that if you go to live with one of those willing relatives, your SSI check is reduced by one-third.

I realize there is some theoretical economic basis for that, but I wonder if it is in accord with a policy which wants to put aged people in their own homes, or with people who have genuine interest in them.

Some of the other problems are very familiar with the subcommittee, and I will not go into them; the definition of an institution, which we think now is too rigid—I believe in the social security laws, it is four or more unrelated persons receiving treatment or services beyond food or shelter—that means many bona fide community homes cannot take care of people who are dependent on social security payments, because SSI payments cannot go to pay for institutional care.

Also, public contributions to community homes are often counted as income for SSI income eligibility criteria, another squeeze play for old people.

We also found it takes so long for people to get their benefits, that they are caught in a "Catch 22" situation.

We have seen this actually happen. Under the present social security benefits, you can apply for, but you cannot receive, your check until you are out of the institution, but many people need the check to pay for their rent, so they have a place to go when they get out of the institution. What happens, is that they can neither get the check, nor pay the rent; they are caught in this "Catch 22" situation. We know of a released paraplegic who for months wandered from relative to relative until the check could finally get processed.

We have also encountered what Mr. Donaldson referred to, the problem of the way social security representative pay provisions are interpreted.

These are provisions which are quite apart from any judicial findings of incompetency and are determined by the social security authorities, that is somebody is not able to receive and dispense their own funds, thus many people emerging from the hospitals find that either the proprietor of the nursing home, or the hospital, still doles out their money, and decides how it can be spent.

I might add that there are a number of legal challenges to both the substantive and due process aspects of the representative pay provisions going on around the country.

COHERENT PROGRAM NEEDED

My bottom line is that with all of the Federal moneys going into mental health care, and the social security moneys going into the support of people who have mental problems, that there ought to be a more coherent program which insured that those moneys are used to bring about the kind of mental health care that we care so much about.

My last point involves some of the problems in monitoring the quality of care in the community.

Obviously, it is harder to monitor hundreds of small facilities than one mental hospital. Heaven knows, it took us years to even begin the monitoring process on the State mental hospital. The District of Columbia has 350 personal care homes of six patients or less. Some of the problems leading to substandard conditions are inadequate training of home operators, misplacement of patients who need more skilled care and services and vice versa, no standards for foster care homes, no centralized placement service for patients who need different kinds of facilities, there is no agreed-upon definition of who should go into different levels of care, but most important is the lack of facilities and money to buy slots in those that exist.

The suggestions are numerous, and we do not have any monopoly on the right ones. Some of the ones we are looking into are central licensing and inspection services for all facilities, so that some kinds of community care facilities do not fall between the cracks.

Centralized placement services, which are manned by interdisciplinarians—both lawyers and mental health people—will assure that the different needs of the aged, with different skilled personnel, et cetera, are met.

We also believe in certain legal minimums for all residential facilities in the community; there should be a so-called patient's bill of rights, to which all facilities have to adhere, so that we do not have people, as in one of our cases, locked up in their room, not able to see visitors, with communication with the outside world cut off.

A critical point is to make these facilities accessible and open, not just to the public inspectors on their annual or semiannual visit. We would like to see a mobilization of community people, whether it is the Gray Panthers or other groups which actively go out, visit the people, see them, keep in touch with the public officials, so that we have an active, ongoing kind of monitoring service, and, finally, we think that the problems of the aged, and especially the mentally ill aged, require a patient advocacy service, which is made up of both specially trained lawyers and good mental health professionals, so that they can have a ready source of expertise, for the multitude of problems that beset them both in mental hospitals and out of the community.

Now Ms. Marker is very briefly going to translate theory into practice in relating the very genuine problems of a case study of one of our actual clients.

Senator MOSS. Ms. Marker, we are glad to hear from you.

STATEMENT OF GAIL MARKER, M.S.W., SOCIAL WORKER, MENTAL HEALTH LAW PROJECT, WASHINGTON, D.C.

Ms. MARKER. Before I begin, I would like to note that Mr. Donaldson has described what conditions are like in many of our large State mental hospitals.

I would like to take a few minutes to describe what conditions are frequently like in what we euphemistically call "alternatives" to these hospitals, and I would like to tell you specifically about what happened to Bill Dixon, a named plaintiff in the case of *Dixon* v. *Weinberger*.

Last week we went out to St. Elizabeths Hospital to read to Mr. Dixon that part of the testimony which applied to him for his comments and approval. We also informed him about the general nature of the rest of the testimony we will be giving today. I wanted this subcommittee to know that although Bill Dixon is not physically present at these hearings, and although he is sitting out on a ward at St. Elizabeths Hospital, he is here in spirit, and he greatly appreciates the concern of this committee to hear not only about his plight, but about the thousands of patients like him.

Mr. Dixon is a 65-year-old involuntary patient at St. Elizabeths Hospital who is confined to a wheelchair. Like Mr. Donaldson, he is a gentle, intelligent, sensitive man. He has been hospitalized for 23 years.

In 1952 he was transferred to St. Elizabeths from a general hospital because he was confused, disoriented, and depressed.

From 1964 to 1972, he spent most of his life in foster homes in the District of Columbia. During those 8 years he was periodically returned to St. Elizabeths for treatment of problems relating to his physical condition.

When he was returned to the hospital in October 1972, he expressed a strong interest in going to another foster home as soon as possible, but was concerned that it be a good home.

"ISOLATED AND SHUNNED"

In his last placement, he had spent most of his time sitting alone in his room. He felt isolated and shunned. He was confined to the second floor of the home—a clearly dangerous situation, since he was in a wheelchair.

We first met Mr. Dixon about 3 years ago on a ward at St. Elizabeths. He had been referred to us by the Public Defender Service at the hospital.

He told us that he desired to leave the hospital and we agreed to represent him in these efforts. In checking his hospital records and talking with the staff, we learned that Mr. Dixon had been repeatedly recommended for outplacement by his doctors in a suitable foster home which could accommodate wheelchair patients.

In May 1974, 3 months after the lawsuit of *Dixon* v. *Weinberger* was filed, Mr. Dixon was placed in a room and board facility in Washington, D.C.

On July 5, 1975, we visited him at this facility. Ms. Susan Opdyke, a social worker from the public defender service at the hospital, accompanied us. The conditions we found at this facility or which Mr. Dixon told us about, were unconscionable.

Mr. Dixon's sleeping room was about halfway below ground level. There were two exit doors in his room—both were closed. The only windows in the room—which were located at or slightly above ground level—were also closed and had a glass plate in front of them, making them difficult if not impossible for Mr. Dixon to open.

They appeared to be painted shut. There was no fan or air-conditioner in the room and although it was only 10 a.m., the room was already hot and stuffy.

Mr. Dixon did not have a phone in his room, nor was there any phone on his floor. There was no buzzer. We do not know how he would have contacted anyone if there were a fire or other emergency.

In fact, we tried to call Mr. Dixon at this outplacement on July 3, 1975, and were told by the operator that it was not a working number.

Irregular Serving of Meals

At the time of our visit, Mr. Dixon had not been served any breakfast, although he had been out of bed since 7 a.m. He stated that mealtimes were usually irregular and that sometimes he would get so hungry waiting for lunch he would ask a roomer to buy him sandwich meat and bread.

He could remember having only one glass of milk during his whole stay at the facility, which lasted 6 weeks, and virtually no fresh fruit.

Senator Moss. What time were you there?

Ms. Marker. I arrived at quarter of 10, and I stayed until about 12 o'clock.

When he first went to the facility, all of his meals were served to him in his sleeping room. After he objected, he was allowed to eat in the kitchen.

The bathroom on Mr. Dixon's floor, which was located near his room, was small. He did not have ample space to maneuver his wheelchair to use the toilet, bathtub, or washbasin. He could not close the door for privacy. He had so much difficulty, he said, that he was only able to take two baths in all the time he was there.

Mr. Dixon did not have any laundry facilities available to him, nor were provisions made by the home operator for regular washing of his clothes.

For the first 2 weeks at the facility, he had to stay in dirty clothes because he didn't have any extras. His sheets were changed twice during his 6-week stay. He was given one towel and one washcloth which were never laundered while he was there.

There was no area of the facility accessible to Mr. Dixon where he could go to leave his sleeping room other than the bathroom, the small kitchen, or the narrow corridor. There were virtually no recreational or diversional activities available to him even in his sleeping room including cards, TV, magazines, and books. As Mr. Dixon told us: "I was like a prisoner in my cell."

In short, not only did the facility fail to provide a therapeutic environment necessary for Mr. Dixon's continued rehabilitation, it did not even provide for his basic subsistence needs, including adequate nutrition, personal hygiene, and health.

Consequently, on the same afternoon of our visit, Ms. Opdyke contacted the hospital staff, described the conditions we had found, and strongly urged that Mr. Dixon be promptly returned to the hospital. He was returned that evening.

ONE VISITOR FROM HOSPITAL

The hospital social worker who arranged the placement accompanied Mr. Dixon to the facility. To the best of Mr. Dixon's recollection, she never visited him again at the facility, despite his telling her that he did not like the facility and that he wanted to go back to the hospital until a better place could be found. Only one other person from the hospital visited Mr. Dixon during his entire 6-week stay, and he came only once.

When he saw Mr. Dixon several days later on his hospital ward, he expressed mixed emotions about coming back to the hospital—he recognized that the conditions in the outplacement were deplorable, but also realized that he had been free of the mental hospital.

Mr. Dixon is still on this same hospital ward today, waiting to be outplaced.

In his 1974 psychiatric evaluation he is described by his doctor as "alert, coherent, cooperative, personable. He is seen to exhibit significant inertia, but his usual apathy and inertia are seen to be quite understandable for a man who has been waiting over 16 months for community placement."

According to an assessment by the hospital superintendent, there is a "significant risk of emotional and/or psychological deterioration" because Mr. Dixon cannot be placed in the required alternative facility and his stay in the hospital is prolonged.

Mr. Dixon's situation is not unique. Hundreds of thousands of patients in this country are placed in the same dilemma—they must either live in a mental hospital or in a substandard community-based facility.

They have no choice—provisions have not been made for a system of adequate mental health care services. But it does not have to be this way.

It presently costs about $24,000 a year to keep Mr. Dixon in St. Elizabeths Hospital. It is hard to imagine that he could not receive the services he requires for a great deal less. Since Mr. Dixon does not have psychiatric or medical problems which require active intervention, these needs could be probably best met on an as-needed basis, although he should be examined once a year to insure his condition does not deteriorate.

LITTLE OPPORTUNITY FOR SOCIAL CONTACT

Since he is confined to a wheelchair and has little opportunity for social contact, he should be provided with appropriate and diverse recreational activities on a regular and frequent basis, preferably outside his residential setting, that is, in a community recreational center or in a senior citizens program.

He should be taught how to maximize his ability to care for his personal needs and how to become more independent in his wheelchair, both in and out of his residential placement.

He should be evaluated for physical therapy, although these services might best be provided within the framework of his recreational program.

He should be seen by a social worker at least every 2 months to insure that his total treatment needs are being adequately met. And above all he should be placed in a small, homelike residential setting which can physically accommodate his wheelchair and which provides an atmosphere where he can regain the skills and dignity he has been denied for 23 years.

Experience has taught us that many patients are not as lucky as Kenneth Donaldson. They cannot be released outright but require ancillary, transitional, and sometimes long-term care to help them live as normal a life as possible.

If Bill Dixon and other patients like him are to survive outside of mental hospitals, we must come to grips with the day-to-day survival problems they face and must recognize that their needs go far beyond purely psychiatric and medical services.

We must construct comprehensive systems which provide for the careful evaluation of the client as a total human being and which carefully tailor the critical service areas, daily living activities and personal care, residential, recreational, social, vocational, social work, restorative, medical and psychiatric, to the needs of the individual.

And, most important of all, we must provide the necessary fiscal resources which, first, give a high priority to training nonprofessional mental health manpower; second, maximize the use of sophisticated and specialized staff and services, such as those which should be found in inpatient psychiatric hospitals; and third, give as high a priority to residential, recreational, social, vocational, and daily-life training programs as they do to psychiatric and medical services.

The substantive and legal issues represented by Mr. Dixon's case are slightly different from those of Mr. Donaldson's, but one thing is clear: Bill Dixon and the thousands of patients like him are the Kenneth Donaldsons of the future.

COURT DECISION BRINGS HOPE

As Mr. Donaldson stated shortly after the Supreme Court issued its opinion:

> . . . It is such a tremendous victory that the full import of it has not yet sunk into my being. But already the court decision has brought hope to others. I hear of it on every side . . . .

We urge this subcommittee and this Congress to take the necesary steps which will help realize this hope for all Bill Dixons.

Thank you.

Senator Moss. Thank you very much, Ms. Marker. That story is sordid, and one wonders how it could come about.

Is this place where Mr. Dixon was taken a licensed home of some sort?

Ms. **Marker.** It was a room-and-board facility. It is not a foster home. It does have to meet certain requirements, which are held at very, very minimum, just the normal housing requirements in the District of Columbia.

Senator Moss. I was wondering why a social worker would bring Mr. Dixon to a place like this, where they had no services provided for him.

It was shocking indeed that this type of a thing can happen. Little wonder you say he was dejected and did not want to stay.

Mr. Heineman, is the right-to-treatment litigation widespread? Are there a lot of cases being brought?

Mr. **Heineman.** There are a fair number, Senator.

I think the Justice Department will probably discuss later in the morning the number of cases brought by the institutions section of the Civil Rights Division. That section is bearing a heavy load. And litigation is very necessary. But although we are litigators, and we think litigation is critically important, we really want to emphasize here the limits of litigation we are talking about. In our cases we seek establishment of constitutional rights, so that people are not involuntarily confined in substandard conditions. But obviously the Constitution can only do so much, and the real task for society is providing the right kind of care. Basic responsibility for achieving that goal must rest with the legislature.

Senator Moss. I was wondering if the litigation intruded on the exercise of proper discretion by mental health professionals; do you think it does?

Mr. **Heineman.** We do not think so. Properly conceived, we do not believe it does.

PATIENTS BEING TREATED "BELOW FLOOR"

Again, what we are trying to do is establish a decent floor under involuntary patients—and I think most responsible professionals could agree as to what that floor is. I think they could also believe many of the patients are being treated below that floor in the basement, and the way to determine constitutionally required treatment is to look to reasonable and responsible practice in the medical and other related professions, and to define the constitutional right in that way. Even when you define it that way, and give professionals latitude and discretion, many situations fall outside of the reasonable range, the responsible range for services.

Ms. **Wald.** In many of the cases, we found the so-called defendants were all on the same wavelengths, and many of them have been fighting for years for sufficient appropriations for decent institutions. But they have lost, and in our experience, many times armed with a court decree and saying you have to hire so many people, they are able to get new moneys to infuse into the system.

I think this happened down in Alabama. It happened in here in the District, in the special education field; there are millions more in that field since the Mills court decree, which says you have to educate those handicapped children, so there is a valuable use of the legal decree in different arenas, such as the legislative. I think on balance, in our experience, it has been more useful than detrimental, though I admit it is annoying for them to have to live under a court decree. I am well aware of that, and they are too.

Senator Moss. You say there is more money now showing up though in the social arena?

Ms. Wald. I am speaking of isolated instances, where I know that litigation has brought that about. I have not made a study to examine the consequences of every case, but that is our experience.

Senator Moss. Is the real problem with Mr. Dixon his lack of money?

Ms. Marker. No, Mr. Dixon has his own social security—he gets over $200 a month—so that is not a problem in his case. This placement cost $150.

Mr. Heineman. While I am on the subject of financing, although new moneys may be required, I think one of the things that really should be explored, and may be explored in some of this litigation, is restructuring current budgetary patterns.

Careful Examination of Budgets

We are not saying dismantle the hospital. We are not saying end the 24-hour psychiatric hospital. We are saying a careful examination of the budgets of those hospitals should be undertaken and some of the money might be used in different ways, while retaining the best hospitalization has to offer.

Mr. Donaldson. I would like to add, while I was in Florida, the HEW money was going into the State's general funds, and it was not given to the hospital.

Senator Moss. Are you saying that the Federal money that came in was taken by the State and not sent on to the patients, or to the hospital?

Mr. Donaldson. That is right. They figured that was just a rebate on what they were doing.

Senator Moss. What about the problem, Ms. Wald, of commingling mental patients, with those who have physical disabilities; is that a problem?

Ms. Wald. I think it certainly can be a problem. Our present feeling is that. for instance, we know several of our plaintiffs in the St. Elizabeths cases, including Mr. Dixon, can get along very well on the basis of a normal social system with other elderly people. As I pointed out in our testimony, 75 percent of the elderly people in nursing homes have mental symptoms of some sort. But of course there are situations where you do not move somebody with active paranoia delusions into a facility with physically ill patients, where there is any problem of danger to physically handicapped patients, where there is any problem of assault. So I think you have to have careful, sensitive people making that decision, but I think it would be wrong to say anybody who has come out of a mental hospital cannot be put into a community facility with nonmental patients.

One of our other patients, not mentioned by Ms. Marker, was on an outpatient status, went back to the hospital for his medication, and was assaulted on the hospital grounds by another patient, and thereafter suffered a stroke—whether it was causal or not is probably undeterminative—but my point is you have many of the same problems inside the hospital setting as out.

I would not exclude mixing as a general rule, but I would certainly be cautious about the criteria.

MEDICATION GIVEN INDISCRIMINATELY

Senator MOSS. Mr. Donaldson, in your written statement, you say that medication was given indiscriminately by the doctors to the patients who sometimes had not been seen by a doctor for months or even longer. How does the doctor know what to prescribe? What was the prime objective of this medication?

Mr. DONALDSON. It is hard not to be facetious when you answer that question, but I think they did it with some kind of guessing.

Senator MOSS. Was it primarily tranquilizers?

Mr. DONALDSON. That is all. There are the so-called long-term wards, and that is the only treatment that was given.

They gave electric shock treatment in the receiving wards, but not the long-term wards. Most of the patients were in the long-term wards.

Senator MOSS. Has that practice increased recently? Has there been many changes in tranquilizing?

Mr. DONALDSON. Any change in it—in the amount of tranquilizing?

Senator MOSS. Yes.

Mr. DONALDSON. I would say no.

Senator MOSS. It has been going on for a long time?

Mr. DONALDSON. That is right. They found out—I have not had time to read everything in the field, but doctors have found out that if one tranquilizer will not do it, two will knock a person out, that is why they give them two, and the idea is to keep them so tranquilized that they cause no housekeeping problems.

There is nothing scientific to it beyond that. I say these people do not need any medical treatment.

That is my observation, and over 15 years, I know I probably have brushed shoulders with 10,000 people on the various wards, coming and going, and I actually know of three that were schizophrenic during that time, who really needed some kind of care, who were afraid to go out in the free world. But the rest of them were no different than you and I are, except that they have been beaten down. That is all.

Senator MOSS. Now, you said you refused medication because of your basic belief?

Mr. DONALDSON. That is right.

Senator MOSS. Is that what enabled you to keep your health and alertness as contrasted with some of the others?

Mr. DONALDSON. Yes, sir. That is what enabled me to live through the experience.

Senator MOSS. Senator Domenici.

SERIOUS INDICTMENT OF SYSTEM

Senator DOMENICI. Mr. Chairman, needless to say, the testimony to this point has caused me a great deal of personal concern.

I have not heard in my 2 years and 9 months in the Senate of a more serious indictment of our system than I have heard here. I do not think you intended it to be that, but rather to lay it out as it is.

I wonder if you would have just an opinion for me. It appears to the lawyers, at least, that you have gotten involved in this issue, and now see a lot of things we ought to be doing that are legislative policy matters. Certainly these are issues that you are not going to entirely solve in the courts. It comes to me, as I listen to this, that I would just suspect that we have the same set of facts with reference to the commitment of young people who are so-called mentally retarded, or mentally deranged, because that has been sort of a thing that has been developed. Do you have any views on this problem, although that is not within our purview, as we deal with the elderly, but could you comment on that?

Ms. WALD. Yes; there is a comparable set of issues. Obviously, they are slightly different, because of the disability and the age. In fact, the mental health law project has been actively involved in the problems of institutionalization, and the proper community-based kinds of resources, for retarded people and youngsters.

We participated in the *Willowbrook* case, which ended in the consent decree signed by Governor Carey some months ago. It is a 50-page consent decree, and very onerous reading, but within those pages there are some very new and important concepts.

One is a requirement for phasing out over a period of several years a large portion of the people in the retarded institution into suitable community facilities, with a review panel set up to look at both the discharge criteria and the facilities into which they go. It is the beginnings of an attempt to get the right kind of monitoring system.

This general idea of normalization, which has taken over many of the social areas, not just the aged, but the juveniles and the retarded, of trying to get people to live up to their maximum potential to cope and survive in a normal environment, is now one which is a prevailing principle in that field.

I think we on the legal side and you on the legislative side are going about it in the same way, but basically, legislatures can do much more to implement it than we can.

We see our role trying to establish a baseline, trying to be another push, another catalyst in the direction of setting up the right kind of system, but you are absolutely right, there is a whole set of issues very parallel in that field.

PROBLEMS NOT SOLVABLE BY COURTS

Senator DOMENICI. Let me give you one more observation. Obviously, as you move through the courts, trying to establish constitutional limits in this area—I think, Mr. Heineman, you have almost admitted that obviously a number of the problems you have discovered are not going to be solvable by the involvement of the courts.

There are some other issues involved. We are going to get down to the point where you have the constitutional issues, and yet you still have a lot of problems. You may not have 15 years of litigation for the kind of person we have here.

Would you care to express the kind of shopping list of what you find we ought to be doing, as a Congress—some kind of immediacy of legislation, as you see it, either to effectuate the constitutional right to establish, or otherwise?

Mr. HEINEMAN. I can only speak generally to this point. We are talking about standards for a mental health system, not just for institutions, not just for the mental hospitals. The hospital has been the focus in the litigation.

The nursing home scandal has shown the problems of the nursing homes. We have to deal with both problems together. We have to realize they are part of the same system and, as Ms. Wald said, we have to see the relationship between the total mental health system and other social service systems.

To the extent the Congress can give guidance via financial incentives to the States to deal with these problems comprehensively, I think the Congress must act.

I think the limits of litigation are that the courts cannot administer the systems, they cannot plan the systems, they should not really budget the systems. They can only provide the prods and say: "This is the constitutional right; you have to meet this at a minimum."

Congress could tell the States: "There should be a comprehensive mental health system with planning turned out at the local level." The Federal planning incentives would be the prod.

"CONTINUAL HASSLE" OVER REGULATIONS

Ms. WALD. I would say one thing in the community field, about the number of Federal programs which somehow come into the picture, be it medicaid, medicare, SSI, and the variety of regulations and conditions which apply to each type of recipient and facility resulting in many discrepancies. I think if there were some mechanism whereby a look could be taken at the total pattern of Federal funding, including the SSI input, and see whether or not there are things in there, if you have a goal, or a vision of what a proper mental health care system is, that are either impeding that or encouraging that, so that it becomes a consistent pattern, the funding partly becomes consistent with your goal, and not a continual hassle to get out of one regulation into another.

If you improve nursing homes, people going into nursing homes will be better off, but you will find the system will bulge someplace else.

You will get more people into the unregulated homes, and unless the system is looked at in terms of what you want to come out of that system so it makes a coherent whole, every time you plug up one part, your abuses will show up in another part.

Senator DOMENICI. And I would assume in your research and preparation you might even go beyond the mental health treatment field here and say that permeates medicare and medicaid in terms of its categorizing, and in not being flexible, thus creating as many problems as it solves, or costing far more than what it does—than it could—and could do more things, you come to that also would you say?

Ms. WALD. I would think so, although, our experience tends to be confined to the mentally ill aged.

Senator DOMENICI. Thank you very much, Mr. Chairman.

Senator Moss. Thank you.

I have one final question that I wanted to ask of Mr. Heineman. In your statement, you said: "Finally such a plan would build on the perception that many existing alternatives to 24-hour hospitalization are alternatives in name only." And you go on to say that nursing homes may offer a poorer environment than mental hospitals. I would like to know, is that based on your personal observation, or does that come from research or hearings that have been published? How do you get that characterization?

ALTERNATIVES—SUBSTANDARD OR NONEXISTENT

Mr. HEINEMAN. Both sources, Senator. Ms. Marker, who has worked with the patients, has been in the District of Columbia talking with people about this particular suit, and she has learned that the alternatives are not there. And the ones that are there are substandard.

In fact, as I mentioned before, the hospital itself has nearly 1,000 patients who it would like to put out in the community—that the staff thinks should be in the community for their own good. And yet in the District of Columbia, the facilities are not there.

They either do not exist, or they are substandard, and that is the view of the defendants, of the hospital itself, so it is those sources that lead us to this conclusion.

Senator Moss. Do you concur with that, Ms. Marker?

Ms. MARKER. Yes.

Senator Moss. You do?

Ms. MARKER. Yes.

Senator Moss. That is fine.

This is one of the recurring problems that this committee is trying to deal with. We hope to be able to find an answer.

Well, we do thank you very much for appearing as witnesses here. You have helped us a great deal with bringing this testimony to us, and I am grateful to all of you for being with us.

Mr. HEINEMAN. Thank you very much.

Senator Moss. Your full statement will be made a part of the record; it is very comprehensive, and very well prepared.

We do thank you for your fine contribution.

[The prepared statement of Ms. Wald follows:]

PREPARED STATEMENT OF PATRICIA M. WALD

RELATIONSHIP BETWEEN THE MENTAL HEALTH SYSTEM AND OTHER SOCIAL SERVICES

Our experience has been that many aged patients in mental hospitals are indistinguishable from those in other community based facilities such as nursing homes. In both cases, these elderly people present a combination of physical and mental symptoms; very often the mental conditions are not the most prominent disability they suffer. Quite often, where they are is an accident of what alternate resources are available instead of the mental hospital, and what their relatives first choice was. Almost any disabled elderly person can satisfy a mental commitment criteria that he or she is "dangerous to himself" if left unaided.

Studies have shown that the decision to admit a person to a mental hospital is not as much related to the severity of his presenting symptoms as to whether alternative community resources or relatives are available (Mendel and Rapport, 1969). Statistics indicate that although the number of aged in mental hospitals is decreasing, the number in nursing homes is increasing, and up to 75 percent of aged residents of nursing homes have symptoms of mental illness (HEW Statistical Note 107 (NIMH)).

One of the most difficult practical problems, therefore, is to decide who among these multidisabled elderly persons belongs in the mental health track and when they should leave it. The goal of the mental health system is to "enable the patient to maintain himself in the community in a normal manner" (Action for Mental Health, Joint Commission on Mental Illness, 1961) ; this means training and equipping him with the social and survival skills he needs to live in the community (APA, 1971; Gittleman, 1974) which are atrophied by prolonged institutionalization.

Training in basic social skills such as feeding, bathing, dressing oneself, taking public transportation, budgeting one's money, getting along with others is as essential a component of a patient's treatment plan as therapy or drugs to remit pathological symptoms (Paul, 1969). These skills can seldom be taught or learned in the hospital setting (Fairweather, 1969; Weiman, 1970). Community based programs aimed at resocialization in general have proved more efficacious than hospital based programs (Weiman, 1970; Marx, 1973; Stein, 1972). Studies have shown that in general the environment to which a hospitalized mental patient is returned, the amount of support he receives in that environment and the amount of stress to which he is exposed are the main determinants of whether or not he will be readmitted, rather than the kind of treatment program he receives while in the hospital (Fairweather, 1964; Graham, 1974).

"INSTITUTIONAL NEUROSES"

We are sure the committee is by now familiar with th crippling effects of over-institutionalization; there is, in fact, an identified and diagnosable condition known as "institutional neuroses" which is apt to set in around 2 years after a patient is admitted which compounds his original disorder. This syndrome reflects itself in a patient's apathy, dullness, passiveness, solitariness and in his decreasing ability or desire to control his own destiny. He now has two diseases instead of one (Barton, 1977; Goffman, 1961). "Institutional neuroses" can occur not only in back wards of State hospitals, but in understaffed nursing homes as well.

The major thrust of the evidence is that living in an institution has harmful physical and psychological effects upon an individual, whether young or old, and regardless of the particular characteristics of the population or the unique qualities of the total institution (Prock, 1969).

Our aim, even with our elderly patients, is to insure that they receive the kind of treatment in the right setting which will assist them in regaining social competence. At that point they should be discharged from the mental health system. It may be, of course, that they will need to be picked up by other social services to continue the kind of housing or personal care assistance that aged persons typically need. The point, however, is that we need a much more intimate interface between our mental health tracks and our other social services than now exists, so that patients whose most pressing needs are social and economic are not needlessly "dumped" into the mental health track and patients who are recovering from mental problems but still have social needs will not have to stay in the mental health track to get the services they need to survive.

All mental patients need individualized post-hospital treatment or aftercare plans that evaluate their needs in the following categories:

(a) A safe, comfortable, and hygienic physical environment consistent with any physical handicaps the patient has: wheelchair, walker, inability to climb stairs, poor motor coordination. Fire hazards, ventilation, location of bathroom, proper heating have to be considered; the safety factor must also take some account of the neighborhood. An older person may be just as imprisoned and isolated in a high crime neighborhood where he or she cannot walk unmolested or use public transportation as in a rural mental hospital.

(b) A humane psychological environment where the occupant has personal privacy in sleeping and bathing, the right to control his personal possessions, to call and write freely, to entertain visitors, to the extent of his ability move about in the community. The size of the facility comes into play here—is it homelike, normal, or is it cold, impersonal, institution-oriented?

(c) Sufficient nutritious and attractive meals to provide for the patient's physical and social needs. Food means a great deal to the elderly; it has to substitute for many of life's other pleasures.

(d) A structured daily program of activities consisting of social and recreational opportunities; outside the living facility if possible, and possibly full or part-time employment or sheltered workshop experience so as to cut down on idleness, provide a sense of social usefulness and even additional income. The value of work in a person's life does not cease with age and should be cultivated assiduously. If an older person is bedridden or confined to a facility, provision for regular visiting by a "friend" and socializing outside his room.

(e) Specific help and training, where necessary, in coping skills—learning how to manage their own checking account and to take buses to see friends or visit spots of interest; how to use the telephone in emergencies; housekeeping, preparing meals, sewing, shopping; to take one's medicine. The corollary to this is help on a regular or special need basis in daily living activities to the extent it is needed, i.e., help in bathing, in grooming, in moving about, in taking medication, in summoning emergency help.

(f) Medical and psychiatric care, to the extent needed, i.e., regular checkups by a doctor, weekly visits by a visiting nurse, a program of physical therapy, personal counseling.

(g) Opportunities for the aged person to make meaningful choices and exercise autonomy—in how to spend money for recreation or pleasure, in how to spend his time, in where to go, what friends to pick.

(h) Perhaps most meaningful of all, some one person who is continually concerned with his welfare to see that all of these components of his treatment package come together and to whom he can confidently turn in times of trouble, depression, and crisis. It can be a social worker, a community advocate, a family member or friend.

IMPLEMENTATION OF LEGAL RIGHTS

There is, however, another facet to the definitional problem of who should be in the mental health track. That is how we can justify priority in the allocation of scarce economic and social resources to those aged who are in the mental health track. For this could be the result of lawsuits such as *Dixon* which compel adequate quality residential treatment and attendant social services for patients leaving the mental hospital. We might say first off that we are lawyers concerned with the implementation of legal rights, and so we inevitably focus on the necessary relief for our clients when those rights have been violated. Our focus is thus a narrower one than social planners or Congressmen obligated to legislate for the general welfare. Nonetheless, we do not apologize for this focus. If the Constitution and our laws are to mean something for the aged, their rights under these laws and constitution must be vindicated, even if vindication raises questions of overall resource allocation.

But aside from this important consideration, we think there are several sound policy reasons for developing an adequate network of residential and social services for mental patients in the community. First, patients coming out of mental hospitals have traditionally been most discriminated against in the allocation of alternate care spaces in the community. Many private home operators or proprietary nursing homes refuse to take them at all. The segment of older people who have been saddled with the label of mental illness as well as the actuality of physical and mental deterioration have a double load. Exceptional advocacy on their behalf can be justified on the basis of their past discrimination and present double handicaps. Second, the development of the kind of community service network we envision for our patients will benefit other aged as well, for it is not exclusively or even primarily medically or psychiatrically-oriented one, but rather a treatment system that stresses the learning and reacquistion of social and survival skills that allow a person to cope with the stresses of everyday life, that "normalize" his existence to the maximum extent possible, and that encourage independence, activity and meaningful choices about his own life. This is a model replicable not just for ex-mental patients but for all aged persons and the financial and planning assistance that goes into its development to meet constitutional and legal obligations to the mentally ill will result in use and benefit by other elderly persons as well. We believe that too many elderly persons are now consigned to nursing homes because of the lack of other less medically oriented but high-quality facilities and an efficient social service network that can provide the regular or occasional help they need. If we can help to mandate the creation of such a diversified system for our clients, we would assume it will prove its worth for non-mental patients as well.

FINANCING AND MONITORING A COMMUNITY CARE SYSTEM

This committee and others have already documented the human tragedies of inadequately staffed and structured nursing homes, of substandard personal care and independent room and board homes where the old people or mental patients are "dumped." Our legal efforts are as much targeted at these conditions as at the over-institutionalization syndrome in mental hospitals. It has been said that economy-minded State administrations "dump" to save money; State hospitals cost $800 a month on the average ($1,930 in the District of Columbia), while residential care boarding homes (especially unskilled ones) cost much less.

Only 8 out of 44 States responding to questionnaires planned to close up mental hospitals in the foreseeable future; several States planned "modifications" in their mental health systems (Future Role of State Mental Hospitals, 1975). The District of Columbia does not have as strong an economic incentive to deinstitutionalize as other States; the District of Columbia government pays only $780 of the $1,930 per month per patient cost at St. Elizabeths Hospital. HEW pays the rest.

FINANCING PROBLEMS

There is little doubt but that the kind, quality, and level of community facilities available reflects State, local, and Federal funding. Perhaps it is time for a reevaluation of where the present State and Federal financing patterns lead. We are surely not as expert as your committee in Federal funding patterns, but in our lawsuit to provide alternate community care, we have encountered the following obstacles to adequate placement of patients in the community:

(a) There is always a hassle as to who will pay for the social services—counseling, training in coping with daily living skills, transportation to social and recreational centers, home health services, when a patient lives in a nonmedicaid private or foster home, group home, or halfway house. Title 20 funds are traditionally available for such programs but the demands on them by all needy groups in the community are so furious that few are actually available to pay for these services for the elderly. There is rarely money for lay advocates, ombudsmen, to police the alternate care system for personal care and companionship assistance for the elderly. Nonmedical living arrangements consistent with humane environmental and quality standards have to be encouraged—not discouraged—by Federal and State payment programs, and this means financial provisions have to be made for the kind of occasional or regular personal care, medical, psychiatric, social, and even legal services aged persons need in such homes. As it is, skilled nursing homes and medicaid eligible ICF facilities are being deluged unnecessarily by applicants who don't need that level of care because funding is not available for specialized human services for residents in personal care and group homes. Title 20 money which the States control doesn't appear to be enough, and although medicaid money is available for home health service, up to now it has not been widely utilized for this purpose. Proposed medicaid home health care regulations were finally promulgated on August 21, 1975.

(b) Relatives or friends who take disabled persons into their homes are financially prejudiced under present Federal funding schemes. Although the hallmark of *Donaldson* is a mandate to release all persons "capable of surviving with the help of willing friends and family in the community"—an SSI-eligible individual "living in the house of another" has his or her check reduced by one-third.

(c) There is an abiding principle in the social security system that Federal benefits may not be paid to a resident of an institution, on the grounds that such persons are traditionally the State's responsibility and Federal funds should not be used to subsidize institutionalization. Yet the definition of what constitutes an institution so that its residents are ineligible for social security payments is now so broad that it encompasses many bona fide community-subsidized group residences. (*See, e.g.*, 248.60 C.F.R. 45, 248.60(b)(1), 4 or fewer unrelated persons receiving treatment or services beyond food or shelter.) Residents in publicly funded group homes and halfway houses suffer because the public contribution toward such facilities (which we all want to encourage) is added to the resident's income so as to possibly disqualify him from SSI eligibility. Minimally, the definition of an institution ought to be modified to exclude a residence housing 15 residents or less where they go and come as they please and where they do not receive regular medically oriented care. The Church amendment has already excepted private nonprofit contributors that subsidize such facilities from being counted in income eligibility for group residents. Public contributions should enjoy similar exemption.

(d) Aside from the definition of who is an excluded institutional resident, we found it takes so long for institutionalized residents about to be released to get the SSI benefits that they often cannot pay initial rent in community facilities until they get their SSI checks and they cannot get their checks until they are on the outside of the institution. (A Catch-22 situation.) We know of one case of a released paraplegic St. Elizabeths patient who had to wander from relative to relative for months until his check got processed. There is, theoretically, provision for advance emergency payments, but it doesn't seem to work well in District of Columbia.

(e) There is also the nettlesome problem of whether Federal payments are or should be available at all to residents of nonmedicaid facilities. The controversial Section 1616(e) would prohibit SSI payments if the facility was theoretically eligible for but could not meet medicaid ICF standards. S. 1555 sponsored by Senator Moss would modify that prohibition, and allow SSI payments (accompanied by not less than $100 State supplement), for residents in a "supportive sheltered environment for persons without extraordinary health needs," i.e., in nonmedical shelter care facilities. This amendment seems eminently in order, although we question the limitation to "ambulatory" residents since, in our experience, many aged, not technically ambulatory, patients can cope, survive, and flourish in a normalized community home without skilled nursing care if provisions are made for their individual needs. One of our named plaintiffs, Mr. Dixon, whose case history will be capsulized shortly, is just such a case.

(f) Special attention also needs to be given to the way in which the representative payee provisions of our social security laws are administered. Many times we have found competent patients cannot regain control over their benefits when they have left the hospital: the hospital or the home operator is still the "representative payee" and determines how much of his own money the recipient can get. Because representative payee provisions are administered wholly apart from formal judicial decisions about incompetence or guardianship, there is the potential and we find, the actuality of arbitrary decisions that make community care impossible. Several legal challenges are being made across the country to the substantive and procedural provisions of the social security representative payee provisions. We note here only that it is essential to an aged person's sense of well-being and identity to keep control over important aspects of his life such as money, and there should be a compelling showing before he can be denied such control.

These are only small pieces of a giant financial riddle: How to provide economic incentives, Federal or otherwise, locked in mental health systems to make them infuse money into the creation of this kind of alternate system. The recent amendments to the Community Mental Health Centers Act requiring transitional residential care as an essential service all CMHC's must provide is a beginning. In our own area, some of the Federal money pumped into St. Elizabeths each year should be directed toward a restructuring of the hospital to provide diversified levels of care even within its own 230-acre setting so as to encourage independence and movement back into the community. With all the Federal moneys going into mental health care and all the social security moneys going to the mentally disabled, our common purposes and goals for a community based system should provide greater direction for the way in which the money is spent.

MONITORING THE QUALITY OF CARE

The problem of the quality of care in hundreds of small facilities is a formidable one—the District of Columbia has 350 personal care homes of six patients or less. In our experience, some of the greatest trouble spots are due to:

(a) Inadequate training of home operators;

(b) Misplacement of patients in personal care or boarding homes who need more skilled care and services;

(c) No standards for foster care homes;

(d) No centralized St. Elizabeths placement service for patients who need different kinds of facilities or programs;

(e) No requirement of a physician's certificate for admission to skilled nursing homes;

(f) No agreed-upon definition of who goes into different levels of care; and

(g) Most important, a lack of facilities and money to buy slots in those that exist. (There are no publicly-run facilities except D.C. Village.)

There are many partial solutions proposed: a central licensing and inspection service for all facilities housing dependent populations, to centralize responsibility and avoid jurisdictional disputes, more public-operated facilites rather than total dependence on proprietary operators (although to be candid the track record of public facilities is not an impressive one), a centralized placement service to assure that all the aged are appropriately placed so their needs will be met, required training for operators in proper care and dispensation of medication, etc.

The bottom line, however, is a commitment to community facilities and programs as the core of a mental health system, with the willingness to allocate the lion's share of mental health money to that purpose and to fight for more. That commitment must also be expressed in reasonable Federal and State regulations and funding criteria that insist in high-quality living conditions but that recognize not everyone belongs in a nursing home. There are many forms of good custodial care for older people if they are supplemented by a healthy program of activities and services elsewhere in the community or provided by outsiders.

For instance, one model for a District of Columbia community-based alternate care system would include a number of small residential facilities scattered throughout the community to accommodate those who are not bedridden or do not need full-time nursing care. Specialized psychiatric and other therapy services needed by such patients could be rendered through a centralized social service mechanism. All residential facilities would provide high quality custodial care, private rooms, bathrooms, laundry and in-house assistance for those who need help in personal hygiene, eating and walking; they would be run by trained operators including training in safely storing, dispensing and maintaining patients' medication. A central placement service would assure that patients with special needs were not indiscriminately or inappropriately mixed or placed where there were not sufficiently skilled personnel to care for them.

The theory behind such a model is that basic maintenance payments should go to insuring safe, clean housing, and good, nutritious meals; operators should be trained and required to render personal assistance in daily living, but all such facilities cannot realistically be required to have in-house specialized skills in counseling, recreational or occupational therapy, or psychology. (The District of Columbia has 350 personal-care homes of six residents or less, desperately in need of upgrading.) A separate program of nursing, social service, recreational, vocational, and psychological specialists would render these services on-sit or at accessible service locations. Residents would be regularly transported to service centers, daycare programs or social events if they could not travel independently.

All residential facilities should be required to adhere to a patient's bill of rights specifically setting out their liberties and rights which cannot be infringed. Follow-up of patients and community residents by some one person with a legal obligation for their continued welfare is also a must. Physical "dumping" is not the only danger; social service and psychiatric dumping by hospital personnel who do not follow or insure followup of a patient's progress into the community is just as reprehensible.

All community facilities must be regularly visited by outsider ombudsmen or lay advocates, not tied to the State or local government, as well as by public inspectors. Organizations such as the Gray Panthers may be co-opted into this kind of community service. And, finally, we need an independent, publicly funded patient advocacy service made up of specially trained lawyers (and other mental health professionals) whose clients are the aged and the mentally ill who live in the hospitals or in community facilities.

Senator Moss. We will now hear from Mr. J. Terrence Brunner of the Better Government Association of Chicago, Ill. Will you please introduce your associate?

STATEMENT OF J. TERRENCE BRUNNER, EXECUTIVE DIRECTOR, BETTER GOVERNMENT ASSOCIATION, CHICAGO, ILL.; ACCOMPANIED BY PETER MANIKAS, RESEARCH COORDINATOR

Mr. Brunner. With me this morning is Peter Manikas, who is the research coordinator of the Better Government Association.

Mr. Chairman, we are called the BGA in the Chicago area, and we attempt to ferret out inefficiency, waste, and corruption in local and State government.

We have now about 20,000 members in the State of Illinois.

Senator Moss. This subcommittee is aware of the good work you do.

We have received help from you in times past. I remember in particular your aid in looking into nursing home problems. We appreciate your assistance. We are looking forward to continue working with you.

Mr. Brunner. We go way back as you know on this issue.

For the last several months the Better Government Association has been examining conditions in Chicago shelter care facilities and their regulation by the State Department of Mental Health. This represents a longstanding commitment of the BGA to upgrade the treatment provided to former mental patients.

Over 3 years ago the Better Government Association, in conjunction with the Chicago *Sun-Times* and channel 7, ABC News, investigated conditions in shelter care facilities. BGA staff, and *Sun-Times* and channel 7 reporters obtained jobs in halfway houses throughout the city to examine first-hand the conditions in which discharged mental patients lived. Scores of public officials were interviewed and State and city records were examined in detail. Our findings constitute a serious indictment of the treatment of discharged mental patients in Illinois.

Pursuing a policy of "deinstitutionalization," the State of Illinois has encouraged the exodus of mental patients from State hospitals to neighborhood-based, privately operated facilities. Here they are to be provided care and integrated into the life of the community.

Proper Treatment and Placement Lacking

It has not worked. Yet the policy continues. In 1972 our investigation found that overcrowding, understaffing, and pressure to discharge patients prevented State mental health workers from providing proper treatment and from preparing the patients for placement in shelter care homes. Shelter care residents appeared lethargic due to overmedication. This observation was confirmed by State officials who were highly critical of the heavy use of tranquilizers. There was poor security in the homes in guarding drugs that have potential value if sold on the street. Numerous employees—including an undercover BGA investigator who had received no training—had access to the drugs. Some shelter care homes had long records of building and fire code violations. Few recreational programs existed in the homes. Most provided no therapeutic treatment. The staffs at the homes were often well-meaning but almost always untrained.

Most importantly, shelter care seemed to provide just another form of institutional existence. The homes were found to be depressing, gloomy places where indigent, troubled people were provided, at best, the minimum treatment the State required. State inspection was inadequate to insure even minimal compliance by the privately owned homes on a consistent basis.

This year the BGA again focused on shelter care facilities and the Department of Mental Health—renamed the Department of Mental Health and Developmental Disabilities. We found conditions in the homes to be substantially the same. Cosmetic changes have occurred. Walls that were covered with chipped plaster 3 years ago are adorned with colorful posters and nicely printed meal schedules. More recreational activity is provided. Homes that once saw 40 elderly residents huddled around a single television now include classes in personal hygiene, sewing, and arts and crafts. But the basic problems remain: The privately owned facilities lack trained personnel, many residents are continuously oversedated, and there is no real attempt to accomplish the primary mission of integrating the residents into the life of the surrounding community.

Despite the publicity that surrounded the 1972 BGA, *Sun-Times*, and channel 7 findings, as well as the recent nationwide publicity concerning private shelter care homes, the State's policy of shifting its responsibility to ill-equipped private homes and unprepared local communities continues. And it continues when the State's own statistics and reports present convincing evidence that the policy is a disaster.

FIFTY PERCENT REDUCTION OF PATIENTS

Since 1969 the resident population of State mental institutions has declined from 28,233 to 14,179 in 1974, or about 50 percent. The present State plan calls for a decrease of an additional 18 percent over the next 5 years.

Geriatric patients have been especially targeted for discharge from State hospitals. While the total residential population fell 55 percent between 1970 and 1974, the geriatric population fell 71 percent during the same period.

It is important to note that the elderly patients that are being discharged are not merely "boarders" at the hospital. Many suffer from serious chronic illness that require skilled medical attention.

The State's figures reveal that in 1974, 50 percent of all geriatric discharges were diagnosed as having some form of organic brain syndrome associated either with cerebral arteriosclerosis—29 percent—or with senile or presenile brain disease—11 percent. Twenty-one percent of the geriatrics discharged in 1974 were classified as schizophrenic and 4 percent as manics. Approximately 10 percent suffered from alcoholism.

The State has continued its discharge policy despite every indication that it merely leads to a "revolving door." Since 1970, readmissions as a percent of total admissions has held steadily at about 60 percent. Surely, if the shelter care and skilled care facilities were performing their stated function, many former patients would not return again and again.

The emphasis on discharges has led to a numbers game that borders on the absurd. The bureaucratic techniques employed to reduce the resident population would be terribly amusing if they did not have such a disastrous consequence for the patients concerned.

For example, at the Read Zone Center in Chicago the name of the game appears to be "musical beds." Read personnel told BGA investigators that the ward census is not to exceed 28 patients. If it does so, home visit passes will be issued to the excess patients. The patients will live in the ward during the day but will be released to their homes at night. The census of the wards only count those patients that are sleeping in the ward so in this way the excess patients would not be included in the official census.

Nobody told us what happened to those excess patients who did not have a home. We do not know where they might have spent their evening hours.

Elderly Discharged From Acute Ward

At Manteno State Hospital the pressure to discharge is equally as strong. According to its staff, the discharge rate is to hold firmly at four per month. For the first time at Manteno, patients are being discharged from the acute ward. Staff personnel there said that these were mostly elderly patients with severe physical as well as mental problems.

The stories are repeated in dozens of interviews. Patients are discharged prematurely, often contrary to the recommendations of the professional staff. Readmissions are the rule rather than the exception. Many patients return several times in the same year. It is no secret. The figures are contained in the State's own reports. Yet the policy continues.

Of course the State's discharge policy would make good sense if the theory conformed to reality—if there were adequate community-based facilities to care for the discharged patients. It is quite clear, however, that adequate facilities do not exist.

Where do the discharged patients go when they do not have a home to return to? In Chicago, many end up in Uptown. And Uptown is a problem-ridden community that already contains the heaviest concentration of former mental patients in the State, and perhaps in the Nation.

It has become the chief depository of former mental patients because of its abundance of old, decaying, unprofitable hotels that can easily be converted into profitable subsidized shelter care homes.

There are no accurate figures on how many former mental patients live in Uptown. Estimates range from 3,000 to as high as 15,000. It is known that in 1972, 47 percent of all Chicago's shelter home beds were in this neighborhood. It is an odd place, to say the least, for the State to attempt to integrate its former wards into "community life."

Following our investigation of 1972, the State did announce a new policy regarding its placements in Uptown. The Department of Mental Health said they would place only Uptown residents in the Uptown shelter homes and place others in new homes being built in the suburbs.

But in the city of Chicago, a substantial percentage of shelter care beds remain in Uptown. And these beds are contained in homes that are among the worst in the area.

An analysis of inspection reports of the State Department of Public Health reveals that four shelter care homes in Uptown are chronic violators of State standards. Together, these homes—Somerset House, Traemour House, Commodore Inn, and Stratford House—supply 1,465 beds for patients requiring shelter care.

SERIOUS DEFICIENCIES FOUND IN SOME HOMES

Based on these homes alone, about 20 percent of the shelter care beds available in Chicago are contained in homes where the State has found serious deficiencies.

For example, Somerset House has consistently been found to provide inadequate care, and in January 1975 was threatened with decertification. Among the problems cited at Somerset was the "inadequate and indifferent care" received by one resident, Cletis Weaver, during his fatal illness. A cutoff date was set for State aid to the institution, but somehow the facility managed to pass an inspection the day before aid was to be terminated.

Public health files on Stratford House, located on the southern edge of Uptown, expressed a sense of urgency. One report stated: "In the light of the overall horrible conditions at Stratford Home, we feel drastic action is necessary to safeguard and protect the residents of this facility."

The events that led to the report include findings that there was inadequate personnel. There were several periods when no registered nurse was on the staff. There was a lack of coherent, up-to-date medical records, treatment plans, and records of medications administered to the residents. The facilities failed to take a patient to the hospital until drastic symptoms developed—a loss of 20 pounds in 48 hours—forced the home to call an ambulance. The patient died 2 days later. Fifteen to twenty percent of the residents were oversedated.

Despite these serious problems, and the ominous warnings contained in the report, Stratford Home continues to receive State funds and is trusted to care for the State's former wards.

At Traemour House, which is also located in Uptown, State inspection reports disclosed a particularly lucid example of one theme that emerges repeatedly: lack of trained personnel.

At Traemour, one nurse serves 271 beds. The nurse is also burdened by having to supervise 22 nurses aides. As a result, monthly inservice training is conducted by a drug company representative.

At Fellowship House, located on Chicago's west side, BGA investigator Jim Huenink was able to obtain facilities charts that indicate irregularities in the use of certain medication and dangerous drugs. I have provided the subcommittee staff with copies of the charts for your examination.*

---

* Retained in committee files.

DISCREPANCIES IN ADMINISTERING DRUGS

These charts show that certain medications cannot be accounted for; for example, there are discrepancies between the number of pills ordered and administered to residents. We were also able to confirm that narcotic drugs were improperly stockpiled in the safe of the facility's administrator. These drugs have a considerable street value.

Curiously, inspection by the Department of Public Health did not uncover any of these findings.

The serious problems outlined here are not confined to the Uptown area where abuses in shelter care facilities have received the most attention. BGA investigators examined the annual and monthly facility reports of the Department of Mental Health and 14 facilities containing 2,559 beds. These facilities represent 27 percent of the total number of shelter care homes in Chicago and over one-third of the shelter beds.

According to the State's reports, 83 percent of the sampled beds were contained in homes that did not have adequate activity programs for their residents. Over half—53 percent—of the beds examined were contained in facilities with inadequate care plans—plans designed to deal with the residents physical, psychological, and medical needs. Homes containing 64 percent of the shelter care beds in the examined facilities neglected to post a patient's bill of rights as required by State regulation.

In summary, the State's own records constitute a serious indictment of shelter care in Chicago. Their reports charge facilities containing 40 percent of the city's shelter care beds with glaring deficiencies. But the policy of emptying the State's mental institutions continues.

The BGA does not argue with the concept of community-based treatment. In theory, the concept makes a lot of sense. However, in the context of our findings—inadequate private shelter care facilities, spotty State inspection, and lax State enforcement—the policy degenerates into a practice whereby the State abdicates its own responsibilities to provide care for those who desperately need it.

HIGH RATE OF DETERIORATION

Little research has been done on what becomes of individual patients after they are discharged to the community. However, the data that is available confirms our worst fears. In a paper submitted to a recent National Institute of Mental Health sponsored conference on the closing of State mental hospitals, one study of geriatric patients discharged from Modesto State Hospital in California observed:

> Relocation was dangerous for a majority of my patients: deaths were increased, there was a high rate of deterioration, many patients were sent to environments which lacked the basic necessities for a decent life. . . .

The situation is not likely to improve until we stop dumping our problems on unprepared local communities. We should not allow the existing treatment of mental patients by State institutions—with all of its obvious shortcomings—to be replaced by something even worse.

We do thank you, Mr. Chairman, for the opportunity to testify. We would be happy to answer any questions.

Senator Moss. Thank you for your statement, Mr. Brunner, and I see you have a list of your sheltered care facilities attached to your statement.

That will be made a part of the record at this point.

[The list follows:]

LIST OF SHELTER CARE FACILITIES FOUND DEFICIENT IN PROVIDING SERVICES

(Based on Department of Mental Health annual and monthly facility reports and Department of Public Health Inspection reports)

Shelter care home and address	*Number of beds*
Bethune Plaza, Inc. 4537 S. Drexel	276
Beverly Hills Rest Home, 10347 S. Longwood	29
Central Plaza Hotel, 321 N. Central	238
Chapman House, 4707 N. Malden	139
Clayton Residential Home, 2026 N. Clark	252
Commodore Inn, Inc., 5547 N. Kenmore	180
Fleetwood Shelter Care Center, 6026 N. Winthrop	157
Grasmere Residential Home, Inc., 4621 N. Sheridan	244
Maple Terrace Shelter Care Home, 4743 W. Washington	12
Mount Pisgah Shelter Home, 4220–28 Champlain Ave.	24
Somerset House, 5009 N. Sheridan	704
Stratford Home, Inc., 4131 N. Sheridan	310
Traemour Home, 5427 N. Kenmore	271
Total	2,836
Total number of shelter care beds in Chicago	7,018
Percent of beds found in deficient homes to total	40

Senator Moss. Now, in your statement, you talk about the pressure on State hospitals to discharge at a rate of four per month without any regard as to whether the people are ready to go out in the community or not. Is that policy in effect now?

Mr. BRUNNER. I believe it is; yes, sir.

Senator Moss. And even if facilities are as lacking as you have described, they still are pressing those people out, is that your information?

REPORTING SYSTEM CANNOT BE TRUSTED

Mr. BRUNNER. That is correct. It is purely a matter of money, and essentially the sort of thing we found back in 1972 when we did a much deeper in-depth look at these facilities. BGA staff then took jobs as night janitors and recreation directors, and we photographed inside the shelter care facilities. We placed a television reporter, Larry Buckman, from ABC inside one home. It is clear that you cannot trust the reporting system of the State.

What we found then, and it appears to be the same now, is that the State is in a financial bind.

It is not a matter of politics or Governors. The present Governor is following the same policy of the former Governor, and that is to discharge patients to cut down on the expenses. I wish we could bring down the movie that we filmed for the investigation in 1972, because it is so graphic. Unfortunately, ABC was unable to find it, but the photographs of these people in these situations, in these institutions, are so much more devastating than anything I can say or write.

As I suggested, the photographs sometimes show these poor people, many of them were clothed very badly and were in very bad physical shape, just sitting in a room, lined up in rows of chairs. For instance, in this room filling a section about that large [indicating], and the only recreation being a broken television set, the residents would just sit there, staring at it for hours.

Senator Moss. In 1972, when you first completed your investigation, there was no SSI, and now that we have had this program for about 18 months now, what has been the impact on the financial operations of shelter care homes?

Mr. Brunner. I think I will let Mr. Manikas answer that.

Senator Moss. All right, Mr. Manikas.

Mr. Manikas. I do not know that there has been a great deal of difference. The enforcement of the State-Federal regulations is so confused that it is difficult to make any kind of determination as to what the financial arrangements are, and whether they have had any impact.

Poor Elderly in Constant Jeopardy

Mr. Brunner. Back in 1972, we found that the sums coming to people in shelter care is sort of like per diem of the Federal Government. It was something like $12.16; it went to $25, and the hotel operators raised their Government rates from $12 to $18. When you get to $25, you are in the same position. But we found in many cases the individuals in the uptown area would be receiving approximately a little over $200—say, $210 a month—and so the fellow running the facility would charge $190 for room and board. It ended up that the poor older person who has very little money to move around found himself in a very tough deteriorating community where even his small pocket money was in constant jeopardy.

Uptown is a community that is a terrible poverty area, filled with people who have come to seek jobs and cannot find them.

The buildings in this area are in disrepair. In many instances, it looks similar to scenes of Germany after World War II. For these people, the only recreation is the wine drinking in the streets of this community.

It is not safe. That was first called to our attention by an alderman in Chicago, who received a tremendous number of complaints regarding what has happened to the former patients in the area. An additional problem is the patient's effect on the community, of having this many former mental patients in a small area.

Of course, many individuals are from small towns in downstate Illinois, and they are dumped into an urban setting of large apartment buildings and are not able to cope with the problems they encounter.

Senator Moss. Your statement says that the State inspects homes and should close them down if they do not meet standards, but on the other hand, if they do close them, there will not be any beds to meet the discharge quotas. Is this the main reason that substandard homes stay open?

Mr. Brunner. Well, in Chicago we also have a historical background of lax regulation. I cannot document that specifically today, but previously we found that the State is not doing a good job. Too often the word gets around that inspectors are coming out, and the sheltered care owners get the place shaped up. We have heard that from the patients, and from our chief investigator who observed the practice. But I think there is a real paradox. You are asking the State to police the sheltered care system when their basic thrust is to keep those homes open. We found again and again that that is a major problem. State policy appears to stress keeping the homes open almost at any cost as opposed to enforcing existing regulations with the possible consequence of closing them.

Senator Moss. What your testimony says, in short, is that it is a good policy to try to get the people out of the mental institutions and into the community; however, there are no adequate facilities to take them.

Mr. Brunner. Well, that is true.

I am not sure why the system has failed so badly, Senator, but I think designing Government programs such as this one is rather like throwing food to the sharks.

Program Not Working

There are sharks out there. We have talked to a lot of sheltered care facility operators, many of whom are unscrupulous. They see the program, understand how it works, find a building, convert it, and make money off of it. The difference between their lifestyle and that of the patient is unbelievable. I can think of one fellow in particular who in the wintertime flies to Miami Beach every other weekend and drives a Lincoln Continental. He ran one of the absolutely worst homes where people were treated very, very badly. I do not know whether the operators feed on the program or whether it is the reverse. But there is no doubt that this particular program does not work.

I do not know how you avoid that, whether you ask the State go one step further, and start to figure out better regulations, so you can set up sheltered care facilities around the State, or in the suburbs, because you cannot let the thing ride and you cannot dump people out. It comes down to the simple denominator of how to you make a buck off the residents and the State. It is fairly easy to convert an old beat-up apartment hotel into a sheltered facility and obtain financing from the State. You get the discharged patients in there, and you receive a check every month.

It is easier than trying to run a hotel.

Senator Moss. As you point out, there are people who make money out of the system, and so simply increasing the rate of payment is not going to upgrade the system.

Mr. Brunner. It has been our experience that if you raise the payment, they raise the cost. They are going to make money on these people if it can be done. I think that it would greatly improve matters if the State thought through the process a little better. For example, if you came from downstate or southern Illinois, the State could make sure you will go back into a community with which you are familiar. To just take people and put them in the worst possible area of the city of Chicago just does not make sense.

Senator Moss. Well, thank you, Mr. Brunner and Mr. Manikas, for your response to our request for testimony.

You have added another facet to this record. Thank you for helping to show us the problems with which we are confronted.

Thank you.

Mr. BRUNNER. Thank you, Senator. We certainly appreciate the opportunity to testify here today.

Senator MOSS. Our next witness is Mr. Louis M. Thrasher, Director of the Office of Special Litigation, Department of Justice, Washington, D.C.

STATEMENT OF LOUIS M. THRASHER, DIRECTOR, OFFICE OF SPECIAL LITIGATION, CIVIL RIGHTS DIVISION, DEPARTMENT OF JUSTICE

Mr. THRASHER. Mr. Chairman, Mr. Stanley Pottinger was originally scheduled to testify, but he has been called away for another meeting, and he has asked me to sit in for him and to present his address, if that is acceptable to the committee.

My name is Louis M. Thrasher, Director of the Office of Special Litigation of the Civil Rights Division, which is the office which is responsible for the litigation the Department is conducting concerning the right of treatment of mentally ill and mentally retarded persons.

Senator MOSS. Well, you may proceed.

Do you have Mr. Pottinger's statement—are you just reading his statement or are you making a separate statement?

Mr. THRASHER. I am prepared to read his statement, Senator.

Senator MOSS. All right. Go ahead.

Mr. THRASHER. Permit me to express my pleasure in being invited to appear before the Subcommittee on Long-Term Care and Health of the Elderly.

RIGHTS OF INMATES PROTECTED

The Civil Rights Division has been playing an active role in establishing and protecting the rights of mentally handicapped persons since 1973 when we initiated our participation in the *Wyatt* case, which established the constitutional right to treatment for such involuntarily confined persons.

In 1974, we established a litigation office which is charged with protecting the rights of inmates, including children and physically and mentally handicapped persons of all ages.

I might point out at the outset, there is no statutory authority for the Division to be participating in such cases.

It is our experience that constitutional rights of persons throughout the country who are institutionalized in all kinds of government-operated institutions are being seriously violated, and we have been conducting litigation in this area since 1971.

Our Office of Special Litigation is now participating in 17 cases throughout the country concerning the rights of mentally ill and retarded persons, juvenile delinquents, dependent and neglected children, the aged and chronically, physically ill.

We have continued our participation in the landmark "right to treatment case," *Wyatt* v. *Stickney*, 344. F. Supp. 377, 344 F. Supp. 387, M.D. Ala. 1972, which established minimal constitutional standards of treatment for involuntarily committed mentally ill and retarded persons.

We supported the right to treatment on appeal and Wyatt was affirmed sub nom. *Wyatt* v. *Aderholt*, 503 F. 2d 1305, 5th cir. 1974.

The Wyatt court held that when a person is involuntarily civilly committed for purposes of receiving treatment, that basic principles of due process require that treatment in fact be provided.

We have conducted the Wyatt type right to treatment litigation for retarded persons during this period in cases in New York: New York Association for Retarded Children and *Parisi* v. *Carey*, C.A. Nos. 72-356/357, E.D. N.Y.; Pennsylvania—*Halderman and United States* v. *Pennhurst*, C.A. No. 74-1345, E.D. Pa.; Maryland—*United States* v. *Solomon*, C.A. No. 74-181, D. Md.; North Carolina—*North Carolina Association for Retarded Children and United States* v. *North Carolina*, C.A. No. 3050, E.D. N.C.; Nebraska—*Horacek and United States* v. *Exxon*, C.A. No. 72-L-299, D. Nebraska; and in Montana—*United States* v. *Kellner*, C.A. No. 73-138, D. Montana.

Lax Commitment Standards

It has been our experience in all of this litigation of the right to treatment, while commitment standards are fairly lax, and, therefore, many people can easily fit within the commitment standards of different States. All of the States institutions which are involved in these lawsuits are released upon recovery to normal condition to such an extent the person may return to the community.

Obviously without treatment, this condition would never be achieved, and the committed would return to a lifetime sentence without any treatment being involved. In such a case we conducted litigation, which was the *Wyatt* case, and litigation was conducted in the States I mentioned.

During this period we have also conducted the *Wyatt*-type right to treatment litigation for mentally ill persons in Ohio—*Davis* v. *Watkins*, 384 F. Supp. 1196, N.D. Ohio 1974; South Carolina—*Alexander and United States* v. *Hall*, C.A. No. 72-209, D. S.C.; and in Texas—*Jenkins* v. *Cowley*, C.A. No. 3-74-394-C, N.D. Texas.

We are also participating in cases to determine due process standards for civil commitment of mentally handicapped persons in Pennsylvania—*Bartley* v. *Kremens*, C.A. No. 72-2272, E.D. Pa., mentally ill and retarded children; Iowa—*Stamus and United States* v. *Leonhardt*, C.A. No. 73-126-2, S. D. Iowa, all mentally ill persons; and in Ohio—*Ewing* v. *Gaver*, C.A. No. C-74-147, N.D. Ohio, all mentally ill persons.

We are actively participating in the landmark right to rehabilitation case concerning incarcerated juvenile delinquents in Texas—*Morales* v. *Turman*, 383 F. Supp. 53, E.D. Texas 1974.

The theory of the right to rehabilitation for juvenile delinquents who are incarcerated for purposes of receiving rehabilitative care and treatment is modeled on the right to treatment found in the *Wyatt* case for mentally handicapped persons.

We have extended our activities in the juvenile rights area by intervening in a Louisiana suit—*Gary W. and United States* v. *Stewart*, C.A. No. 74-2412, E.D. La., concerning the care and treatment provided to Louisiana children, dependent and neglected, emotionally disturbed, mentally retarded, and delinquent, who are placed in privately operated child-care facilities in Texas.

DIFFERENT STANDARD OF PROTECTION

Pat Wald, a previous witness, testified before the committee and has pointed out that on many occasions State statutory schemes provide a different standard of protection when children are being committed to institutions than when an adult is so committed, and we have participated in the cases I mentioned in North Carolina, in Pennsylvania, attacking that discrepancy, so as to better protect the commitment of children, and the courts have held in our favor.

We have similar cases concerning standards for commitment of mentally ill persons in Iowa and Ohio. We are also participating in litigation in what we believe is a landmark juvenile right to juvenile case, which I already mentioned, *Morales* v. *Turman*, throughout the State of Texas.

In that case, we argued that the basic principle of care for delinquent children was essentially the same as enunciated by the district court of Alabama, concerning mentally retarded and mentally ill persons, so that even when a State elects to take a delinquent child and commit him for purposes of rehabilitation, as opposed to criminal punitive care, then the State has an obligation to live up to this promise of rehabilitative care. In *Morales* v. *Turman* we proved substantial, cruel, and unusual punishment, and the court in that case found the constitutional right to treatment; in fact, ordered two State institutions closed because of conditions. That case is now on appeal in the fifth circuit, and we are participating in this.

We are also participating in a lawsuit, *Gary W. and United States* v. *Stewart*, which is a case which should interest this committee.

That is the State of Louisiana which has a practice, as many States have, of taking retarded or emotionally disturbed persons, delinquent children, and contracting with private care facilities out of the State. The facilities in this particular case are in Louisiana and in east Texas, where many of the persons are entrusted to the care of the State of Louisiana, and are shifted across the State line in Texas. That suit should go to trial earlier next year.

Probably more in the line of interest of this committee at this time is a suit that we have against the State of Pennsylvania, to enforce the fire safety standards associated with the HEW medicare and medicaid programs in privately and publicly operated skilled nursing facilities which house the beneficiaries of those programs throughout the State of Pennsylvania.

FATAL NURSING HOME FIRES

As the committee knows, Pennsylvania receives money in return for what it promises—to conduct the safety code standards and to enforce the standards. We allege in a suit, after taking money, Pennsylvania did not do the service, and as a result thereof, several nursing home fires—fires that were fatal—did occur.

That case is proceeding through pretrial discovery, and should go to trial sometime in the spring.

We believe our litigation program in the right to treatment area concerning mentally ill and retarded persons and juvenile delinquents has been particularly productive in establishing basic constitutional principles which have been followed by Federal courts and by several States in recently adopted legislation and administrative practices.

The Supreme Court of the United States in its recent opinion in *O'Connor* v. *Donaldson*, June 26, 1975, held that:

> . . . a State cannot constitutionally confine without more a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends.

We have long been aware of the danger of over-institutionalizing our mentally ill citizens both in the sense of confining too many of such persons and in the sense of too severely restraining their personal liberties.

We strongly support the principle that mentally handicapped persons who require care by the State are entitled to such treatment in that setting which is the least restrictive of personal liberty.

To support State efforts consistent with this principle, we filed an amicus brief in *Stoner* v. *Miller*, a suit by persons released from mental hospitals in New York seeking to strike down a local ordinance which had the effect of keeping them from living in hotels in Long Beach.

While the case had very limited direct impact, we felt it was important that the State's program of releasing nondangerous patients not be thwarted by local resistance. We believe that the *O'Connor* opinion in its basic thrust is supportive of the principle that persons who require mental health care are entitled to receive such care in the least restrictive setting.

HEAVY BURDEN PLACED ON STATES

The decision places a heavy burden on the States to justify involuntary commitments. The Court indicated that such a massive infringement of personal liberty must be based upon a showing of dangerousness to self or to others.

While we have not yet found that the elderly mentally ill pose a unique legal problem—1970 census data reflects 113,043 residents of mental health institutions age 65 and over—we have become aware that many elderly persons are placed in mental institutions solely because they are aged and senile, but not mentally ill.

It will be difficult for States to justify retention of such persons in mental institutions under the principles set forth in *Donaldson.* We presume that the presence of such elderly residents in mental hospitals is a reflection of a lack of quality nursing home facilities, which problem these subcommittees are intimately familiar with.

As the rights of the mentally handicapped become more firmly established, it is likely that more and more residents of mental institutions will be moved to nursing homes. Therefore, the nursing home problems are likely to get worse in terms of whether such facilities can provide safe, proper care for their residents.

As I have pointed out earlier, we are involved in one lawsuit concerning nursing homes in Pennsylvania. The thrust of our suit there is to enforce the fire safety standards associated with the HEW medicaid and medicare programs.

In addition, we are presently investigating the caliber of care provided in nursing homes which are operated by local governments to determine whether *Wyatt*-like legal principles supportive of a right to treatment would apply to such settings.

In conclusion, we commend the committees on their interest in this very important area. If we can provide any further information, we will be glad to do so upon request.

Senator Moss. Thank you very much for that statement, and we are pleased that the Civil Rights Division is engaged in litigation of these matters. The mentally ill, of course, are entitled to care. We would be pleased if you would let us know if there is any statutory authority you need to enable you to do your job better. We would be glad to get your recommendations.

Interpretation of Law Question

Mr. **Thrasher**. Well, the problem is, Senator, in terms of standing, to initiate a lawsuit, and that is, while the person whose constitutional rights are being denied, obviously he has standing to seek redress. There is some legal question, though, as to whether the Attorney General of the United States can seek to protect those same constitutional rights.

It is our theory in the litigation, in accord with the cases, the Attorney General has standing to seek relief of the rights, where there is a widespread and severe denial of such constitutional rights of these persons.

In all of the right-to-treatment cases, if I may address an issue raised by the Senator, when questioning a prior witness as to whether or not such litigation interfered too much with the administrative discretion of the State hospital superintendent, all of this litigation goes to, not what the decisions will be made concerning an individual person's treatment, but rather all of the litigation goes to what levels of staffing and care and procedures are necessary before any kind of care whatever is capable of being delivered.

The courts have not found whether any individual person's treatment program is appropriate for that person, but what they have established is a basic minimum upon which care would be capable of being ordered.

Senator Moss. Well, thank you. We do appreciate your response.

Our next witness will be Dr. Robert N. Butler, M.D., psychiatrist and author, Washington, D.C. Dr. Butler, we are pleased to have you come before us, and we look forward to your statement.

STATEMENT OF DR. ROBERT N. BUTLER, PSYCHIATRIST AND AUTHOR, WASHINGTON, D.C.

Dr. **Butler**. I appreciate the opportunity to be here, Senator Moss.

This historic *Donaldson* decision is a significant extension of civil liberties of Americans.

People alleged to have mental and emotional problems should not be incarcerated against their wishes and not given treatment. That is one side, the right to release.

The other side of the right-to-treatment concept is precisely the right to treatment, when it is desired, and when it is necessary. It is to that respect that I would like to particularly address my remarks.

I will be discussing the situation of older people, their mental health, their illnesses, and their need for mental health care, from the mental health perspective—one which I hope will be a comprehensive one—ranging from the physiological needs of older people, to personal needs, and to social needs. I have dealt with these matters in my book, "Why Survive? Being Old in America" Harper and Row, 1975.

There are two large groups of older patients from the mental health perspective: those who develop their mental health problems for the first time in later years, and those who have been chronically ill and/or in hospitals for long periods of time—often unnecessarily, as we have seen this morning.

"DUMPING" OF OLDER PATIENTS

One of the possible unfortunate effects of the landmark *Donaldson* decision could be the increased discharge or release of patients, including and perhaps especially older patients, without treatment.

We have already seen the systematic dumping of older State mental hospital patients into the so-called community. I say "so-called" community because, for example, here in Washington, in Chicago, and elsewhere, as we have noted, there is usually inadequate after-care, no social, medical, or recreational services, frequently overdrugging, which has given rise to what might be called older person's apathy and to older person's abuse—as common as child abuse.

It is true that many older people need not be in mental institutions if there were other facilities and services, which could properly meet their diverse needs. But these alternative facilities—foster care, boarding houses, nursing homes—are sometimes scandalous in their range of services. Correction has only begun to emerge as a part of public policy.

From the perspective of civil liberties, as well as of health care, of the two sides of the right-of-treatment concept, such facilities as foster care homes have even less protection than do mental hospitals. They are repressive; there are no commitment procedures. Social security checks may disappear into the hands of operators.

The Mental Health Law projects represented here by Ms. Wald, Mr. Heineman, and Ms. Marker, have been involved in a very important case in the District of Columbia. This class action case is against St. Elizabeths Hospital, the District government, and NIMH/HEW.

We must be conscious of the failures of community facilities as well as of public institutions, as set forth in the *St. Elizabeths* case. I serve as consultant to those being sued as well as to those suing, so it is of much interest to me to be able to look at the situation from many standpoints.

The financial incentive to "dumping" has been the enactment of the medicare and medicaid amendments to the Social Security Act in 1965, and the supplemental security income.

Governors and legislators have often rejoiced at these newly available Federal moneys, because it mitigates the financial burden upon the State level.

Now, let me get into some practical matters. What are the mental health needs of older people? Can older people really be helped? Do older people want to be helped? What are the pragmatic consequences?

HIGH ELDERLY SUICIDE RATE

First, what are some of the mental health needs? There are 21 million older Americans. Some 1 million are in nursing homes; perhaps 50 or 60 percent of those have mental health problems; many have problems of depression, the incidence and prevalence of which rise from decade to decade as people move through the course of life. It is important to know that one out of every four suicides in these United States are committed by people over 65 years of age.

In addition, there are many of what I call nonflamboyant suicides—patients do not take medications, they give up, they do not eat properly, which is a function of depression and which results in suicide. There are the more obvious and flamboyant efforts through the use of guns, pills, or whatever.

There are not only these massive problems that one can see measured in the Biometrics Branch at the National Institute of Mental Health, but there are also the everyday emotional and human problems of survival.

There are those who grieve in the latter period of life, and the problem of dealing with the loss of a loved one is enormous.

The 1970 estimates suggest that at least 3 million older people have emotional needs, and that they do not have these emotional needs met.

All right. So much for a very superficial, quick, general picture of the mental health needs of older people, but can they be helped?

Yes. You raised, Senator Moss, a very important question at the very beginning: What is senility, and is it the same as mental illness?

There has been too much mental gymnastics, and I may say this is one place, despite my allegiance with the efforts of the lawyers on behalf of the legal rights of older patients, and of patients of different ages, where we do, somewhat, part company.

We know from studies at the National Institute of Mental Health, that go back to the 1950's, that senility is not an inevitable consequence of chronological age: it is, in fact, a collection of a variety of different diseases.

Senility is not a myth. It is a real problem. We know that too many older people are confused, they have memory loss, and they are suffering from malnutrition.

This is true even of those who are more affluent, who may be living alone, and not preparing adequate food for themselves: they suffer from the "tea and toast syndrome," and they get admitted to the medical service and perk up, and become alert.

PROBLEM OF ALCOHOLISM

That is a strange kind of senility. We also know that there is an unexpected, unrecognized—although I did not see it 20, 25 years ago—increase in alcoholism in our older population. They try to end or mitigate pain, grief, or depression through alcohol.

We know, too, from studies in other nations, and in San Francisco, that up to 50 percent of patients who are admitted to general psychiatric wards of city hospitals, like San Francisco City and County Hospital, have brain syndromes, confused states, resulting from such conditions as congestive heart failure, and so forth.

Depression is very frequently present in the form of senility. We must not find another way of dodging a legitimate authentic human issue. The reality of older people is that they do suffer from a wide range of illnesses, which all too quickly are characterized as senility. It becomes easy to say senility is not really a mental disease, and, therefore, people do not belong in a mental hospital.

They may not belong in mental hospitals, but they are very, very much in need of mental health care. They need comprehensive diagnosis, and they need appropriate placement—that does not automatically mean in a mental hospital. They need early, quick placement, and early treatment; otherwise it becomes incredibly expensive to the individual and to our society, because we then create fixed conditions.

Is it too expensive for us to handle the mental and emotional problems of older people? The September 1975 issue of the Journal of Gerontology contained an article entitled: "Dementia in the Elderly—A Search for Treatable Illness," which demonstrates that as expensive as radiological and laboratory examinations can be, their cost is a mere pittance compared to the expense of nursing homes and of mental hospitals due to missing early precise diagnosis of a medical condition.

Dr. Robert Gibson, president-elect of the American Psychiatric Association, demonstrated what we all know: How much money counts. In a survey of private mental hospitals, it was found that 75 percent of all patients over 60 years of age who were admitted could be returned to their own homes, and once returned, improved within 2 months.

Now, do older people want help, or are we simply talking about social, physiological, or medical problems which they have.

STEREOTYPED AS "CROCKS" AND "VEGETABLES"

Indeed, through some 25 years of efforts in this area, there is much knowledge of the extent to which older people need and want help, but I regret to say that my own mental health field and the medical field at large have not been sufficiently responsive to older people. They are often referred to painfully and cruelly, as "crocks" and "vegetables." We see them stereotyped, prejudiced against in the medical and mental health fields. We observe this in our community mental health centers, public hospitals, and in private practitioners' offices.

I learned at a board meeting of the National Council on the Aging that some 5 million older people seek out some 5,000 senior centers which now exist in the United States.

They are trying to overcome the loneliness of the aged. These senior centers provide not only recreation, but health screening, opportunities to talk and to review lives, an important resource from the mental health perspective.

What can be done? We can provide a range of services, not just social, but personal as well, because a person cannot be carved up into bits and pieces.

Ms. Marker pointed out that the problems of older people are not just medical and social, but combined.

I was very grateful to Senator Muskie's efforts. I had hoped he would be here.

I know Senator Moss has helped similarly. Since 1971, Senator Muskie sponsored legislation to create a Presidentially-appointed Commission on Mental Health and Illness of the Elderly, which is not to be "just another commission," but an action commission which would deal with prevention, with costs, with planning, to meet mental health needs, training and research for older people.

As a result of a congressional compromise, we do have a HEW secretary-appointed committee. My hope is that one of the judgments of that committee will be that we must move beyond the committee form to a commission, to give visibility to these major problems.

When you consider that one out of every four suicides in the United States are committed by people over 65, there can hardly be any doubt that we must do better work in the field of mental health care.

Reforms Needed in Medicare

A second thing we can do is immediately reform medicare. We should eliminate its discriminatory aspect in the outpatient treatment of emotional and mental illnesses. There is a $250 annual limit, which means we tend to push patients from the community into the much more expensive care of hospitals, private and public, rather than treating them on an outpatient basis.

Third, as Mr. Donaldson brought out, in Florida and in many States, medicaid money is not used in the field of mental health care, but rather goes into the State's general funds.

Fourth, we now have a new coordinating center on aging within the National Institute of Mental Health. I stress "coordinating." There should be some pressure to have a funded, operating, line-budgeted center on aging, because up to now, far less than 1 percent of mental health money at NIMH has been directed toward the three big components: Service, research, and training.

Fifth, we need collaboration from what I hope will be a very effective new National Institute on Aging, with cooperative research with the Heart Institute, NIMH, et cetera, to try to have breakthroughs in the understanding of so-called senility and the dementias. We must have research to break through this enormous problem which so impairs the quality of later life.

Sixth, we need education and training, of paraprofessionals running small homes, as well as in our medical schools.

Seventh, we really need adequate pay levels for our health paraprofessionals.

No wonder there is a 75-percent turnover in nursing homes, and a high turnover in hospitals too, because health workers do not get adequate pay, nor educational opportunities which can be rewarded by career advancement.

I would like to conclude by congratulating Kenneth Donaldson for his courage, Dr. Morton Birnbaum, the father of the right-to-treatment concept, the legal representatives that spoke here this morning, and to say now that I hope they and those of us representing the mental health field will move to that second side of the concept of the right to treatment.

The genuine right-to-treatment concept must be enforced, and standards must be high. Treatment must be appropriately comprehensive—sociological as well as mental. We must provide inpatient as well as outpatient, residential as well as institutional services.

We must have liberty and dignity for older people, yes; but we must also have efforts to see that adaptability and survival are possible for our older population through every kind of assistance that we can provide for them.

I am really grateful for this chance to participate in these hearings.

Senator Moss. Thank you, Dr. Bulter, for your very lucid and well-prepared statement. We do appreciate very much having you come to testify before us.

Your book said psychiatry has failed the elderly. If so, what is the answer?

Dr. Butler. You know, one of the things I have been very, very struck by is the openness of my own profession to my criticism. I was invited to write an overview article, a critique of the American psychiatric profession's care of the elderly. The article "Psychiatry and the Elderly: An Overview," appeared in the September 1975 issue of the American Journal of Psychiatry.* It has given me a kind of hope that maybe the academic departments and the hospital departments of psychiatry may be more open to the possibility of training residents to help in the effort. But I do not think we can depend alone on psychiatry. It is too expensive a modality. I would like to see a massive effort made in the paraprofessional, social work, and nursing schools, so that an attention can be paid to the many emotional needs that older people have in a variety of settings.

Lack of Geriatrics Teaching

Prevention is important. We have this year run over $100 billion in health care costs in the United States, about 50 percent of which is probably related to chronic illness in later life, yet we do not have departments of geriatric medicine in our medical schools. We must make some major steps along this line. I know we all share that goal.

Senator Moss. Well, thank you. We would like to have statements for the record, if we could, from some of the professional societies.** If you could help us to secure statements from the American Psychiatric Association, the American Psychological Association, the Group for the Advancement of Psychiatry, it would be very helpful. I want you to know I value your book, and I am glad to have your testimony here this morning.

My colleague, the Senator from Maine, just came in, and he has not had a chance to hear you. I do not know whether he has any comment to make or not.

---

*See appendix 2, p. 87.
**See appendix 4, item 1, p. 138.

Dr. Butler has given us a very fine statement.

Senator MUSKIE. I would presume, to walk into a hearing room, and to add something—it is not easy.

The support you have given us in the past, especially for the legislation that created the Commission on Mental Health, is greatly appreciated.

There is a problem surfacing rather rapidly. I know that Senator Moss has read his statement and my statement into the record, but it is surfacing very rapidly at all levels in this country, at the community level, and the problem of dumping, in effect, at the State level, and moving in the direction of throwing the problem out into the open. The question of whether or not we are just brushing the problem aside and putting it on the backs of people not equipped to handle it or, alternatively, the process of dealing with it more effectively and dealing with patients better. I think we are at that crossroads, and I am afraid the answers to those questions are very disturbing. We hope we will solve it quickly, so I will not ask questions at this point.

I want the doctor to know that I appreciate his interest and the work he is doing. I hope with the help of hearings such as this, and with Senator Moss' leadership, we can begin to find some answers.

Senator Moss Thank you; and thank you very much, Dr. Butler.

Dr. BUTLER. Thank you.

Senator Moss. Our next witness is Ms. Nancy Perlman, director of the Program Development Department of the American Federation of State, County, and Municipal Employees.

STATEMENT OF NANCY PERLMAN, DIRECTOR, PROGRAM DEVELOPMENT DEPARTMENT, AMERICAN FEDERATION OF STATE, COUNTY, AND MUNICIPAL EMPLOYEES

Ms. PERLMAN. I am Nancy Perlman, director of the Program Development Department of the American Federation of State, County, and Municipal Employees. AFSCME is a union of 700,000 public employees, over 150,000 of whom work in State institutions for the mentally ill and retarded.

As you well know, the American labor movement has often been accused of resisting social change because of limited vision or the narrow self-interest of its members.

As an institution, AFSCME recognized the need for dramatic change in health care delivery, and, 2 years ago, in the face of apprehension and resistance on the part of many of our 150,000 health care members, supported the deinstitutionalization of the mentally handicapped.

We did so because we believe, as do millions of others in this country, that something has to be done to improve the quality of care provided the mentally ill. AFSCME views institutions as places for treatment—not confinement—and so supported the movement for patient rights. We further supported deinstitutionalization as a method of moving patients out of large, impersonal, understaffed, unfunded, and out-of-the-way institutions—we were never reluctant to call them warehouses—to facilities which were smaller, more homelike, more independence-producing, and closer to family and the community.

PATIENTS "DROPPED" ON STREETS

Recently, however, we are receiving an increasingly heavy volume of calls from our members and local affiliates reflecting a depressingly similar story. It is a story of a "psycho bus" which drops hallucinating released patients off on southside Chicago streets. It is a story of Nebraska nursing home owners bidding on patients in State hospitals depending on how difficult or easy they will be to deal with.

It is a story of the acting director of the Michigan Department of Mental Health admitting that he has set quotas of patients to be released—with no medical justification for their release and with no assurances—if anything, with assurances to the contrary—that these people have anywhere to go. It is a story of one patient being released and readmitted 27 times, or in another State, of hospitals assigning different identification numbers to readmitted patients to hide the readmission rates.

It is a story of documented cases of malnutrition, insect infestation, and dehydration among former mental patients now living in board-and-care homes. It is a story of 600 such board-and-care homes in the city of Philadelphia which have not been inspected or licensed since 1967. It is a story of Federal legislation which bankrolls irresponsibility, and of States so eager to budget-cut that they don't care what happens to released patients as long as the Federal Government picks up the tab.

As a result of what it has become, we have, as an institution, modified our support of deinstitutionalization. We have done so because of the scandal our members see first hand. We have done so because of the fact that this unregulated change has fallen prey to opportunists and profiteers such as Bernard Bergman in New York, or the politician in Wisconsin who owns Mt. Carmel Nursing Home, a 600-bed facility with over 400 nursing home code violations which receives "deinstitutionalized"—and I put that word in quotes—patients from a county mental health facility.

These profiteers, and the officials that let these things happen, have prostituted the concept of deinstitutionalization to the point that it has become a national disgrace.

Toward putting an end to this scandal and toward making the original promise of deinstitutionalization a reality, AFSCME recommends the following:

First medicaid and supplemental security income—SSI—must be amended to provide coverage of residents in State mental hospitals. Current legislation does not allow Federal funds to cover services given to patients in State facilities between the ages of 21 and 65. Under a myriad of Federal programs, private entrepreneurs can receive subsidies from the Federal Government for the same services which the State, ineligible for the Federal subsidies, could and is providing better.

LOOPHOLES SHOULD BE PLUGGED

This policy has encouraged the efforts of budget-cutting Governors and State legislators to rid themselves of their responsibility to provide quality patient care. Amendments of medicaid and SSI should close the current loopholes that allow unregulated private profiteers to receive funds for services which are not meeting the intent of Federal legislation.

Second, in 1963, President Kennedy proposed—and Congress approved—the construction of 2,500 community mental health centers. But today only 443 are fully operational. Last year alone discharges from State hospitals reached a high of 448,203.

In order to meet the needs of these released patients, community mental health centers must be expanded to include adequate public transitional living centers, public sheltered care workshops, public nursing care, and public board-and-care facilities. In other words, the Federal Government must guarantee that patients don't go out of their bed and into the streets—that they don't take a "psycho bus" trip to the southside of Chicago—before there are facilities fully operational, regulated, staffed, and equipped to handle their needs. Recognzing employees as a vital resource to any mental health delivery system, institutional workers must have the right to retraining and transfer rights into these alternative community facilities.

In addition, Congress must recognize that services to the mentally handicapped delivered by community mental health centers require sustained assistance from the Federal Government if they are to expand beyond their present numbers and if they are to continue for more than the 8 years currently funded under Federal law.

Third, medicaid, medicare, and SSI legislation must be amended to preclude the discharge of former inpatients to facilities which are incapable of serving them. New regulations specifying staffing, safety, and therapeutic standards must be developed for nursing homes or board-and-care facilities that receive Federal funds.

REGULATORY SAFEGUARDS MISSING

The reality of the situation is that while Congress moved in a compassionate way to deal with the needs of the mentally ill, the lack of regulatory safeguards has created a situation where the mentally handicapped of the Nation are falling prey to a system far worse than what existed; instead of facing the inadequacies that resulted from overcrowded institutions, they are now being victimized by a process which warehouses the mentally ill for profit.

In an era where Congress is willing to stand up to the powerful automotive lobby and call for safety regulations governing the chrome and steel which rolls off Detroit assembly lines, it is clear that Congress could move and should move for regulations which will protect the flesh and blood that are the mentally ill of this Nation.

Thank you.

Senator Moss. Thank you for a very fine statement and, although you summarized it, your message came through. The full statement will be in the record.* We do appreciate it.

You referred to the community health centers. Can you describe how effective they are? What is your opinion on the conditions and services rendered?

Ms. PERLMAN. I think they have been quite effective. I think their number is so small that they are certainly limited to how much service

---

*See p. 63.

they can provide. What we had hoped for is an expansion of the type of services they could provide.

I also think that having community mental health centers will not do away with the need for inpatient services for some types of illnesses.

Senator Moss. But if there were more centers, it would mean patients could be released from mental hospitals and we might achieve the goal of better service.

Ms. Perlman. That is right. What we had hoped for, and I hope it came across in my testimony, is that the provision of mental health services, which cost all citizens money, be provided publicly, because that is a much more accountable system.

Senator Moss. What opinion do you have about the foster homes, such as we have in Washington, D.C.? Have they worked out?

Ms. Perlman. Unfortunately, I do not think so. As I stated in my testimony, and certainly as our members reported, it is not working out. What we see are patients admitted, released, and readmitted, because these foster homes are not ready to take care of them, and often times their first priority is making a profit.

Inadequately Equipped Foster Homes

Senator Moss. Many of these people require a fair degree of services. They are unable to care for themselves. Foster homes are probably not equipped to care for them. Is that part of the problem?

Ms. Perlman. That is right. Foster homes usually just provide a place to live. If the released patients need any kind of medical or social services, they cannot get them; can't even get the most basic activity therapy.

One of the places we have pointed to in the past, as a place where deinstitutionalization was working relatively well, was the State of Massachusetts, where originally the State planned to close its mental hospitals, but realized there was need for backup services. They moved to publicly provide alternative services in the community with AFSCME-trained attendant nurses at the hospitals to be community mental health workers. The function of these workers is to provide the kind of backup services released patients need to make it in the community.

Unfortunately, the State of Massachusetts is threatening to cut back not only on the institutional programs, but on the community health centers as well.

Senator Moss. So up to this point, you think Massachusetts has had the best record in this regard?

Ms. Perlman. The best record we have seen. It is not that there are not scandals there. It has been reported extensively in the Boston Globe, that patients end up in unregulated nursing homes even though the State has made a real attempt to provide sheltered workshops and other alternative programs.

Senator Moss. The Senator from Maine.

Senator Muskie. Do you think that the discharge of patients has proceeded at too fast a pace? I get the impression that the response to the deinstitutionalization concept, without really adequate provision, had been started to absorb them in some other kind of program, some other kind of facilities, et cetera. Is that part of the problem?

Ms. PERLMAN. Absolutely, and, the fact that Federal funds encourage this has become very clear.

In the State of Wisconsin, which has had a record of providing excellent mental health services, they are saying: "Listen, we would like to provide these services, but it is costing us a lot of money, and if we send people out to the community the Federal buck will take care of it. We do not really care whether it is as high a quality of service."

CHANGING TRENDS OF CARE

Senator MUSKIE. I have seen the transition in this whole area since I was first elected Governor 21 years ago, and at that time the problem was that the institutions were inadequate. We spent much of the 21 years since bringing those institutions up to standard—providing enough beds and providing more care—but we never did achieve what we hoped to achieve by way of improvement. Then, overnight, the trend went the other direction, and it seemed almost an irresistable impulse to open the doors and let the patients out. But there was nothing in place in the community.

The result is the institutions which have emptied out—there is talk about closing one—and there is no substitute for them that is adequate anywhere. There have not been the Federal dollars adequate to the challenge. Have we moved too fast and just sort of panicked in the direction of this new idea?

I am afraid once the patient is out in the community without facilities in place, the pressures to do something for them will dissipate.

As long as they were in the institutions at least there was pressure on the legislature to provide better care, but now that there is the situation that they are out of the institutions, I do not know where the pressures will come from. Are we likely to forget them?

Ms. PERLMAN. I hope not.

Senator MUSKIE. Am I overstating it?

Ms. PERLMAN. I think not; no. Hopefully, the unfortunate scandals will cease, and there will come some move toward balance. I think we are moving in this direction.

Senator MUSKIE. I guess we should have had a more positive and more rationale policy and program of transition than we have had. That seems to be what you are saying.

Ms. PERLMAN. Right.

Senator MUSKIE. I appreciate your testimony and your concern about these people. I think it is well placed, and I hope if you can help us to make that transition, you will do so.

Senator MOSS. We thank you very much. We appreciate your testimony, and we appreciate your being accompanied by Mr. Robert McGarrah. I have here the report, "Deinstitutionalization," published by the American Federation of State, County, and Municipal Employees, which is an excellent report, and without objection, we will place that in the record.*

Ms. PERLMAN. Thank you. I do appreciate the opportunity to appear, Mr. Chairman.

---

* See appendix 3, p. 95.

[The prepared statement of Ms. Perlman follows:]

PREPARED STATEMENT OF NANCY PERLMAN

Mr. Chairman and members of the committee, my name is Nancy Perlman, and I am director of the Program Development Department of the American Federation of State, County, and Municipal Employees.

Your committee is to be commended for holding these hearings on the impact of institutional cutbacks and closures on health care for American citizens. Our union has heard alarming stories of abandonment of patients—and abuse in private facilities—from our 150,000 members who work in State and local facilities for the mentally ill. They work as psychiatrists, mental health aides, technicians, support workers, and nurses.

I am testifying because our members care about the people they serve, because our union cares about conditions in the facilities where our members work, and because AFSCME's 700,000 members—like all Americans—are consumers of health care.

In Illinois, our union sent out a routine questionnaire to our members, asking them whether patients are being discharged from institutions before they are ready to leave. For AFSCME members who have taken the terrifying bus ride from Manteno State Hospital to the southside of Chicago, this questionnaire offered an opportunity to reveal the scandalous neglect of Illinois mental patients.

This bus is officially called the "transportation bus," but it has come to be called the "psycho bus."

CONFUSED AND DISORIENTED

A registered nurse reported, and I quote her: "Many of the patients who are discharged off of the bus are hallucinating, many have urinated on themselves, and some are so confused and disoriented they don't know how to find their way home."

She continues: "The police have picked up patients before they had reached their home and had brought them to a State hospital or clinic for safekeeping, and we have received them back the next day. . . . Patients who have been placed in half-way houses are also frequently brought back to the State hospitals."

Asked whether there is sound professional reason for discharging these patients, the nurse said: "A social worker will be told any number of patients have to be discharged by a certain date even if there are none fit to be discharged."

One of the great goals of the 1960's was to shift the emphasis in social and health care services from large impersonal institutions to smaller facilities in the community. As this goal—which encouraged much legislation concerning facilities for the mentally ill, the mentally retarded, the aged, the young, and even the delinquent—developed, it took on the label "deinstitutionalization."

To AFSCME, in 1973, deinstitutionalization meant positive reform of the mental health and mental retardation systems. It meant a replacement of institutions we have never hestitated to call warehouses—understaffed, under funded, underequipped, and out of the way—by facilities which were to be smaller, more homelike, more independence-producing, and closer to family and the community.

Because of our commitment to this goal, 2 years ago AFSCME held a national leadership conference on "Health Care in a Time of Change." At that time the union publicly announced its support of deinstitutionalization provided that:

—Current patients would be guaranteed proper care,
—State planners and administrators could demonstrate that the proposed changes would improve health care,
—Employees would have the right to be involved in decisionmaking, and
—Employees jobs would be protected.

In the year following the national conference, AFSCME held 12 regional health institutes across the country to take this message to the union's rank-and-file leadership. It was during that year that AFSCME learned—in all too tragic human terms—about the reality of the effects of deinstitutionalization gone awry.

Although the concept had been sold in terms of the replacement of large institutions with smaller ones, the commitment to build new alternative facilities never matched the zeal to dismantle old institutions.

MENTAL HEALTH CENTERS APPROVED

In 1963, President Kennedy proposed—and Congress approved—the construction of 2,500 community mental health centers. But today only 443 are fully operational. In the absence of publicly operated, innovative and accountable mental health care facilities, the private sector has stepped in to provide lodgings and theoretically health care for the discharged patients and residents.

From a 1955 peak population of 558,900, State mental hospitals served only 215,573 persons in 1974—a drop of 343,327—or 61 percent. Inpatient admissions in fiscal year 1974 totaled 374,554 and discharges reached 448,203.[1] Clearly communities from coast to coast are absorbing enormous numbers of discharged patients. But what are the results?

(a) Patients have been dumped into profiteering nursing homes, board and care homes, and welfare hotels in amazing numbers. An estimated 25 percent of the 100,000—25,000—or more residents in New York City's welfare hotels are considered severely mentally dysfunctional. Most of these people are ex-State-hospital inpatients. And according to Dr. Robert Reich, director of psychiatry for New York's Department of Social Services, about half of the 5,500 proprietary beds in the area are filled with former mental patients.[2] Let me assure you that, if patients are resilient enough to even survive in these facilities, they get *no* treatment for their health care needs.

(b) Pennsylvania is just now reeling from a series of investigative news stories documenting malnutrition, insect infestation, and dehydration among former State mental patients confined to board and care homes. Although there are some 600 such homes in the city of Philadelphia alone, the State stopped licensing and inspecting them in 1967.[3]

(c) In Nebraska institutions, nursing home owners, in the most inhumane and indecent way, were bidding on patients depending on how little trouble they would cause. And, if they get patients who are troublesome or difficult to care for, the owners return them to the State hospitals as soon as they can. On a Thursday approximately 1 year ago, a patient at Hastings State Hospital was transferred to a nursing home 100 miles away. This patient had refused to eat and had been fed through a tube for some time. The same patient was returned to the hospital on Saturday because the nursing home had removed the tube and couldn't get the patient to eat. Asked why they didn't replace the tube, the home said they didn't have anyone on staff who knew how. They did have an LPN but she did not know how to do the procedure.

(d) If any proof is needed that residents are being released before there are appropriate alternative services, it is illustrated by these statistics from Nebraska: 12 patients have been released and readmitted a total of 127 times, and one patient has been readmitted 27 times.

(e) In the State of Wisconsin, in order to hide this reality about irresponsible deinstitutionalization, the State gives readmitted patients new numbers each time they come back into the system.

(f) States, in their zeal to get patients out of institutions and out of their budgets, are blatantly setting quotas for numbers of patients hospitals must release. The acting director of the Michigan Department of Mental Health came up with a budget which called for dramatic drops in the hospital census. The projected figures of inpatients for the next 2 years were precise by institution. They declared, in essence: "203 inpatients will be ready for release into the community from such-and-such facility." When asked where he got the figures, the State official said the source was the hospital administrator—the experts. When a legislative committee quizzed the administrators on how they arrived at these figures—asking: "Just how do you determine who is able to make it in the community?"—they replied: "We have no idea where or how the director came up with these numbers.

---

[1] Statistical Note 114, National Institutes of Mental Health.

[2] *Medical World News*, April 12, 1974. Telephone interview with Robert Reich, M.D., director of psychiatry, New York City Department of Social Services, Sept. 24, 1975.

[3] *Philadelphia Inquirer*, Sept. 21, 1975.

In good conscience we could not release the number of patients listed." When the director was pressed, he admitted that he simply had made up the figures. This is not an impressive statement for the man charged with the care of the severely ill in Michigan.

(g) Deinstitutionalization has become a code word for budget-cutting. Even in Wisconsin, which since the progressive era has provided a measure of care for its most dependent citizens, the State is simply emptying its institutions. The released patients are ending up in nursing homes as deficient and abusive as Mr. Bergman's in New York City. In Milwaukee, the 600-bed Mount Carmel Nursing Home is infamous among health inspectors—members of AFSCME—for its record of uncorrected violations. But it is owned by an influential political contributor, and it continues to receive discharged patients—and public funds—to abuse and mistreat them. In contrast, the Mendota Mental Health Institute in Madison runs a special program for autistic children. This program takes these children for no more than 6 months and trains them intensively. It also instructs parents, teachers, and workers in supportive services on how to care for these children when they are returned to the community. Far from being an impersonal, institutional program, this effort is community-oriented—it is "deinstitutionalization" in the best sense of this overused term. No knowledgeable observer questions the success of the program. But this program is being phased down because of a cold-hearted fiscal calculus. The State must pay for the care and training of the autistic children. If the children are farmed out into less adequate private facilities, the Federal Government pays for their care. The taxpayers save not a penny. The children lose the opportunity to lead more fulfilling lives. This cynical calculus has come to govern the provision of human services—even in the State of Wisconsin. Members of this committee, I spoke to one of your colleagues about this problem. He said, quite frankly, that Wisconsin would like to continue providing first-quality care, but the State wants to save money.

When patients are transferred from large public institutions into profiteering facilities, they are sent from one inhuman institution into another, with no medical care at all, and less concern for the individual resident.

We must not let one repressive system replace another. Nor can we forget the need for inpatient care facilities.

OVERCROWDED AND UNDERSTAFFED INSTITUTIONS

Many health care reformers of the 1960's offered a simple and beguiling formula for care for the mentally ill. They said: "Let us build a good community mental health center and we will do away with the need for that terrible, repressive kind of long-term care now given in the State hospitals." Inpatient services had become synonymous with *bad* impatient services in overcrowded and understaffed institutions with inadequate treatment facilities unrelated to the community. As late as 1974, a report of the Massachusetts Mental Hospital Planning Project stated it this way:

". . . It is . . . becoming clear that inpatient care is not the treatment of choice for most acutely disturbed persons but rather a last resort when other alternatives fail. Comprehensive mental health programs providing outpatient, emergency, day-and-night hospital, and consultation services have experienced great success in reducing the need for inpatient care.[4] "

But this view has been contradicted in a report from the Solomon Mental Health Center in Lowell, Mass., a community mental health center with 7 years of operating experience.

The Solomon Center has outpatient, day care, inpatient, emergency and education and consultation services—all of the essential services of a community mental health center. What the center found was that they couldn't replace the services of the hospitals and that they spent an increasing amount of time and staff energy on reproducing those services at great cost to the rest of their program. They reported that: "an increasing proportion of the personnel of the Solomon Center has been and is absorbed in caring for two categories of patient: the acutely psychotic who, in our absence, would be admitted to Worcester State

---

[4] *Report of the Special Commission on the Future of Gardner Massachusetts State Hospital,* May 14, 1975, p. 21.

Hospital, and the increasing number of slowly convalescent and chronically ill patients like the chronic schizophrenic, the severely depressed, and patients with organic brain impairments, who are socially dependent and who would be permanent or near-permanent residents of a State hospital in the absence of local mental health services."

The report goes on to report a dramatic rise in recent years in demand for inpatent care of the above two categories. Most importantly, the report casts doubt on the thesis that "well established community mental health services will virtually eliminate need for the equivalent of State hospital service" and suggests that rationale for transfer of funds from "hospital to community"—a formula that has become a major policy for most State departments of mental health—is based on illusions. This cannot go on.

AFSCME views institutions as places for treatment—not confinement. We support the movement for mental patients' rights.

AFSCME participated as a friend of the court in the case of *Souder* v. *Brennan*, a class action on behalf of patient workers at State hospitals for the mentally ill. We asked the Labor Department to apply minimum wage and overtime standards to patients forced to perform tasks that have no relation to work therapy or vocational training.

A Federal court has issued a preliminary injunction against this practice of forced labor—which affects some 200,000 patient workers in 27,000 facilities.

And our union joined as a friend of the court in Kenneth Donaldson's lawsuit against his involuntary confinement—and denial of treatment—in Florida mental institutions.

We believe that the right to treatment must be the right to receive treatment—not merely the right to be released.

A patient's right to decent care corresponds to the obligations of the community to provide that care—not to the State's prerogative to abandon the patients to profiteers. The freedom to be ignored or exploited is no freedom at all.

WHAT ARE THE CAUSES OF THIS NATIONAL DISGRACE?

The Congress must stop bankrolling irresponsibility. It is meaningless to sit here today shaking our heads at these horrors without assigning responsibility for the situation. Federal legislation actively encourages the abuses documented today. Needy mental patients in State institutions were excluded from coverage under the Social Security Act in 1935. Reviewing the situation in 1965 when it reported medicare and medicaid, the House Ways and Means Committee explained:

"The reason for this exclusion was that long-term care in such hospitals had traditionally been accepted as a responsibility of the States. There have been many encouraging developments, in the meantime, in the care and treatment of the mentally ill . . . Most significantly, progress is being made in the provision of short-term therapy in the patient's own home, in special sections of general hospitals, in specialized mental hospitals, and in community mental health centers.[5] "

Although it decided to include medicaid coverage for persons over 65 in 1965, and despite the 1972 amendments that added coverage for persons under 21 in State mental hospitals, there have been no funds available for the 21–65 age group—by far the largest population of State mental hospitals.

This policy has encouraged the efforts of budget-cutting Governors and State legislators to rid themselves of their responsibility to provide patient care. Rather than meet the judicial and medical demands for humane conditions and treatment for each State mental hospital inpatient, States have taken advantage of readily available Federal aid in the form of medicaid, medicare, and the new supplemental security income program to discharge their inpatients to nursing homes, board-and-care facilities, and, worse, to the streets.

Medicaid and medicare requirements for nursing homes have failed to adequarterly protect patients, and the Department of Health, Education, and Welfare has *consistently* refused to enforce them. The work of this committee and investigatory bodies such as New York's Moreland Act Commission have carefully documented deficiencies, and it will be a long time before senior citizens, released patients, or anyone else, can feel secure in the average American nursing home.

---

[5] *U.S. Code, Congress and Administration News,* at 2084 (1965).

SSI (supplemental security income), another important source of support for discharged mental patients, like medicare and medicaid, is unavailable to support inpatients of State mental hospitals.[6] This preclusion results in still another economic pressure to discharge patients regardless of whether they could benefit from inpatient treatment. Yet what is worse, SSI contains no restrictions on the type of facility in which a discharged mental patient may live. Consequently, even if a discharged patient needs after-care, whether medical or social services, the SSI beneficiary may be assigned to a board-and-care facility which has no treatment of any kind. The State is thus relieved of the cost of caring for another hospitalized patient.

Former mental patients were found in deplorable conditions—malnourished, dehydrated, and infested with insects in one Philadelphia area board-and-care home. SSI was their sole source of support. In California, discharged patients in that State's "Thunderseed" rehabilitation program were recently forced to bring a lawsuit against the State because, in a budget-cutting effort, the State had decided to let the patients stay in board-and-care homes without rehabilitative services of any kind. For those discharged patients who qualify, SSI is nothing but a room-and-board program: the law contains nothing to protect the patient's need and right to treatment.

WHERE DO WE GO FROM HERE?

Quality care for the mentally ill must be accepted as a responsibility of this Nation. In order to stop the nursing home and board-and-care abuses that now plague discharged mental patients, Congress must first recognize that treatment of the mentally ill requires a balanced system of accountable public care—care which includes expanded community services as well as improved inpatient services in State psychiatric hospitals.

RECOMMENDATIONS

(1) Medicaid and SSI legislation must be amended to provide coverage of residents in State mental hospitals. This is a logical step toward alleviating the present pressures that have resulted in pell-mell discharges to the profiteering nursing home and board and care industry. Such an amendment would go far toward recognizing that public inpatient services are an integral part of a balanced system of health care. And, at the same time, the amendments would protect patients from sudden discharge to facilities incapable of meeting their needs.

(2) Community mental health centers must be expanded to include adequate public transitional living centers, public sheltered care workshops, public nursing care, and public board-and-care facilities, in addition to their present services. Recognizing employees as a vital resource to any mental health delivery system, institutional workers must have the right to retraining and transfer rights into these alternative community facilities. In addition, Congress must recognize that public mental health services delivered by community mental health centers require sustained assistance from the Federal Government if they are to expand beyond their present number and if they are to continue after their first 8 years of existence. The recent renewal of the CMHC legislation authorized funding for no more than 8 years, after which the community mental health center is expected to be self-sustaining. The House Health Subcommittee Report on the Health Revenue Sharing and Health Services Act of 1975 makes it clear that there are overwhelming constraints to achieving this goal.

(3) Medicare, medicaid, and SSI legislation must be amended to preclude the discharge of former inpatients to facilities which are incapable of treating them. This means that new requirements must be developed specifying staffing and therapeutic programs in any nursing home or board-and-care facility that receives Federal funds directly—through medicare and medicaid—or indirectly through fees charged to SSI beneficiaries. The Federal Government is not reluctant to impose safety requirements for automobiles: in order to sell a car in the United States, a manufacturer must meet air pollution and safety restraint specifications. How disgraceful it is that the Congress is unwilling to

---

[6] Social Security Act, Sec. 1611(a)(1)(A).

impose therapeutic, safety and staffing standards on facilities which provide services to discharged mental patients.

You know and I know that a society is judged by how it cares for its most needy.

Senator Moss. Well, we have had an interesting hearing this morning. We have heard many disturbing things, and we have pointed up serious problems that we have in society, and especially those affecting the elderly people of our Nation. The witnesses who have appeared here this morning have given us a good overview. We will continue our deliberations to see what there is from our standpoint that we can do to resolve some of these very serious problems.

The hearing will now be in recess.

[Whereupon, the hearing was adjourned at 12:20 p.m.]

APPENDIXES

Appendix 1

SEPTEMBER 1975 PUBLICATION OF THE MENTAL HEALTH LAW PROJECT

The MENTAL HEALTH LAW PROJECT

Summary of Activities: September 1975

1751 N Street NW Washington DC 20036 84 Fifth Avenue New York NY 10011

The Right to Liberty: SUPREME COURT DECISION IN *O'CONNOR v. DONALDSON*

Wide World Photos

Ex-patient Kenneth Donaldson displayed the Supreme Court's opinion for photographers and TV cameramen in front of MHLP's Washington headquarters on June 26.

INSTITUTIONAL DRUG ABUSE? (continued)

Senate Committee Looks at "Chemical Straitjacketing"

"We are concerned about use of potentially harmful tranquilizers -- chemical straitjackets as it were, which assure solitary confinement of the mind -- as a substitute for humane treatment and quality programs," Senator Birch Bayh said this summer at the opening of hearings by the Senate Subcommittee to Investigate Juvenile Delinquency.

MHLP staff members James Ellis and Gail Marker and Project trustees Janet Gotkin and

Continued on page 6

in this issue

The Docket:

TEST-CASE LITIGATION

The following cases are in litigation by Mental Health Law Project attorneys. Full details of ongoing and closed cases appear in the March 1975 MHLP newsletter.

DONALDSON v. O'CONNOR

In 1957, at the age of 48, Kenneth Donaldson was committed to a Florida state mental institution for "care, maintenance and treatment." For most of the fifteen years he was confined there he remained on locked wards, receiving no treatment. To both hospital authorities and courts, he made repeated attempts to win his release. In 1971 he was suddenly discharged -- just two weeks before Bruce Ennis was to argue his case before a federal court.

Continued on page 2

The Mental Health Law Project

is an interdisciplinary public-interest organization devoted to protecting the legal rights of the mentally handicapped (and those so labeled) and improving conditions for their care, treatment, education and community life.

Paul R. Friedman
Managing Attorney
James W. Ellis
Bruce J. Ennis
Christopher Hansen
Joel Klein
Robert Plotkin
Edward P. Scott
Patricia M. Wald
Attorneys
Charles Halpern
Benjamin W. Heineman Jr.
Of Counsel

Gail Marker MSW

Lee A. Carty
Development/Public Relations
Deborah Brown
Assistant
Judy Smolen
Administration
Phillip A. Christopher
Diane Johnson
Christine A. Moran
Deborah Stead
Legal Assistants

SPONSORS

American Civil Liberties Union Foundation
American Orthopsychiatric Association
Center for Law and Social Policy

MHLP Summary of Activities

is published quarterly by the Mental Health Law Project, 1751 N Street NW, Washington DC 20036; Editor, Lee Carty.

The Docket: *Continued from page 1*

On November 28, 1972 a federal jury in Tallahassee awarded Donaldson $38,500 damages, to be assessed personally against hospital superintendent O'Connor and the "treating" physician. In the spring of 1974, the Court of Appeals for the Fifth Circuit upheld the award and affirmed the lower court's decision that Donaldson had been entitled to release in the absence of treatment -- the first federal appellate court ruling for a constitutional right to treatment.

Dr. O'Connor appealed the decision to the Supreme Court, where the Project submitted a scholarly brief written by Ennis, Paul Friedman and Ben Heineman. On January 15, 1975 Ennis argued Donaldson's right to freedom before the justices -- the high court's first consideration of the rights of civilly committed mental patients. The landmark decision handed down on June 26 affirmed the right to liberty for those like Kenneth Donaldson -- nondangerous persons held in custodial confinement.

The damages aspect of the case was remanded to the Fifth Circuit "to enable [that] court to consider whether the District Judge's failure to instruct [the jury] with regard to the effect of O'Connor's claimed reliance on state law rendered inadequate the instructions as to O'Connor's liability for compensatory and punitive damages." On August 5, without briefing or argument by the parties, the Fifth Circuit held that the trial court's instructions were insufficient. It remanded the case to the District Court for further proceedings, if any, consistent with the Supreme Court's opinion in *Donaldson* and in its most recent decision on the scope of qualified immunity possessed by officials under the Civil Rights Act. (Analysis of the Supreme Court's opinion and of the remand appear elsewhere in this newsletter.)

The Project has filed a motion with the Fifth Circuit urging reconsideration of the August 5 order. [*O'Connor v. Donaldson*, ___ U.S. ___ (43 U.S.L.W. 4929, June 26, 1975), 493 F.2d 507 (5th Cir. 1974)]

Right to Treatment and Protection from Harm

IN THE MATTER OF HJB

Joel Klein and Pat Wald are assisting the Public Defender Service of the District of Columbia in a suit involving the right to individualized treatment for a thirteen-year-old Korean orphan girl.

HJB is an autistic child brought to the U.S. by the Catholic Committee for Refugees and Migration for purposes of adoption. Due to her illness the adoption fell through and HJB has been shunted from institution to institution and religious home to religious home, while her mental condition has continued to deteriorate. Last year the Catholic Committee had HJB brought to the District of Columbia, which in turn had her committed to St. Elizabeths Hospital where she was housed on a ward for the elderly. She has been sexually assaulted by another patient and has herself assaulted some of the older people on her ward.

Faced with this horrible situation, the Public Defender sought alternative placements for HJB and finally managed to get the Bradley Hospital in Rhode Island to accept her. Bradley claims to have the treatment programs to aid HJB but the cost of care there is $80 per day, substantially more than the cost of "care" at St. Elizabeths. At the Public Defender's initiation, Superior Court Judge Tim Murphy ordered that HJB be placed in Bradley, and made the District of Columbia and the Catholic Committee jointly and severally liable for the cost of hospitalization. Both defendants have appealed.

MHLP will be co-counsel on appeal, arguing that the local commitment statute, known as the Ervin Act, provides a judge with the authority to commit a patient to a facility that will be able to treat his or her particular illness. Such commitment is permissible even if it costs more than commitment to a local facility and even, in rare circumstances, if it must be to an out-of-state facility. The principle we support in this litigation is a part of our overall strategy of insuring that those who are involuntarily committed are provided treatment or habilitation based on their individual needs.
[*In the Matter of HJB*, Mental Health No. 80-74, Superior Court, D.C., Orders of May 7 and June 3, 1975.]

MORALES v. TURMAN

In this comprehensive right-to-treatment suit for Texas juveniles, the Project (Pat Wald) represents five national organizations as *amici*: American Orthopsychiatric Association, National Association on Mental Deficiency, National Council on Crime and Delinquency, American Psychological Association and Child Welfare League.

In August 1974 the United States District Court for the Eastern District of Texas issued a 200-page opinion upholding the rights to treatment and protection from harm for juveniles in six state reformatories. The court also ordered the parties to engage in negotiations leading to a final injunctive order. *Amici* took part in these negotiations and proposals for final relief are now pending before the court. The case is also on appeal to the Fifth Circuit. *Amici*'s brief has been filed and oral argument is expected in the fall. [*Morales v. Turman*, 364 F. Supp. 166 (E.D. Tex. 1973), *Memorandum Opinion*, 383 F. Supp. 53 (E.D. Tex., August 30, 1974).]

WASHINGTON AREA COUNCIL ON ALCOHOL AND DRUG ABUSE v. WASHINGTON

This right-to-treatemnt suit was filed to require the local government to honor its statutory commitments on behalf of individual alcoholics in the District of Columbia, by Patricia Wald of the Project and Robert Saylor of Covington & Burling. The trial court upheld the motion for a class action and discovery is virtually completed looking towards a summary judgment.

Wald Named Litigation Coordinator

Patricia Wald has been designated Litigation Coordinator of the Mental Health Law Project. In addition to her continuing involvement with several of the Project's cases, she will coordinate all litigation brought by MHLP attorneys and all backup assistance provided to other attorneys litigating in areas of Project interest.

The new post was created to facilitate the Project's pursuit of a cohesive and effective litigation strategy in line with its policy goals and to ensure continuing liaison and cooperation with other lawyers working towards the same objectives.

WYATT v. HARDIN

Ed Scott and Paul Friedman represent *amici* (American Psychological Association, American Orthopsychiatric Association, American Association on Mental Deficiency and National Association for Mental Health).

In light of the district court's April 2, 1975 denial of the plaintiff's motion for a compliance hearing and for the reopening of discovery (see MHLP's June 1975 Summary of Activities), the Project has taken the approach of working with the court-established human rights committees to develop specific information as to the extent of compliance and the need for revision of standards.

On the mental-retardation side of the case, the Project, in cooperation with the Partlow Human Rights Committee, has arranged for several experts to make evaluations of institutional and community programs, psychotropic-medication practices and medical services in Alabama's mental-retardation programs. In September, the results of these evaluations will be given to the Human Rights Committee which will submit them to the court.
[*Wyatt v. Stickney*, 325 F. Supp. 781 (M.D. Ala. 1971), 344 F. Supp 1341 (M.D. Ala. 1971), 344 F. Supp. 373 & 387 (M.D. Ala. 1972), *aff'd in part, modified in part sub nom. Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974).]

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN et al. v. CAREY

The consent judgment signed on April 30, 1975 resolved the two class actions known as the Willowbrook case after three years of litigation. The decree provided for a seven-member Review Panel to oversee implementation of detailed standards set to protect the 5,209 mentally retarded persons resident in Willowbrook Developmental Center at the time the suit was brought.

Continued on page 4

Continued from page 3

Bruce Ennis and Chris Hansen worked with the court and defendants on appointment of the panel, one of whose members is James Clements MD, director of the Georgia Retardation Center and trustee of MHLP. The panel must submit by the end of October a comprehensive community-services plan. (*New York State Association for Retarded Children et al. v. Carey*, 393 F. Supp. 715 (E.D.N.Y. 1975), 357 F. Supp. 752 (E.D.N.Y. 1973).

Deinstitutionalization and Rights in the Community

"DUMPING:" CALIFORNIA'S THUNDERSEED PROGRAM

The San Francisco Neighborhood Legal Aid Foundation had filed a suit on behalf of about one hundred former involuntary patients released *en masse* from state hospitals pursuant to California's Lanterman-Petris-Short Act. These and many other people are what California calls "gravely disabled" -- in functional terms, meaning that if left alone they do little more than sleep or sit still.

The plaintiffs are all kept in private "board and care" homes, paid for by state and federal welfare funds. From 1973 to 1975 they participated in an outpatient day-care program called Thunderseed which provided their only real opportunity for recreational and therapeutic treatment. California mental-health professionals agreed it was an effective program.

In June 1975, California terminated funding for Thunderseed, leaving plaintiffs confined full-time in the board and care homes. Without Thunderseed programs, the extent of their "treatment" appeared to be a weekly visit from a doctor to ensure that they took their medicine.

Plaintiffs sued the state of California and the county of San Francisco for reinstatement of the Thunderseed program or implementation of alternative individualized treatment programs. They alleged that the Lanterman-Petris-Short Act, which provides for their release from commitment, also mandates an effective aftercare program. Alternatively, plaintiffs asserted that, in view of their former involuntary commitment, defendants' failure to provide aftercare to improve plaintiffs' conditions -- or, at a minimum, protect them from further harm -- is a violation of their state and federal constitutional rights to treatment. Defendants argued that these plaintiffs are no longer involuntary patients, that they have been "restored to liberty" and that therefore they have no statutory or constitutional right to further treatment.

The case was filed in California Superior Court in San Francisco. The court denied plaintiffs' motion for a preliminary injunction prohibiting the closing of Thunderseed in June. Joel Klein and Pat Wald of the Project agreed to participate as co-counsel on behalf of plaintiffs. However, defendants voluntarily decided to reinstate the Thunderseed program, thereby mooting the action. The Mental Health Law Project remains concerned about the problem represented by this case -- "dumping" and abandoning former hospital patients -- and will continue to litigate these issues when they are presented in other cases.

DIXON v. WEINBERGER

Patricia Wald and Ben Heineman are counsel for the plaintiffs in this class action involving an extension of the right to treatment that attempts to avoid the two evils of "warehousing" and "dumping." The suit seeks to compel creation of less restrictive alternative facilities for more than one thousand patients at present involuntarily confined in St. Elizabeths Hospital in Washington, D.C. Requested are minimum standards for number and quality of such facilities to ensure that vindication of the right to alternative treatment will benefit rather than harm patients after their release.

In February 1975, the district court denied defendants' motion for judgment on the pleadings, thereby rejecting their arguments that they had neither the authority nor the duty to assure that committed patients are placed in suitable less restrictive settings. The Project filed a motion for summary judgment in April, on which a decision is expected soon. [*Dixon v. Weinberger*, Civ. Act. No. 74-285 (D.D.C., filed February 14, 1974).]

MILLS v. BOARD OF EDUCATION

On July 24, 1975, Federal Judge Joseph C. Waddy appointed Dr. Oliver L. Hurley of Athens, Georgia as special master with powers to implement the court's 1972 order that the District of Columbia must provide appropriate education for mentally retarded and handicapped children. The first such appointment in a contested right-to-education suit, it had been requested by Robert Plotkin and Patricia Wald as part of the Project's continuing efforts to implement the decision won three years earlier.

In March, Judge Waddy had found D.C. officials in contempt for failure "to faithfully comply with the provisions and orders of the court." He requested the local government to submit a comprehensive budget and plan to identify children ages seven to sixteen in need of special education and to provide the necessary services. The master was appointed after the government had failed to submit plans.

The D.C. Board of Education was ordered to provide Dr. Hurley with office space and free access to records and to deposit $15,000 with the court to pay his salary and expenses. Plotkin will continue to provide any legal assistance as it may be needed. [*Mills v. Board of Education of the District of Columbia*, 348 F. Supp. 866 (D.D.C. 1972).]

Confidentiality

WOMELDORF v. GLEASON

Robert Plotkin filed a class action on August 6, 1975, challenging a government's right to ask job applicants about intimate personal-health details. The suit -- which we believe to be the first of its kind to be brought before a federal court -- is brought against officials of Montgomery County, Maryland by the National Association of Social Workers and a woman who was not hired, she said, because she refused to disclose such information.

The complaint alleges that Bonnie Cox Womeldorf was denied employment as a social worker last February because she refused to complete a medical questionnaire which required her to divulge any treatment she may have received in the past five years from any "clinics, physicians, healers or other practitioners," to disclose whether she had ever had "female disorders," "vaginal discharges," "depression or excessive worry" or "terrifying nightmares." The questionnaire further required her to sign a form which would have allowed the county to obtain all of her medical records.

An individual's right to privacy, the suit claims, prohibits governmental inquiries about intimate health records unless there is a demonstrated need for particular information to evaluate an applicant for a particular position. Montgomery County requires all applicants in the final stages of consideration for employment to fill out its form, regardless of the nature of the job sought. Plaintiffs urge the federal court to prohibit the county's further use of the form and to require the county to develop an acceptable questionnaire which does not unnecessarily invade citizens' rights to privacy. [*Womeldorf v. Gleason*, Civ. Act. No. B-75-1086 (D.C. Md., filed August 6, 1975).]

WINTERS v. MILLER

The constitutional issue in this case is now clear: that a mental patient objecting on religious grounds cannot be forced to accept non-emergency medication or physical treatment. Bruce Ennis succeeded in obtaining a U.S. Court of Appeals ruling to that effect, which the Supreme Court declined to review. The case was remanded to Federal District Court in New York for a trial on plaintiff's claim for damages, the question being whether defendants are personally liable for violations occurring prior to definition of the constitutional right.

After considerable procedural skirmishing which twice resulted in appellate court reversals of district court rulings, the case came to trial before a jury on July 22-30, 1975.

After deliberating for seven hours, the jury found that none of the seven defendants was liable -- even though the judge had instructed them that two of the seven defendants had failed to answer the complaint and were therefore in default and must be found liable. Because it appeared obvious that the jury had either ignored these instructions or had been confused by them, counsel moved to set aside the jury verdict with respect to all seven defendants. That motion will be heard by Judge Orrin Judd on September 19.
[*Winters v. Miller*, 466 F.2d 65 (2d Cir. 1971), *cert. den.*, 404 U.S. 985 (1971).]

VOLKMAN v. MILLER

Chris Hansen and Bruce Ennis had filed a suit in New York State Supreme Court on behalf of patients and professional staff at Tremont Crisis Center of Bronx State Hospital, charging that use of a computer data-bank form including names and Social Security numbers of patients was anti-therapeutic and would deter prospective patients from seeking treatment or make it difficult for doctors and social workers to establish necessary trust with patients. The case was dismissed on grounds that the state's insistence on the form is a reasonable exercise of its powers. Dismissal is now on appeal in the New York State Superior Court, Appellate Division.
Volkman v. Miller, dismissed (Sup. Ct., Albany Cty, July 23, 1975), *appeal filed* (N.Y.S., August 20, 1975).

Patient-Worker Rights

SOUDER v. BRENNAN

This class action to enforce provisions of the Fair Labor Standards Act, as amended in 1966, was filed by Paul Friedman and Patricia Wald of the Project and Margy Kohn of the Center on behalf of three named mentally ill and mentally retarded working residents of state institutions, the American Association on Mental Deficiency and the National Association for Mental Health. The American Federation of State, County and Municipal Employees, AFL-CIO, joined as intervenor-plaintiff. In late 1973 the court ordered the Secretary of Labor to implement the Act on behalf of patient-workers in non-federal institutions.

Friedman and Wald continue to provide assistance to lawyers bringing private damage actions for violation of the minimum-wage laws on behalf of individual mental patients. The special regulations governing payment of sub-minimum wages to severely handicapped workers who cannot engage in competitive employment have been very controversial and will be reviewed shortly by the Secretary of Labor's Advisory Committee on Sheltered Workshops, at a meeting which Friedman will attend. [*Souder v. Brennan*, 367 F. Supp. 808 (D.D.C. 1973).]

Continued on page 6

Continued from page 5

DALE v. STATE OF NEW YORK

Damages for back wages and for pain and suffering for violations of Thirteenth Amendment guarantees against involuntary servitude were sought by Paul Friedman and Bruce Ennis for a former patient. Despite expert testimony in support of Mrs. Dale's claim, the New York State Court of Claims ruled against her. That decision has been affirmed on two appeals. Since it was a decision on the facts rather than on the law, Friedman and Ennis recommended to Mrs. Dale that her case not be appealed to the Supreme Court. *Dale v. State of New York, aff'd,* 36 N.Y.2d 833, 370 N.Y.S.2d 906 (May 1, 1975), 355 N.Y.S.2d 485 (3d Dept. 1974)

"Right to Refuse" Treatment (Standards & Safeguards)

DOE v. YOUNGER

California enacted a law to regulate psychosurgery and electroconvulsive therapy (ECT). *Doe v. Younger* is a case in which two patients and three doctors sought to have the law declared unconstitutional as an unwarranted state intrusion into the privacy of the doctor-patient relationship.

Jim Ellis and Ed Scott prepared an *amicus curiae* brief for the National Association for Mental Health, attempting to assist the court (California Court of Appeal, 4th District, Division 1) in sorting out the complex constitutional issues presented by petitioners' request for a writ of mandate. The brief argues that competent patients have a right to refuse such treatments and that psychosurgery and ECT are so intrusive and hazardous that the legislature was justified in attempting to assure that patients' consent to these procedures was competent, informed and voluntary. Decision is awaited.

NELSON v. HUDSPETH

James Ellis is working with David Michaels of Community Legal Services of Mississippi on a case involving the right of hospitalized mental patients to refuse electroshock therapy. On May 12, 1975 the judge overruled defendants' motion to dismiss and accepted an amended complaint. Interrogatories have been served and discovery is proceeding. [*Nelson v. Hudspeth,* Civ. Act. No. GC74-100s (N.D. Miss. 1974).]

CHANGE OF ADDRESS?

Please complete and send this coupon to MHLP, 1751 N St. NW, Washington DC 20036.

NAME ______________________________

CORRECT ADDRESS ______________________

____

OLD ADDRESS __________________________

WYATT v. HARDIN

In the June 1975 MHLP Summary of Activities, two significant actions pertaining to Standard Nine of the court's April 1972 order were described. Originally, Standard Nine prohibited the use of ECT, aversive conditioning and other unusual or hazardous procedures in mental hospitals without the patient's express and informed consent.

One was the court's February 28, 1975 revision of Standard Nine generally along the lines proposed by the Project on behalf of *amici* organizations. The Project had filed a motion to amend the revision in certain procedural respects and to allow aversive conditioning to be administered to incompetent patients under strict standards and procedures similar to those which the new order provides for the administering of ECT to incompetents. On July 1, 1975 the court denied the Project's motion with respect to certain procedural matters.

The other significant matter involved contempt proceedings which had been brought against hospital personnel involved in the administration of ECT in violation of the former Standard Nine. On June 26, 1975 the court found beyond a reasonable doubt that the named individuals -- a staff physician, two psychiatrists and the hospital director -- had violated Standard Nine. However, the court acquitted them of criminal contempt charges on grounds that wrongful intent had not been proven beyond a reasonable doubt, and held them not guilty of civil contempt on grounds that the evidence had not established actual loss or damage on the part of patients given ECT.

"Chemical Straitjacketing"

Continued from page 1

James Clements were among the witnesses who testified during the hearings on the abuse and misuse of controlled drugs in juvenile institutions.

"As chairman of the subcommittee," Senator Bayh said, "I am obligated to assess whether the Controlled Substances Act, which regulates the use and abuse of controlled pharmaceutical products as well as street drugs, is properly enforced.

"In the course of our investigations we have learned of violations involving the phenothiazines in institutions for juveniles," Bayh continued. "Whether it be a violation of the Federal Drug Control Act or a violation of humane treatment standards, I intend to fully investigate and report our findings to the Congress and the American people. We are also concerned to learn more about the role federal agencies should play to more carefully monitor practices in our institutions to avoid these scandalous results."

Excerpts from some of the witnesses' formal testimony follow. Texts of the statements by Ellis, Marker, Gotkin and Clements are available by request (accompanied if possible by $1 to cover copying and postage) from MHLP, 1751 N Street NW, Washington DC 20036.

Janet Gotkin *for ten years "was on the receiving end of what is called psychiatric 'treatment,' always a so-called 'voluntary' patient." She is co-author of a book soon to be published, Too Much Anger, Too Many Tears (Quadrangle).*
I am one of thousands. What makes my story of particular note is that I survived, intact, and am here to speak to you today, instead of moldering, lethargic and drugged, a resident of the back wards... Over the years I took almost every drug on the market: Thorzaine, Mellaril, Taractan, Compazine, Stelazine, Serax, Prolixin (Permatil), Valium, Librium, Miltown, Doriden, Nembutal, Seconal, Tuinol, Chloral Hydrate, Sodium Amytal (by injection), Dexamyl, Kemadrin, Tofranil, Elavil. You name it, I took it; often in combinations; mostly at very high dosages...

In all the years I took these drugs never once did they in any way help me to solve my problems or come in touch with my feelings. Quite the contrary. I never had to face any problems because they were all called 'symptoms' and I was given drugs to deal with them. I became alienated from myself, my thoughts, my life, a stranger in the normal world, a prisoner of drugs and psychiatric mystification, unable to survive anywhere but in a mental hospital. The anxieties and fears I had lay encased in a Thorazine cocoon and my body, heavy as a bear's, lumbered and lurched as I tried to maneuver the curves of the outside world.

James Ellis *is an attorney on the staff of the Mental Health Law Project. He has worked in an institution for mentally ill juveniles and has recently been reviewing the patterns of use of psychotropic drugs in public institutions for the mentally ill and retarded.*
Institutional drug abuse...consists of actions taken by physicians, almost always within the letter of the law, and usually acting on behalf of the government itself. The drugs involved are the co-called psychotropic drugs.

To the extent that they have alleviated suffering, reduced the populations of our large mental hospitals and facilitated the provision of treatment on an outpatient basis within the community, these drugs have had a beneficial impact on our systems of mental-health care. But early overenthusiasm about these drugs, coupled with the administrative convenience their tranquilizing and sedative effects produce for institutional staffs, have produced the current problem...

Institutional drug abuse is more than just a matter of medical concern -- it represents a violation of the constitutional rights of the residents... The right to refuse treatment is not only an outgrowth of the doctrine of informed consent; it is also based on the constitutional requirement of due process, the prohibition against cruel and unusual punishment and the right to privacy. The privacy aspect of the right to refuse medication also has First Amendment support when the medication is aimed at affecting mental processes... The right to free speech would mean little if the right to freely form one's own thoughts could be impeded by state (medical) action...

In juvenile facilities, mental hospitals and institutions for the retarded, courts have held that overuse and inappropriate prescription of psychotropic medications violates patients' constitutional right to treatment. The number of these rulings can be expected to increase...

But litigation alone will not be enough to remedy these abuses. The problem is so widespread and the difficulties of proper regulation are so apparent that a variety of actions -- legislative, judicial and administrative -- will be necessary. Responsible administrators and health-care professionals are beginning to devise procedures which might eliminate many of these abuses. Organizations like the Mental Health Law Project are exploring what role the courts and litigation should play. Legislators on the state and federal level are becoming concerned. None of these avenues will provide an easy solution [but] regulations can be devised which will combat the abuses without jeopardizing the treatment value of the drugs to patients for whom they are indicated. Good medical practice and the rights of patients are not in conflict in this area.

Gail Marker *MSW was a caseworker and acting unit director of social services at a Texas mental hospital. She has completed a study of all research on use of phenothiazines on the mentally retarded; over 70% failed to meet even half the minimal criteria for adequate drug studies (see March 1975 MHLP Summary of Activities).*
About one out of every six prescriptions in America today is for a psychotropic drug. While there is deep concern about their overuse on patients generally, there is particular concern about their use on institutionalized populations.

Many persons confined in institutions for juveniles, the mentally ill and the mentally retarded are without family or friends to keep an 'open window' on their condition. Children and mentally retarded persons are particularly vulnerable since they may be

Continued on page 8

Continued from page 7

unable to fully understand what is being done to or for them and may be unable to adequately communicate their concerns or report critical information about adverse effects...

The weight of the evidence strongly suggests that phenothiazines may slow reaction time, decrease accuracy, decrease learning performance and impair maintenance of attention to details... Although there have been only a handful of studies evaluating the effects of these drugs on learning ability of mentally retarded subjects, they tend to show the same negative results... It is obvious why these adverse effects -- decreased concentration and ability to learn -- are so troublesome for mentally retarded persons. The capacity to learn and perform, at whatever level...may mean the difference between dependence and independence, institutional confinement and community life.

Yet in 1967-68, Dr. Ronald Lipman of the National Institute of Mental Health found that 51% of the residents in institutions for the mentally retarded in this country were on psychotropic drugs... From the reports from institutional personnel and residents with whom we are in contact, it appears that the situation is no different today...

Since we are all concerned that mentally retarded persons should have access to therapeutic interventions which will help them, but not be subjected to interventions which will harm them, it is essential that we obtain the factual data necessary to make rational drug-treatment decisions... Most of the critical questions...could be sufficiently answered in a one to two-year period involving three separate studies with a total of about 120 subjects at a cost of about $300,000. Since it is essential that these studies be unbiased, we would strongly urge the federal government to finance or help locate financing for such research rather than relying upon the drug companies... A national clearinghouse that regularly collects, summarizes and distributes critical drug information in a readable, coherent fashion to institutions would be a most valuable service, not only for the staff but for the residents.

These two actions [would] constitute a major first step towards providing resolution of a national health-care problem.

James Clements *MD is a pediatrician specializing in child development and retardation. He is director of the Georgia Retardation Center, a state-operated residential facility for the mentally retarded.* It would be difficult for me to impart to you the degree of concern that what I have observed may, in fact, be representative of conditions of more than 150,000 mentally retarded people in institutions in the United States today.

...Under what conditions are these drugs given? For those of you who have not visited a residential facility for the mentally retarded, let me briefly describe a typical living unit.

This usually consists of a large day room, a large ward-type sleeping area and a so-called gang bath. Privacy is non-existent. ...People live day in and day out in large groups. They eat in groups, sleep in groups, mill about the day room in groups and attend to toileting in groups -- all in an environment of harsh surfaces, loud noises and areas often permeated with the odor of urine and feces. Furniture is sparse or non-existent.

To compound this tragic situation, there is often no organized activity... Even if there were adequate space to organize therapeutic programs for small groups of residents, there are not sufficient personnel in quality and quantity to do the job...

It is not unusual in these situations for one untrained and unskilled employee to have to attend to the bathing, feeding, toileting and all needs of as many as thirty residents in addition to administering medication to them. Not only are regularly scheduled drugs given by people who may be totally unknowledgeable of dosages, contraindications, side effects, etc., but it is not unusual for PRN (whenever-needed) orders to be left to their discretion...

The extremely depriving, non-stimulating environments described above do in fact foster the very behaviors that drugs are given to alleviate -- head-rolling, head-rocking, head-banging, picking, pulling and rubbing habits, teeth-grinding, masturbation and disruptive behavior (frequently the target for drug control) -- are due in part to the general environment in which drug therapy is being utilized. Nelson's *Textbook of Pediatrics* describes the treatment of choice for these conditions as correcting the environmental situation. It does appear, therefore, that a condition is being altered by medication inappropriately when the condition is caused and/or accentuated by an alterable environmental situation...

It would be naive to assume that a few regulations relating to proper use of drugs would give adequate relief to so large a problem. Ultimate solutions involve better medical education relating to mental retardation, improvement of institutional environments, adequate quality and quantity of staff, development of proper individualized programs for people in institutions, providing adequate procedural safeguards, as well as providing massive systems of community programs and community living arrangements for mentally retarded people in the least restrictive environment possible.

• • • • • • •

MHLP position paper: Implications of the *Donaldson* Decision

I. What the Supreme Court Held

The central holding of the *Donaldson* opinion was set forth by the court as follows: *"A State cannot constitutionally confine without more* [*i.e.*, without providing more than custodial care] *a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends."*

In practical effect this holding means that any state presently hospitalizing a nondangerous person against his or her will is violating that person's constitutional right to liberty unless the state is providing the patient with treatment. This is not to say that (1) if a person is a danger to self or others, or (2) if a person is being given treatment, he or she can be involuntarily hospitalized. The Supreme Court's decision simply defines one set of circumstances in which a person cannot be confined.

There were also several ancillary holdings of significance.

1. The court summarily rejected the argument that, when treatment is the rationale for commitment, the adequacy of treatment provided the patient is a non-justiciable question. In the court's words, *"*[*w*]*here 'treatment' is the sole asserted ground for depriving a person of liberty, it is plainly unacceptable to suggest that the courts are powerless to determine whether the asserted ground is present."*

2. The court also held that states are under a continuing obligation to insure that the justification for an initially valid commitment is present after the initial commitment: *"Nor is it enough that Donaldson's original confinement was founded upon a constitutionally adequate basis, if in fact it was, because even if his involuntary confinement was initially permissible, it could not constitutionally continue after that basis no longer existed."* The clear implication of this holding is that states will have to adopt meaningful procedures for periodic review of those people involuntarily confined. It is also at least an arguable inference from this holding that at such periodic reexaminations the state has the burden of proving that the criteria for confinement are still satisfied.

3. The court further held that mental-health officials who staff state hospitals can be held personally liable for violating a patient's constitutional rights. Although the court remanded the damage issue in this case for a future determination whether Dr. O'Connor knew or reasonably should have known that continuing to confine Mr. Donaldson against his will was unconstitutional, it unequivocally rejected Dr. O'Connor's argument that he should be given unqualified immunity from damages. Rather, the court held that such doctors are subject to the same standards of immunity that traditionally apply to government officials. Thus, doctors at state institutions who in the future confine a "Donaldson-type" patient may clearly be held liable in damages for violating the patient's constitutional rights.

Finally, there are some suggestions or implications in the court's opinion that are worthy of note:

1. Although the court did not specifically define what it meant by *"danger to self or others,"* it did suggest that these criteria should be viewed narrowly. In particular, when speaking of people who could be considered dangerous to themselves, the court indicated that such people do not include those *"who are capable of surviving in freedom"* or who are not *"helpless to avoid the hazards of freedom."* While the court did not amplify on these concepts, when describing Donaldson's behavior it was careful to note that he had never *"committed a dangerous act"* and that *"there was no evidence that* [he] *had even been suicidal or been thought likely to inflict injury upon himself."* (Emphasis supplied.)

2. The court relied on *Shelton v. Tucker*, its principal "least restrictive alternative" case, for the proposition that *"incarceration is rarely if ever a necessary condition for raising the living standards of those capable of surviving safely in freedom on their own or with the help of family or friends."*. By relying on this doctrine the court indicated that it thought the "least restrictive alternative" doctrine was an appropriate constitutional

approach in this area. This doctrine would require the state to use the least intrusive means, maximizing individual liberty, in achieving any legitimate goals of involuntary confinement.

3. The court also gave indications that the term "mental illness," when used as a basis for confinement, could raise serious problems. The court noted that, for present purposes, it would *"assume"* that the *"term* [mental illness] *can be given a reasonably precise content and that the 'mentally ill' can be identified with reasonable accuracy."* The court's skepticism about the possibility of formulating a workable definition of mental illness, making the "assumption" necessary, opens the possibility that, in future cases, the justifications for confinement will have to be in terms of behavior and not in terms of a status or condition such as mental illness. It also raises the possibility of challenges to the reliability of psychiatric diagnoses.

II. What the Court Left Open and Where MHLP Stands

In noting that its decision was a narrow one, the court made clear that it was leaving open two questions: *"Specifically, there is no reason now to decide whether mentally ill persons dangerous to themselves or to others have a right to treatment upon compulsory confinement by the State, or whether the State may compulsorily confine a nondangerous mentally ill individual for the purpose of treatment."*

The Mental Health Law Project has established positions on both of these issues that we will seek to implement in presently ongoing and future litigation. First, we believe that if the state may involuntarily */ confine people on the basis of their danger to themselves or others, the state must provide the opportunity for constitutionally adequate treatment. By constitutionally adequate treatment we mean the standard used by the Fifth Circuit in *Donaldson* -- *"such treatment as will give* [the patient] *a reasonable opportunity to be cured or to improve his mental condition."* **/

This position was explicitly rejected by the Chief Justice in his concurring opinion, but, significantly, no other justice shared his views. Indeed, subsequent to its decision in *Donaldson*, the court declined to review *Burnham v. Georgia*. *Burnham* was a companion case to *Wyatt v. Aderholt*, another Fifth Circuit opinion which explicitly adopted the *Donaldson* position that civilly committed persons have a due-process right to treatment or release. Thus, by denying *certiorari* in *Burnham*, the Supreme Court consciously left that rationale as the governing law of the Fifth Circuit.

In addition to the *Wyatt* theory as a constitutional rationale for treatment, the Willowbrook decision suggests that much of what might be considered "treatment" is essential simply to prevent confined people from being harmed. Although this theory is conceptually distinct from the *Wyatt* analysis, the effects of judicial acceptance of either approach should be similar. Accordingly, MHLP will rely upon both these theories in its efforts to establish meaningful services and programs for the mentally handicapped.

Second, the Mental Health Law Project believes that, at a minimum, a person like Donaldson who is both competent and non-dangerous could not be legally committed against his will even if treatment were to be provided. In such circumstances the individual's right to liberty overrides the state's parental power. As the Supreme Court itself noted, *"the mere presence of mental illness does not disqualify a person from preferring his home to the comforts of an institution."* Moreover, the court made plain that "[*m*]*ere public intolerance or animosity cannot justify the deprivation of a person's physical liberty."* For such people it is our position that the state should provide treatment opportunities on a genuinely voluntary basis in community facilities.

---

*/ Our use of the term "involuntary" commitment does not mean that we believe that all patients presently labeled "voluntary" under state laws are voluntary for purposes of constitutonal analysis. On the contrary, we support the conclusion recently noted by courts and commentators that many patients presently defined as "voluntary" by state laws, may functionally be "involuntary" for constitutional purposes.

**/ Although we support a constitutional right to be given an opportunity for meaningful treatment, we also believe that if competent people can ever be involuntarily confined, as has heretofore occurred in virtually all states, such people also have a right to refuse hazardous or intrusive forms of treatment such as psychosurgery, electroshock, psychotropic medications and aversive conditioning.

The Supreme Court Unlocks Doors

by Paul R. Friedman

On June 26, 1975 a unanimous United States Supreme Court opened for judicial scrutiny the locked doors of the back wards of many shameful institutions which we euphemistically call "mental hospitals."

While the actual holding in *O'Connor v. Donaldson* is very narrow, its significance is great indeed and its ramifications are only beginning to be felt. *Donaldson* is one of the very few cases in its almost two-hundred-year history in which the Supreme Court has addressed the constitutional rights of civilly committed mental patients. At its most basic level, the opinion says that the members of our highest court care about the plight of the mentally handicapped and recognize that the United States Constitution protects this under-represented minority just as it protects other citizens.

What does the opinion say?

The narrow legal holding of *Donaldson* is that *"a state cannot constitutionally confine without more* [presumably, without treatment] *a non-dangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members and friends."*

Writing for the unanimous court, Justice Stewart rejected the notion that mental patients might be exiled by a community which finds their presence upsetting: *"May the state fence in the harmlessly mentally ill solely to save its citizens from exposure to those whose ways are different? One might as well ask if the state, to avoid public unease, could incarcerate all who are physically unattractive or socially eccentric. Mere public intolerance or animosity cannot constitutionally justify the deprivation of physical liberty."*

The court held further that *"mental illness alone"* cannot serve as a basis for *"simple custodial confinement."* May someone be confined because he or she would be better off in an institution? *"That the state has a proper interest in providing care and assistance to the unfortunate goes without saying. But the mere presence of mental illness does not disqualify a person from preferring his home to the comforts of an institution."*

What else does it imply?

While the *Donaldson* case was decided narrowly, the opinion is rich in ancillary holdings and implications. The court noted that adequacy of treatment is a justiciable question, that states are under a continuing obligation to review periodically the justifications for individual commitments and that mental-health personnel can be held personally liable for bad-faith violations of a patient's constitutional right to liberty. Moreover it suggests that dangerousness should be defined narrowly, that the "least-restrictive alternative" principle protects patients against unnecessary institutionalization and even that the term "mental illness" may be unconstitutionally vague.

Two interpretations have appeared in the press which are, in the opinion of the Mental Health Law Project, inaccurate.

First, some reports intimate that the decision is a signal to lower courts not to enforce the right to treatment. In his separate concurrence, Chief Justice Burger does indicate an unwillingness to recognize a right to treatment. But no other justice joined him, and only four days after the *Donaldson* decision the Supreme Court refused to review the *Burnham* right-to-treatment case from Georgia. By declining to hear and decide the right-to-treatment issue directly, the court left in effect a number of lower-court decisions recognizing a constitutional right to treatment, including the *Wyatt* decision in the Fifth Circuit.

Second, some newspapers have reported that the court held that mental patients cannot recover damages from their physicians. True, the Supreme Court reversed the lower courts' award of damages against O'Connor and remanded the issue for rehearing. But the remand is specifically to determine whether at the time he unlawfully committed Mr. Donaldson, Dr. O'Connor knew -- or reasonably could have known -- that he was violating Donaldson's right to liberty. Now that the right to liberty has been clarified and mental-health professionals put on notice, there is no doubt that they will be liable for damages if they illegally deprive a mental patient of freedom under state commitment laws.

What must states do now?

In the wake of the *Donaldson* decision, states will have to take several immediate steps. They must re-evaluate all of their involuntarily hospitalized patients to identify non-dangerous individuals who are being held against their will in custodial confinement. They will have to establish procedures to review periodically the status of all patients in the system. They would also be well advised to re-evaluate the standards and procedures for commitment under their state laws, since the *Donaldson* opinion indicates that many may be unconstitutionally vague and are likely to be reviewed by the Supreme Court in the not too distant future.

Continued on page 12

Continued from page 11

How many patients are affected?

Available data permits partial answers only. A high priority is collection of reliable statistics that would help ascertain the impact of this and other judicial decisions.

It has been suggested by some that the number of people directly affected by the *Donaldson* decision is small. The argument goes that there are only 250,000 patients confined to state and county mental hospitals to begin with; that of these, many are either "voluntary" or dangerous; that still more are in facilities that provide more than mere custody or that they would not be able to take care of themselves in the community. Under this line of reasoning, the number of "Donaldsons" in our mental institutions could be relatively small.

However, the 250,000-patient figure applies to the state and county hospital resident population at any given moment. In 1972 -- the most recent year for which this information is available -- there were over 600,000 persons "treated" as inpatients in state and county mental hospitals. In the same year. there were also about 1,000,000 inpatients "treated" in municipal facilities, psychiatric units of general hospitals, VA facilities, private mental hospitals and federally funded community mental-health centers. It is obvious, therefore, that there are many more than 250,000 inpatients being treated in psychiatric facilities throughout the country. Precisely how many are involuntarily confined, non-dangerous and receiving only custodial care? No one knows, but there could be very many.

Moreover, given recent recognition by courts and commentators that patients labeled "voluntary" may often be functionally "involuntary" for constitutional purposes, mental-health commissioners and administrators cannot safely assume that patients labeled "voluntary" fall outside of the *Donaldson* class.

MHLP Implementation - a beginning

Shortly after the court handed down the *Donaldson* decision, the Project was in touch with director Bertram Brown MD and other officials of the National Institute of Mental Health. We requested that NIMH mail to all hospital superintendents across the country a copy of the court's opinion and an analysis of the decision. MHLP provided an analysis of our own (printed in this newsletter), indicating for mental-health commissioners and hospital superintendents what our attorneys felt to be the law on some important issues expressly left undecided by the Supreme Court -- *i.e.* whether a non-dangerous patient could legally be confined if he were given treatment and whether any involuntarily confined mental patient has a constitutional right to treatment. We also asked Dr. Brown to provide an opportunity for state commissioners to meet with the Mental Health Law Project for discussion of patients'-rights issues of mutual concern. We prepared, to include in the NIMH mailing, a brief notice suitable for posting on hospital wards, to inform mental patients of their rights under the *Donaldson* ruling.

We have further urged NIMH and private foundations to support social-science research which would evaluate the impact of the decision across the country. Such basic research is vital to determine the extent to which test-case litigation is an effective instrument for social change.

Needless to say, the Project receives many requests for assistance from past and present mental patients who have read about the Supreme Court ruling and ask for legal help. While we cannot become counsel in most cases, we are making every effort to refer all requests for assistance to interested client-service attorneys.

Kenneth Donaldson

In concluding this brief analysis of the legal principles and social implications of the *Donaldson* case, the Mental Health Law Project pays tribute to a remarkable man -- an ex-mental patient whose name has now become a household word.

Kenneth Donaldson fought for nearly fifteen years to obtain his release, both for himself and on behalf of his friends -- many of whom he saw die during his incarceration. His pleas were ignored by those who should have been responsive to him, and it is a tribute to his extraordinary integrity and will that he persevered in his struggle. Kenneth Donaldson may well be remembered by historians as the first protagonist in a series of landmark cases which radically reformed mental-health law.

Letters

To all my friends at the Mental Health Law Project, this is meant to be the biggest Thank You that you can imagine.

It is such a tremendous victory that the full import of it has not yet sunk into my being. But already the court decision has brought hope to others. I hear of it on every side.

It is such an uncomplicated thing, a constitutional right to liberty for mental patients. But could anything be more worthwhile fighting for, to see it established for the first time in 200 years?

I am proud to be associated with such a splendid team.

Kenneth Donaldson
York, Pennsylvania

In your list of agencies that provide legal assistance to persons with mental disabilities you did not include the Center on Human Policy. We provide legal information to hundreds of families each year and have filed several legal actions on various elements of the right to education question.

Keep up the good work.

Douglas Biklen, Ph.D.
Coordinator for Advocacy

(The Center on Human Policy, Division of Special Education and Rehabilitation, Syracuse University, Syracuse, New York 13210.)

As you may know, the Division of Mental Health Advocacy represents patients in two New Jersey counties (Mercer and Essex) on commitment, habeas corpus, periodic review and selected right to treatment matters, and, in addition, represents the interests of all patients in state, county and private facilities on selected affirmative class action suits.

Michael L. Perlin
Director

(Division of Mental Health Advocacy, Department of the Public Advocate, State of New Jersey, P.O. Box 141, Trenton, New Jersey 08625.)

We inadvertently omitted these organizations from the list published in response to a letter in the June 1975 MHLP Summary of Activities. A third group from whom we heard is the Prison Research Council of the University of Pennsylvania Law School (3400 Chestnut Street, Philadelphia, PA 19174). According to Roy S. Diamond and Joshua Z. Goldblum, the Council focuses on the daily legal and social injustices practiced at Fairview State Hospital, the state maximum-security hospital. To these three excellent groups -- and others which we may have left out without knowing about it -- our apologies. -- EDITOR

Please accept the enclosed contribution for the important purposes of your Project, and in appreciation of the assistance of Mr. Joel Klein last summer when I was unfortunate enough to be a patient at a psychiatric hospital.

Once out of the hospital, I obtained the services of a proper doctor who disposed of my depression with office visits and a few dollars worth of an antidepressant drug.

I had no idea of the potential for abuse in the area of mental health until I foolishly became involved with the hospital during a difficult period in my life.

Stanford M. Levin
Arlington, Virginia

Development Committee

Under the joint direction of Frances Tarleton Farenthold and Mrs. J. Skelly Wright, a Development Committee is being formed to assist the Mental Health Law Project in meeting its program needs.

Sissy Farenthold, a Project trustee, has recently completed a term as chairwoman of the National Women's Political Caucus. Helen Wright, a past president of the National Association for Mental Health, is a member of the NAMH Litigation Committee and of the American Bar Association Commission on the Mentally Disabled.

In the early stages of its formation, the committee's membership to date includes:

Mildred Bateman MD
The Honorable Ramsey Clark
The Honorable Arthur Goldberg
Jeannette Hopkins
Aryeh Neier
Betty Ann Ottinger
Alvin F. Poussaint MD
Jonas Robitscher JD, MD
Scottie Fitzgerald Smith
The Right Reverend John T. Walker
The Honorable Earl Warren Jr.

The committee will assist in educational efforts throughout the country as well as seeking nationwide support for MHLP.

Joel Klein Rejoins Project

Staff attorney Joel I. Klein has returned to the Mental Health Law Project from his position as law clerk to U.S. Supreme Court Justice Lewis Powell. Klein had been at the Project for several months last year, coming from a law clerkship with Chief Judge David Bazelon of the U.S. Court of Appeals in D.C.

A magna cum laude graduate of Harvard Law School in 1971, where he was Law Review articles editor (February 1970), he had been research assistant to Professor Alan Stone MD. While at law school, Klein also took part in the Concord Prison Program, was a caseworker at the McLean Outpatient Clinic and undertook a study of Deer Island Prison for the Boston Office of Justice Administration.

Specializing in law and psychiatry, he spent a year after graduating law school as a research assistant to Professor Alan Dershowitz at the Center for the Advanced Study of the Behavioral Sciences at Stanford University. He was also an unofficial lecturer in law, teaching a course in Human Relations Problems in Legal Practice, at Stanford Law School, under the supervision of Professor David Rosenhan.

Outreach

¶ Paul Friedman has been meeting regularly with an *ad hoc* committee on Mental Health Consumer Advocacy, members of which are affiliated with the National Association for Mental Health, the National Institute of Mental Health, the American Bar Association Commission on the Mentally Disabled and several private foundations.

The committee's goal is to advance existing advocacy efforts and stimluate new state-level advocacy programs. Among its activities, the committee will try to survey advocacy programs now in existence throughout the country, to identify various models of advocacy and evaluate their effectiveness and to promote adoption of the most effective models by locating funding sources for them, offering technical assistance and recommending legislation.

¶ Robert Plotkin has been appointed to the Human Rights Committee of the Great Oaks (retardation) Center in Silver Spring, Md.

¶ Many important bills under consideration by the District of Columbia's City Council under the capital city's new home rule have been submitted to Project attorneys for comment. Recently, Robert Plotkin has reviewed a "bill of rights" for mentally retarded residents of DC and Pat Wald has forwarded comments on the child-abuse law, a subsidized-adoption bill and the District's proposed plan for using Title 20 monies from the Social Security Act.

¶ Whenever possible, the Project's staff and student interns accept invitations to serve as speakers or faculty for meetings or learning sessions organized by mental-health consumer, professional or academic groups. The following such presentations have been made recently.

Paul Friedman took part in meetings of the American Psychological Association Commission on Behavior Modification and -- as a member -- of the Board of Trustees of the National Legal Center for Bioethics in Washington DC. He also provided consultation to the Mental Health-Retardation Project of Legal Services in Seattle, Washington, and presented a description of the case study approach to a symposium on "Legal and Ethical Problems in Behavior Modification" during the American Psychological Association's Chicago convention.

Another symposium on the program of APA's Chicago convention was "Mental Health Issues, Patients' Rights and Current Litigation." Four MHLP attorneys made presentations in their areas of expertise: Friedman on evolution of the right to treatment; Jim Ellis on children's-rights issues and litigation (evolution of the right to refuse treatment); Chris Hansen on issues of confidentiality and privacy; Pat Wald on providing the least restrictive alternative care for patients.

In New York, Bruce Ennis addressed the second-year residents in psychiatry at Albert Einstein College of Medicine about the legal rights of hospitalized patients. He also discussed the implications of the consent judgment in the Willowbrook case for some two hundred officials of the state Department of Mental Hygiene and community retardation agencies at a meeting sponsored by the New York City regional office of DMH. Chris Hansen addressed another meet-

PUBLICATIONS

Basic Rights of the Mentally Handicapped, published by the Mental Health Law Project, is a consumer handbook featuring discussions of right to treatment, right to compensation for institution-maintaining labor and right to education. It is of particular interest to the mentally handicapped and their friends and families and to attorneys not yet experienced in mental-health matters.
To order: Send $1.25 per copy to National Association for Mental Health, 1800 North Kent St., Arlington, VA 22209.

Legal Rights of the Mentally Handicapped, published by the Mental Health Law Project and the Practising Law Institute, is a three-volume sourcebook containng otherwise unavailable primary source materials as well as outline essays on select mental health law issues and an annotated bibilography.
To order: Send $20.00 per set to the Practising Law Institute, 810 Seventh Ave., New York NY 10019.

Mental Retardation and the Law: A Report on the Status of Current Court Cases, quarterly summary of all litigation relating to the rights of the mentally retarded, prepared by Paul Friedman of the Project. Free.
To order: Write to Mrs. Nancy Borders, President's Committee on Mental Retardation, 7th and D Sts. SW, Washington DC 20201.

To order the above-listed publications, you may complete this coupon or facsimilies and mail, with applicable payment, to the proper source for each publication.

Please send me ______ copies of:

(name of publication)

Enclosed find $________ at $_____ per copy.

(name)

(address)

(city) (state) (zip)

ing under that office's sponsorship, outlining the provisions of the Willowbrook agreement for members of parents' groups.

Before the *Donaldson* ruling was handed down Ennis explored its potential implications with the American Bar Association Commission on the Mentally Disabled. And in two Practising Law Institute symposia on Constitutional Litigation -- in New York and San Francisco -- he lectured on developing rights of mental patients.

MHLP law-student interns Carol O'Neill and Paul Fogel discussed issues of concern with ex-patients at a meeting of the Prince George's County (Md.) Aftercare Services organization. Questions centered mainly on drugs, employment discrimination and Social Security payment problems. Fogel also addressed a meeting of the Prince George's County Mental Health Association.

A meeting of the American Blind Lawyers Association in Mobile, Alabama heard about similarities between mental health-legal issues and the needs of all handicapped people in a speech by Robert Plotkin on rights of the handicapped in the community. For the D.C. Association for Retarded Citizens, Plotkin described the progress of implementation of the decision in the *Mills* case for the right to education and outlined what further action was needed. He spoke about the rights of ex-offenders at the annual lawyers' meeting of the NAACP and on the rights of the mentally ill at a forum held in Reno, Nevada by the Northern Nevada Chapter of the ACLU.

Foundation Assists MHLP

The Mental Health Law Project is pleased to announce the award of a grant of $30,000 by the van Ameringen Foundation, Inc. in support of the further evolution of a body of law to protect the mentally handicapped.

Since 1950, the Foundation has aided a variety of preventive, rehabilitative and scholarly efforts in the field of mental health and related social issues. Some of its current grants are directed to developing access to therapeutic services in inner-city communities and towards programs to meet the needs of youth and of the aging.

The grant brings to nine the number of private foundations which have supported the Project since 1972, enabling establishment and implementation of important legal rights for mentally handicapped Americans. Now beginning its fourth year, MHLP will seek the wider support of the private-foundation community as well as individual gifts to permit continuation and expansion of its work at the intersection of law and the social sciences.

Hod Gray, Executive Director of the van Ameringen Foundation, Inc., noted that the Foundation has recognized the effectiveness of public-interest law, giving to the Legal Aid Society and having provided early support for Bruce Ennis' work with NYCLU. Mr. Gray added, "We are delighted to be associated with MHLP, a leader in what is clearly one of the most urgent areas of concern in the mental-health field today."

Conference on Behavioral Issues

The National Conference on Behavioral Issues in Closed Institutions was held on June 13-15 at the Sheraton International Conference Center in Reston, Virginia. The conference brought together about one hundred invited participants from diverse fields of interest and with varying viewpoints to discuss behavior modification in mental institutions and prisons.

Both staff and trustees of the Mental Health Law Project participated actively. Paul Friedman served with representatives of other organizations, including the American Psychological and Psychiatric Associations, American Bar Association, National Prison Project and Georgetown Law Center, on the steering committee and presented one of the keynote papers. Janet Gotkin gave an ex-mental patient's commentary to another keynote paper. David Rothman presented the opening address. June Jackson Christmas chaired the conference.

Perhaps the most hotly debated issue had to do with the focus of the conference itself. Many mental-patient and prisoner representatives felt that the central issue for discussion should be closed institutions themselves -- whether they can ever be justified and whether there are more effective alternatives to institutions for mental patients and prisoners. Another substantial group of participants came with the expectation of assuming that closed institutions would be in existence at least for the foreseeable future and of discussing whether, and under what circumstances, particular behavior-modification programs would be legally and ethically permissible.

While these conflicting expectations lent some confusion to the sessions, the conference proved valuable in two respects -- first by stimulating a number of helpful articles and secondly by providing a forum where advocates and administrators could meet with representatives of the behavior modifiers and of mental patients, prisoners and the mentally retarded (three groups for whom behavior modification has differing implications) to begin to communicate with each other about an important issue.

Paul Friedman's article, "Legal Regulation of Applied Behavior Analysis in Mental Institutions and Prisons," and Janet Gotkin's commentary, "New Words for an Old Power Trip: A Critique of Behavior Modification in Institutional Settings," appear with the other presentations from the conference in a symposium, Volume 17, Arizona Law Review Number 1 (1975).

BOOKS

. . . about privacy

CONFIDENTIALITY -- REPORT ON THE 1974 CONFERENCE ON CONFIDENTIALITY OF HEALTH RECORDS, by Natalie Davis Spingarn (published by American Psychiatric Association, 58 pp., $2.00; available through APA Sales Publications, 1700 18th Street NW, Washington DC 20009).

The individual's privacy today confronts powerful interests which demand recording, disclosure and dissemination of the most personal kinds of information. Health records, particularly mental-health records as Ms. Spingarn notes, present special problems.

Clients of mental-health services need and want rigorous protections for the confidentiality of the highly sensitive and potentially damaging information developed in the course of treatment. But they also need their bills paid, for care and treatment -- and insurance companies and governmental third-party payers assert legitimate claims to treatment information lest they pay unfounded or excessive claims. Also, researchers and medical historians claim for the advancement of science and public good a need for similar access to records, to further knowledge about disorders and the relative success of various treatment approaches. Courts, employers, schools and others also set forth their own particular requirements for disclosure.

In November 1974, a hundred persons from such diverse groups as the American Bar Association, the professional associations of health-care providers, insurance companies, the federal government and the ACLU met to debate the knotty problems surrounding confidentiality of individual health records and the issue of patients' access to their own records. Ms. Spingarn, "a seasoned health care writer" (to quote former Senator Sam Ervin's preface), has distilled the substance of the conference in highly readable and informative prose. But her short book is more than the work of a scribe. She hangs the small work-group reports, speeches and floor discussions on her own useful analytic structure and provides the reader with a short well-designed course on the nature of the problems and the range of the possible solutions.

The book includes discussions of the mechanics of health-record keeping and the forces that dictate what gets recorded and where, and describes the legitimate and illegitimate courses over which data flow. Special attention is given to computerized data banks and their emergence as repositories of vast quantities of personal data. Also, Ms. Spingarn provides poignant examples of the harms and values of record systems. She cites the case of a file clerk who was skipped for promotion and learns from her friends (who learned from their friends in the personnel office, where health-insurance forms are processed) that she was turned down because she had been seeing a psychiatrist. On the other hand, Ms. Spingarn also cites the research which established a connection between stibesterol treatment of pregnant women and the appearance years later of vaginal cancer in their daughters -- an accomplishment that might not have been possible but for the long-term maintenance and availability of patient-identified health records.

Many important public-policy choices remain to be made in the area of confidential health records. A galaxy of factors combine to intensify the problem: computerization, federally-funded health programs, growing private health-insurance programs and the prospect of national health insurance, and our society's increasing tendency toward dealing with people on the basis of how they look on paper. The chief values of Ms. Spingarn's report lie in raising the issues and giving sympathetic treatment to all competing interests. While not proposing specific solutions (The conference did not produce such results.), the report provides a good starting point for assessing the problems and identifying abuses.

In an epilogue, the report notes the one concrete conclusion of the conference: recommendation that a National Commission on Confidentiality of and Access to Health Care Records be established. Such a commission would be a consortium of national associations, e.g., professional groups like the American Psychiatric Association and the American Nursing Association and consumer groups like the National Association for Mental Health. So far some twenty organizations have indicated a desire to participate. Objectives would include promoting and preserving the confidentiality of health records through establishment of guidelines, proposing and backing legislation, supporting studies and educational activities. An organizational meeting is planned this fall with a view towards incorporation and election of officers.

-- EDWARD SCOTT

To obtain more information about the Commission, write to Robert L. Robinson, Executive Secretary Pro Tem., c/o American Psychiatric Association, 1700 18th Street NW, Washington DC 20009.

. . . and other legal issues

JUVENILE JUSTICE ADVOCACY -- PRACTICE IN A UNIQUE COURT by Douglas J. Besharov. $25, Practising Law Institute (1974). Criminal Urban Law Practice Handbook Series

LEGAL PROBLEMS OF CORRECTIONAL, MENTAL HEALTH, AND JUVENILE DETENTION FACILITIES edited by William A. Carnahan. $20, Practising Law Institute (1975). Criminal Law and Urban Problems Course Handbook Series

MEDICAL MALPRACTICE LAW by Angela Roddey Holder JD. $22.50, John Wiley & Sons (1975) A text dealing with the legal principles behind the physician-patient relationship, it gives special attention to recent court decisions on controversial issues -- abortion, compulsory sterilization and medical rights of prisoners and patients involuntarily confined to mental institutions.

MENTAL RETARDATION: NATURE, CAUSE AND MANAGEMENT by George S. Baroff. $17.95, Hemisphere Publishing Company (1974), distributed by Halsted Press. A textbook indexed in detail by subjects to serve as a reference for workers in mental-retardation programs, special-education teachers and other retardation professionals.

LAW AND TACTICS IN JUVENILE CASES, $15, National Juvenile Law Center, 3642 Lindell Boulevard, St. Louis, Missouri 63108 (2nd edition 1974). A practical manual for attorneys working in juvenile courts, this looseleaf book includes a section on disposition and treatment alternatives which may help the legal practitioner work his way through mental-health jargon.

THE FUTURE ROLE OF THE STATE HOSPITAL edited by Jack Zusman and Elmer F. Bertsch of the Department of Psychiatry, State University of New York at Buffalo (1975) Published by Lexington Books, D.C. Heath & Co., Lexington, Mass. Includes a chapter by Bruce Ennis: The Impact of Litigation on the Future of State Hospitals.

Reader Survey

In June, we surveyed one thousand people whose names are on the mailing list to receive this newsletter. Almost one third of the questionnaires were returned, many with thoughtful comments. In summary of the responses:

Part I: We asked readers if they wished to continue receiving the newsletter and if we should charge for it. Twenty-four percent of respondents said we should charge a nominal subscription fee, 8% said "continue to send it free," and 68% marked "send it free but invite contributions." As a result, we will continue to provide this service at no charge. However, we will ask each reader who can afford to do so to make an annual contribution towards MHLP's work.

Part II: "Who are you and how do you feel about the Mental Health Law Project's objectives and activities?"

1. The majority of respondents noted a general interest in the rights of all mentally handicapped people by checking more than one of the categories -- the mentally ill, mentally retarded and behaviorally disturbed youth. Responses where only one was checked were evenly divided between interest in mental illness and retardation.

2. Over 90% of respondents said they are professionally involved in the field(s) of interest they checked:
45% as lawyers (over half in advocacy);
23% as social-science professionals;
6% as medical professionals;
23% "other" -- many in administration.

3. We asked respondents to rate the Project's five priority objectives.
* Right to treatment/habilitation in the least restrictive setting was seen as most important by 45%, most controversial by only 15% of the respondents.
* 18% considered rights in the community most important; 27% found this goal most controversial.
* The right to refuse treatment (protections/safeguards for hazardous procedures) was considered most important by 16% but most controversial by 43%.
* Civil-commitment and confidentiality issues were rated low, both in importance and controversial nature.

4. We also asked readers to rate Project activities for effectiveness in improving care, treatment and/or habilitation for the mentally handicapped. Sixty-four percent put test-case litigation at the top of the list, followed by a close tie for number-two rating between implementation of court decisions and litigation backup for client-service lawyers.

Part III: -- in which we asked for your help, either financial and/or in the form of a list of people whom we might later invite to contribute towards the Project's future work. A heartwarming 38% of respondents sent contributions from $1 to $50 (the average was $12). Just as cheering was the response to our request for names and addresses: 46% took the time to compile lists, which we have matched to our mailing list to avoid duplication.

Comments: Among the comments on the questionnaires came many compliments for the newsletter. "An excellent way of keeping practitioners up to date and leading to increased communication in a vital area," wrote a lawyer. Another said, "It is a comprehensive and valuable publication."

"Suggest expansion of coverage of cases in which MHLP not directly involved," wrote a lawyer. We agree that "there is great need for a comprehensive review of current cases." With research aid by Project staff, a mental-health law reporter will soon be published by the American Bar Association's Commission on the Mentally Disabled. Meanwhile, to augment MHLP's summary of its own activities, Mental Retardation and the Law is available quarterly, free of charge, from the President's Committee on Mental Retardation. -- ELLEN McPEAKE & LEE CARTY

Mental Health Law Project
1751 N Street NW
Washington DC 20036

Address correction requested

Nonprofit Organization
U S POSTAGE
PAID
Washington DC
Permit No. 46091

Printed by the Sheltered Occupational Center of Northern Virginia

HOW MANY KENNETH DONALDSONS ARE THERE?

How many people are now covered by the Supreme Court's ruling -- involuntarily confined to psychiatric facilities, dangerous neither to themselves or others? Comprehensive figures for all types of facilities are not available past 1972, when over 1,600,000 inpatients were "treated" in the U.S. according to National Institute of Mental Health statistics (including those admitted more than once during the year, those hospitalized for decades and those confined only for days).

How many patients are "involuntary"? If by this we mean court-committed, then of the 403,924 admissions to state and county mental hospitals in 1972, about 169,000 were admitted on an "involuntary" basis; 196,000 were admitted as "voluntary" and 23,000 were admitted on a "non-protesting" basis. (NIMH Statistical Note #105)

In addition, 278,500 inpatients were resident in state and county mental hospitals (Statistical Note #106). There are no figures on their legal status. If as many as 70% are involuntary, we could assume a total of 364,000 "involuntary" patients (over two times the number calculated by NIMH). On the other hand, the percentage may be lower since many may have had their status changed to "voluntary" during hospitalization.

There are no data available on the legal status of the remaining one million patients "treated" annually in inpatient psychiatric facilities other than state and county mental hospitals -- psychiatric units of general hospitals, private mental hospitals, other multi-service mental-health facilities, residential treatment facilities for emotionally disturbed children and community mental-health centers.

If half of the 1,600,000 inpatients in all facilities were ever under court commitment, we are dealing with roughly 800,000 people -- or with a more conservative estimate of thirty percent, about 480,000 people; with a liberal estimate of seventy percent, about 1,100,000. Whichever estimate we choose, we are now talking in terms of three to six times more people than the 169,000 "involuntary" admissions to state and county mental hospitals recorded by NIMH.

Since *Donaldson* involves only "involuntary" patients, hospital administrations may opt to change the status of many patients to "voluntary." To discover whether or not this does occur, there is an urgent need to collect data on the legal status of admissions and residents both pre- and post-*Donaldson*.

-- GAIL MARKER

FOR PATIENT ADVOCATES:

This notice may be posted on wards of mental hospitals, after inserting the location of a copy of the Donaldson decision (e.g., Superintendent's office, library, etc.). It is similar to the sample notice provided by the Mental Health Law Project to the National Institute of Mental Health for distribution to state and county mental-hospital administrations.

Notice to Hospital Patients

The United States Supreme Court ruled recently that any involuntarily hospitalized mental patient who is not dangerous to self or others and who is being kept in custodial confinement has a constitutional right to liberty -- that is, a right to be released from the hospital.

The court's decision is available for any patient to read

____

(location of copy of decision in *O'Connor v. Donaldson*)

If you believe that this Supreme Court ruling has any bearing on your present status, please feel free to discuss these questions with the hospital staff. In addition, if you would like to consult with an attorney regarding the implications of this decision, the following groups may be able to assist you:

- * Local chapter, American Civil Liberties Union
- * Local chapter, American Bar Association
- * Local Legal Aid or Public Defender Office
- * Local chapter, National Association for Mental Health.

Appendix 2

EXCERPT FROM THE SEPTEMBER 1975 ISSUE OF THE AMERICAN JOURNAL OF PSYCHIATRY, SUBMITTED BY DR. ROBERT N. BUTLER*

Psychiatry and the Elderly: An Overview

BY ROBERT N. BUTLER, M.D.

The author notes that the elderly in our society have not been provided with treatment, research, and services commensurate with their needs. These needs are reflected in the increasing incidence of psychopathology, suicide, and poverty with increasing age. The psychiatric profession's therapeutic nihilism toward the elderly may reflect unresolved countertransference issues that result in a form of prejudice called "ageism." Many of the conditions labeled "senility" are actually manifestations of socioeconomic or medical problems that could be resolved with prompt, appropriate treatment. The author makes several recommendations—the creation of a multidisciplinary nongovernmental commission on mental health and illness of the elderly, reexamination by psychiatrists of their attitudes toward the elderly, and proportionate representation of older individuals in psychiatric services, training, and research.

PSYCHIATRISTS, INDIVIDUALLY AND COLLECTIVELY, are taking a fresh look at the content and procedures, theories and applications, and strengths and weaknesses of their field. Although this remarkable specialty has done much to alleviate human suffering, there are areas where we must go farther. Psychiatry is currently being scrutinized by consumers, legislators, and public policy makers. In this paper, I will explore our profession's inadequate efforts in the care of older people.

Levels of psychiatric research, training, and service have not been commensurate with the intrinsic theoretic interest or the service needs of older people. There are over 20 million older (i.e., 65 and above) Americans. The elderly are the fastest growing segment of the population, but they are not a homogeneous group. Rather, there are two major components—the healthy, vigorous aged who represent an extended middle-age and the "old-old," plagued by disability and disease. Obviously, those who do not fall within either of these groups are on a continuum of health to illness. Since there is such great diversity in the elderly population, its medical, personal, and social needs must be met by an equivalently diverse set of responses.

The elderly are disproportionately subject to emotional and mental problems. The incidence of psychopathology rises with age (1). Functional disorders—notably depressions and paranoid states—increase steadily with each decade, as do organic brain diseases after age 60. One study by the National Institute of Mental Health (NIMH), reported by the World Health Organization in 1959 (2), listed the following incidences of new cases of psychopathology of all types per 100,000 population: under age 15, 2.3; age 25–34, 76.3; age 35–54, 93.0; and above age 65, 236.1. Clearly, individuals over 65 are the group most susceptible to mental illness.

Suicide also increases with age, and the rate of suicide is highest in elderly white men. There are several probable reasons for this: loss of status (in a society dominated largely by white males), the desire to protect finances for the surviving wife, and the decision to escape unavoidable physical helplessness and obdurate pain.

The suicide rate curve for nonwhite women and men and for white women is bell shaped, with the peak during the earlier adult and middle years. Twenty-five percent of all known suicides take place in the over-65 population, which represents only 10 percent of the general population. It is probable that the true rate is even higher, since families are frequently unwilling to report suicides because of shame or guilt.

In addition to the major disorders, older people are affected by many common everyday emotional problems. It was estimated in 1970 that about three million older people with significant psychiatric problems do not receive help. According to the Biometry Branch of NIMH, if present trends of mental health service continue through 1980, about 80 percent of elderly people who need assistance will never be served (3).

Despite these striking figures, academic departments

This paper was written at the invitation of the Editor.

Dr. Butler is Research Psychiatrist and Gerontologist, the Washington School of Psychiatry, Washington, D.C. Address reprint requests to him at 3815 Huntington St., N.W., Washington, D.C. 20015.

---

*For statement, see p. —.

do not ordinarily admit older patients to the teaching services where medical students and residents gain their first crucial clinical experiences. Scientific studies and clinical investigations with elderly subjects are rare. State mental hospitals have worked to reduce the admission of older persons on the grounds that they are senile or social rather than mental cases. Only 2 to 5 percent of older persons are on the rolls of community mental health centers (CMHCs) and public and nonprofit clinics. Perhaps no more than 2 percent of the time of psychiatrists in private practice is spent with older patients (1).

COUNTERTRANSFERENCE AND AGEISM

Why has psychiatry shown so little commitment to the elderly? Inadequate medical school and psychiatric training and the resulting incomplete knowledge about older people, their problems, and treatment are partially responsible. In part, this lack of commitment has been a matter of economics—so many older people are poor. However, the latter explanation does not account for the low treatment contact of private practitioners with affluent older people and of clinics and CMHCs with the low-income elderly. Moreover, Medicare has not resulted in the increases in psychiatric care that might have been anticipated with even the restricted benefits and payments it provides for psychiatric treatment.[1]

Many psychiatrists and other mental health specialists share our culture's negative attitudes toward older people, the pervasive prejudice I have called ageism (4), which is the process of systematically stereotyping and discriminating against people because they are old. Old people are categorized as senile, rigid, and old-fashioned in morality and skills. Ageism allows those of us who are younger to see old people as "different." We subtly cease to identify with them as human beings, which enables us to feel more comfortable about our neglect and dislike of them.

There is an added factor in ageism. Unlike racists and sexists, who need never fear becoming black or female, ageists are dimly aware that if they live long enough they will end up as old people—the object of their own prejudice. Ageism is a thinly disguised attempt to avoid the personal reality of human aging and death.

Psychiatry has shown a sense of futility and therapeutic nihilism about old age. Psychiatrists are quick to assume that the older person is too old for treatment, a poor investment for psychotherapy, too resistant to change, boring and garrulous, or untreatable because of age, hardening of the arteries, or senility.

These reflections of ageism are disguised in professional trappings—a curious disguise, given psychiatry's usual sensitivity about countertransference issues. A Group for the Advancement of Psychiatry report (5) listed the following as some of the reasons for psychiatrists' negative feelings: the old arouse psychiatrists' apprehensiveness about their own old age, they incite conflicts about psychiatrists' personal relationships with their own parents, and they induce feelings of helplessness.

"THEY ARE ONLY SENILE"

All too many psychiatrists use the term "senility" indiscriminately, applying it to anyone over 60 with a problem. Having invoked this magic word, they need not undertake the kind of careful diagnostic assessment that is necessary to determine a proper course of treatment. Indeed, in most cases, when the label "senility" is applied, no course of treatment is started.

Senility is not, properly speaking, a medical diagnosis but is instead a wastebasket term for a range of symptoms that include (minimally) some memory impairment or forgetfulness, difficulty in attention and concentration, decline in general intellectual grasp and ability, and decreased emotional responsiveness to others. Studies at the National Institutes of Health and elsewhere have shown that this condition is not an inevitable consequence of age per se (6). Rather, it is a cerebrovascular disease, destruction of central nervous system cells, or an emotional state such as severe depression. For example, the depression of an older person may be inner preoccupation and constriction manifesting itself as disturbed concentration, forgetfulness, and withdrawal. The term "senility" should be discarded altogether in favor of "emotional and mental disorders in old age." This issue involves more than semantics. Viewing disorders in the way I have suggested would encourage a more careful diagnosis and treatment plan, as well as a broader perspective on the everyday problems and disorders of old age.

PSEUDOSENILITY

The disorder that is mistakenly labeled senility should not, however, be ignored, for it is the all too real product of an extraordinary list of "causes." These problems, summarized by Libow (7), can often be treated effectively if speedily recognized. I would emphasize a factor that is given insufficient consideration, namely, that malnutrition is often a basis for conditions labeled senility. Such malnutrition is frequently due to poverty, which affects about 35 percent of older Americans, and to poor eating habits, which can result from grief and loneliness as well as inadequate knowledge of nutrition—the "tea and toast syndrome." The second underrecognized cause is long-term or recent alcoholism. Persons with long-term alcoholism now survive longer because of more effective treatments, e.g., intravenous feeding and antibiotics. Alcoholism can also appear for the first time in old age as a result of loss and grief, which are almost invariant accompaniments of the later years. A third group of causes presents as "confusion" and other senile symptoms which, when scrutinized, prove to be serious and revers-

---

[1] Outpatient coverage is especially limited. The $250 annual limit encourages hospitalization, which is much more generously covered, especially in psychiatric services of general hospitals.

ible physical conditions—unrecognized incipient congestive heart failure, infection, heart attack, nonketotic hyperosmolarity diabetic syndrome, excessive tranquilization, etc. The presentation of such symptoms—even in someone with a history of chronic (essentially irreversible) brain syndrome—necessitates immediate, indeed emergency, diagnostic evaluation and prompt care and treatment. Unfortunately, this is rarely the case with the older person. Patients with reversible ("acute") brain syndromes are usually turned away from both private and public hospital emergency rooms, even though prompt treatment of their underlying physical conditions could produce good chances for recovery (8).

A SOCIAL OR MEDICAL PROBLEM?

One of the main reasons people are turned away from hospital care is that they are typically seen as "social problems." A sterile theoretical dispute in modern psychiatry centers around two positions: 1) that human behavior is socially determined and the medical model is therefore ill advised, and 2) that psychiatric "illnesses" are best conceptualized and treated exclusively within the medical model.

A consequent and invalid notion, increasingly shared by psychiatrists, lawyers, and politicians, is that the emotional and mental disorders of old age are not bona fide "mental illnesses" and that psychiatric diagnosis and treatment are therefore unnecessary. It is argued that forms of social assistance and ultimately custodial care are what is needed. But human behavior is complex, multiply determined, changeable, and profoundly influenced by socioeconomic circumstances, cultural conditioning, personality development, physiological processes, and mental diseases. Thus we must respect and follow a broad "model" and humbly seek the research help of a wide variety of intellectual and scientific disciplines ranging from the humanities, criminology, psychoanalysis, and sociology to molecular biology, physiology, and pathology.

Admittedly, the psychodynamic and medical contributions to the treatment of emotional and mental disorders in old age often appear to be overridden by the severe social and economic conditions under which so many older Americans live. Older people in 1974 had a median income of about $75 a week. Thus half of them try to pay for their food, shelter, transportation, medical care, etc., on less (usually much less) than $10 a day.

Older people are disproportionately frequent victims of street crime and fraudulent consumer practices. Thirty percent of them live (exist) in substandard housing. The elderly do not have the services they need—home-health services, social dining, home-delivered meals, legal representation, social work aid, etc.—available to them in the community. Because of inflation and new restrictions on Medicare benefits, the elderly now pay more for their medical care than they did before Medicare became law in 1965. They have every reason to fear being placed in nursing homes that have a collective record of scandal, inadequate personal care, fires, poor sanitation, fiscal mismanagement, and corruption (9–13). Since older people know all too well the manifold problems of the later years, it is not surprising that we see a kind of "dread and despair" syndrome that overshadows but does not eliminate the standard clinical psychiatric conditions affecting them. They require treatment that can help in their struggle against the socioeconomic as well as emotional and mental problems that affect them.

CAN OLDER PEOPLE BE HELPED?

Do treatment results for the elderly justify the expenditure of time and money for their care by the psychiatric profession? As I have noted, the many older people who develop acute reversible brain syndromes can be effectively helped if diagnosis and treatment are prompt and skillful and the collective and intricate import of social, personal, and medical factors is recognized. Those suffering from a variety of other conditions can also be aided, and the full range of treatment modalities is useful. Persons experiencing the common emotional problems of the later years—depression and anxiety—can be given considerable relief, and those suffering from the severe functional disorders such as major depressions can be assisted. Even people with chronic brain syndromes or chronic physical illnesses can benefit, since associated anxiety and depressive symptoms are responsive to treatment.

Research and clinical evidence confirm that older people benefit from mental health care. Gibson (14) reported on 6,400 patients admitted to 49 private psychiatric hospitals between 1960 and 1964 and found that as many as 75 percent of patients over 65 are returned improved to their own homes within 2 months. Outpatient work in clinics and private offices also reveals capacities for change and recovery. Even severely brain-damaged patients respond in a prosthetic (artificial) milieu with well-planned programs for orientation, activities, and socialization in both day-care and institutional settings. The judicious use of psychoactive drugs—tranquilizers, antidepressants, and lithium salts—has been effective in the treatment of both inpatients and outpatients. Electroconvulsive therapy also has its place. As with any age group, a combination of resources and genuinely motivated interest on the part of professionals is essential.

One function of mental health specialists that has direct application to work with older people is the art of listening. The "garrulousness" of old people and their wish to tenaciously hold onto someone's attention is often a social symptom related to loneliness. Patience, listening, and simply spending meaningful time with them are of great therapeutic value—but this is not all. Older people use reminiscence to review their lives and resolve problems, much as is done in classical psychoanalysis. Individual psychotherapy—insight oriented as well as supportive and short term as well as long term—can be effective. Psychotherapy is often helpful in a surprisingly brief time, perhaps because of the older person's predilection to review his life and his realization that he has little time left.

One approach, life review therapy (15), capitalizes on this interest in reminiscence. It includes taking an extensive autobiography from the older person and from other family members. Family albums, scrapbooks and other memorabilia, genealogies, and pilgrimages back to places of emotional import evoke crucial memories, responses, and understanding in patients. In writing his philosophical late life reflections in *Beast or Angel* (16), René Dubos returned to his native tongue of French after 50 years to reexperience his past, recapturing earlier moods and spontaneity. A summation of one's life work by some means is useful. The consequences of taking these steps in the presence of a therapist or listener include expiation of guilt, exorcism of problematic childhood identifications, resolution of intrapsychic conflicts, reconciliation of family relationships, and transmission of knowledge and values to following generations.

The following brief case history presents one of my experiences illustrating these concepts.

Case 1. A 72-year-old retired Southern businessman and lawyer entered intensive psychotherapy with chief complaints of great tension and restlessness, guilt over cowardly acts in his past, and current episodes of anxiety about death. He was encouraged to recount acts of omission as well as commission that troubled him (e.g., failing to stand up for a black man who was subjected to verbal abuse), to work through his long-term antagonism toward a sister to whom he had not spoken in 20 years, to visit his home town, to make out his will and explore his feelings about his death, and to commit himself to significant public service.

Group therapy is especially useful to older people because it helps to overcome their loneliness and offers the possibility of sharing common worries. It is also more practical than individual therapy for those with limited incomes. Older people benefit especially from participation in groups composed of individuals of all ages. Family therapy can resolve serious and long-standing conflicts involving siblings and children, catalyzing emotionally vital reconciliations. It can also deal with more immediate conflicts that have prevented the older person from living with or simply enjoying his/her children. Couples therapy can be invaluable in the treatment of marital and sexual problems in the later years, mitigating or eliminating various types of sexual dysfunction (including impotence). Of course, there is a great need for continuing research into psychological, behavioral, pharmacological, and other treatment approaches.

THE "DUMPING" SYNDROME

Public mental hospitals in general do not have active treatment programs that recognize the capacity of older people to change. There are exceptions, of course. In many hospitals, particularly those that have been unitized or decentralized, older people are integrated into regular treatment units. In other institutions, elderly patients are segregated in geriatric units that rarely provide active treatment. When patients are physically infirm, they are placed in what amounts to nursing units.

Clearly, flexibility is advisable if we are to meet the varied needs of the heterogeneous older population. We need studies of the effects of age integration and age segregation, including measures of process (e.g., intergenerational relationships), treatment results, and physical dangers (e.g., accidents and assaults). In many states, older people are "excluded at the gate" or, if admitted, are rapidly transferred. Recently admitted older patients are joined by thousands of elderly and chronic mental patients who are transferred out into what has been euphemistically called "the community." This includes nursing homes, foster care facilities, and welfare hotels where psychiatric services are virtually nonexistent. Much of the current massive transfer of elderly patients is motivated by interests unrelated to their needs. Financial incentive was provided by the enactment of the Medicare and Medicaid amendments to the Social Security Act of 1965. State governors and legislators were pleased to be relieved of much of the financial burden of care as a result of federal funds. The number of aged patients in state mental hospitals decreased by 40 percent between 1969 and 1973, from 133,364 to 81,912 (2). Another financial incentive is that of the nursing home operators. At hearings before Senators Charles Percy (R-Ill.) and Adlai Stevenson, III (D-Ill.), of the U.S. Senate Special Committee on Aging, the following exchange occurred between Jack Weinberg, M.D., and Senator Percy:

> *Dr. Weinberg:* I criticized . . . the idea of transferring inordinately large numbers of people into nursing homes from mental hospitals. I was amazed when . . . the new Governor of the State of Illinois . . . announced that he was going to release 7,000 elderly patients into the community. I didn't know who made the important clinical decision that these 7,000 people were not mentally ill.
>
> *Senator Percy:* Don't you imagine that there is the possibility that the operators of these nursing homes organized into an association and an officer . . . put pressure on the state and other government officials to release patients so they want to fill beds? They have got stockholders' reports to show. They have got empty beds and they are going to fill them with bodies and maybe those bodies are going to have to come out of the mental hospitals. Don't you think that sets the pressure up then to fill those beds.
>
> *Dr. Weinberg:* It certainly does. May I reveal something personally, that when I was asked to supervise this program and it was announced, someone in my family was approached by a nursing home operator, asking my brother, to be exact, to approach me to direct patients into his home and that he would offer me a stipend of $100 per head. This actually happened and appalled both my family and me. (3, p.14)

There is no doubt that many older patients would prefer and should be in various facilities other than the state mental hospital. If they cannot be at home, they may prefer a residential setting such as a hotel for older people; others may prefer a nursing home. In some states, some nursing homes may be superior to state hospitals. Unfortunately, there are only a few high-quality studies of various types of aftercare in nursing homes and the effects of transfer (17, 18). The usual nursing home situation is more nearly that described in the December 1974 report of the U.S. Senate Special Committee on Aging.

> There are numerous examples of cruelty, negligence, danger from fires, food poisoning, virulent infections, lack of human dignity, callousness and unnecessary regimentation, and kickbacks to nursing home operators from suppliers. . . . (13, p.7)

There are 23,000 commercial nursing homes in the United States with over one million patients. These institutions are outside the mainstream of psychiatry and of the health care system in general. Despite data indicating the high incidence and prevalence of psychopathology among nursing home patients (19), psychiatrists are rarely available and social services are uncommon in nursing homes. The report continues,

> Of 815,000 registered nurses in the U.S., only 56,235 serve in nursing homes (usually in administrative positions) although there are more patients in nursing homes than hospitals. From 80 to 90 per cent of care is provided by over 280,000 aides and orderlies, a few of them well-trained, but most literally hired off the streets. Most are gravely overworked and paid at, or near, the minimum wage. With such working conditions, it is understandable that their turnover rate is 75 per cent a year. (13, p.3)

In New York State about $10,000 per patient bed per year is paid to nursing homes under Medicaid (1974 figures). These patients do not receive psychiatric care—in fact, they often receive only minimal physical care. This money, $833 per month, could better be spent in giving an older person and his/her family a choice of various facilities and services in the community. With financial help, many could remain in their own homes or with their families. The crucial issue is choice, and the most important goal is to make it possible for older people to stay at home as long as they choose to. The availability of alternative community services, including outpatient psychiatric services, can mean the difference between institutionalization and living in one's own home.

THE IMPORTANCE OF HOME

I would like to expand on the concept of home and its meaning to the elderly, since this is an important factor in maintaining their mental health. The place where one lives is profoundly connected with who one is and how one expresses this sense of self. Home is where all of us feel most comfortable to be ourselves and to drop social facades. Many older people also associate home with autonomy and control. The home provides an expression of one's personality through furnishings, decorations, memorabilia, ambience, plants, and pets. It is a familiar place in what may be a changing and unsteady world. Ties to the past are maintained through personal possessions, household routines learned and carried out through the years, and associated memories. For an older person to have a home of his or her own is to have the opportunity to socialize, to give and receive invitations, to have privacy with chosen companions, or to be alone.

Older people may strongly resist the thought of having to leave their own home, particularly to move to totally strange surroundings or, worse, to an institution. Some insist on remaining in their homes at all costs to their physical security. Many factors produce such tenaciousness, including pride, desire for freedom and independence, anxiety about change and the unknown (which can be especially frightening in old age), and a need to be in contact with familiar people, places, and things.

There are, of course, actual physical and emotional dangers associated with uprooting older people from familiar surroundings (1). Many studies have shown that moves, particularly abrupt ones, result in increased illness and death in the elderly. This problem can be alleviated somewhat by preparing the person carefully and making the move in a gradual, thoughtful manner, but the threat of increased morbidity and mortality remains. Resettling in an unfamiliar place has its own physical perils. For example, the older person may forget which way to turn on the way to the bathroom at night and fall. There is also the stress of learning to cope with a completely new environment, which can lead to exhaustion and depression.

Psychiatrists and other mental health specialists, often operating as a team, should be willing to travel to the homes of older people. It is not a sign of "resistance" when a chairfast or bedfast patient cannot visit the psychiatrist's office or a CMHC. These patients may be mentally alert but may seek psychotherapy to deal with depression that has developed, for example, following a paralyzing stroke. A home visit is not only indicated but essential in such cases.

It is foolish, of course, to fail to recognize the necessity for an older person to live in a protected environment when it exists, as was the case in the following instance.

> *Case 2.* An 83-year-old woman was brought in by her daughter, age 64 and retired, for an evaluation of whether she could continue to remain in her own home or should live with her daughter. The mother had nervous depression and forgetfulness. She had suddenly developed extreme fear of living alone and imagined that strange men had come into the house at night. She had lived in the same home since 1930. Her husband had died in 1965. Most of her old friends and acquaintances had moved or died. She had one friend in her 90s and another in her 80s, both of whom were incapacitated and housebound. No one visited.
>
> Her physical health was good. She was a quiet, reserved person who had always been cheerful and friendly. She had full insight into her situation, but was troubled by her fading intellectual abilities and her loneliness. She was extremely conscious of her inadequate hearing, memory impairment, difficulty following conversations, and difficulty in maintaining her own thought. She became upset in the presence of others and withdrew, even from company she had enjoyed in the past.

It would be Pollyannaish denial to think that all older people can be maintained at home indefinitely, even if a rich panoply of services including psychiatric house calls were available. Institutional care in nursing homes and mental hospitals may be mandatory on both a short-term and long-term basis. At any one moment in time, only 5 percent of older people are in institutions of any type—a significant, if small, minority. However, according to current practices, approximately 20 percent of older people will need some institutional care at some point in time.

DO WE NEED GERIATRIC MEDICINE AND GERIATRIC PSYCHIATRY?

Specialties in geriatric medicine and psychiatry may be necessary because of neglect and because of the population explosion of the over-65 age group (with zero population growth, older people will soon constitute 15 percent of the population). However, I would argue that the care and treatment of the elderly should and can be ultimately absorbed within psychiatric research, service, and practice. There must, of course, be greater attention in medical school and psychiatric and postgraduate education. Insofar as practice is concerned, there has been serious criticism of psychiatry's commitment to a variety of different neglected groups—children, minorities, drug addicts, and alcoholics. If we cannot or will not do the job ourselves, we may witness the emergence of a "new profession" that would compete with psychiatry as we presently know it by accepting responsibility for the groups we have neglected.

In the area of psychotherapy, for example, the idea of training a new "fifth profession" was proposed by Henry and associates (20) in 1971.

> Out of these four early professional routes [psychoanalysts, psychiatrists, psychologists and social workers] . . . there emerges . . . a fifth profession, the psychotherapist. . . . (p. 6)
>
> It is important to query the social utility of having four highly organized, well-equipped, self-sufficient training pathways, each of which produces psychotherapists. (p. 181)

In 1957, Kubie (21) suggested creating a new profession called medical psychology to combine psychology, the humanities, and pertinent aspects of medicine into one discipline. The proposals for a new subdiscipline and a fifth profession, if implemented, might provide various services to the elderly and other groups that have not been forthcoming from our profession. (Of course, such emergent professions might also neglect these disadvantaged groups.)

A COMMISSION ON MENTAL HEALTH AND ILLNESS OF THE ELDERLY

I hope that psychiatry will become increasingly effective in the care and treatment of the elderly patient, helping him or her to remain at home as long as possible and to secure the best institutional care when necessary. To do this, we will need to deepen our knowledge and better organize our resources. I believe it will be necessary to catalyze the public and private sectors connected with psychiatry through the mechanism of a Presidentially appointed, congressionally approved commission on mental health and illness of the elderly.

The 1961 report of the Joint Commission on Mental Health and Illness, entitled *Action for Mental Health* (22), called for the creation of a network of CMHCs and an end to the traditional dependence on the massive state mental hospitals. Although many of the recommendations for other age groups were sound, the Commission failed the elderly mental patient. No organizations, agencies, or individuals specifically concerned with the elderly participated in the Commission's work.

The establishment of a commission on the elderly would help ensure that the mental health needs of older people are clarified and planned for (2). This would afford an opportunity for various public and private organizations and private individuals in the field of aging to prepare a body of major recommendations for a public policy on the mental health of the aged. Certainly, we already have more knowledge than is applied, but a commission would be a valuable tool to give national visibility to the mental health problems of the aged and to build up a record for use in Congress. Such an action-oriented commission would 1) study and evaluate the mental health needs and resources of the elderly; 2) specify the requirements for manpower, facilities, and research; 3) clarify for older people what they themselves can do to prevent mental illness; 4) estimate the cost now and in the future of carrying out necessary programs; and 5) suggest methods of meeting these costs. Moreover, the commission would conduct feasibility studies on mental health care delivery.

The commission should be nongovernmental and multidisciplinary including professional and lay groups interested in the elderly. Of course, older people should also participate. There should be adequate funds under the joint administration of NIMH and the Administration on Aging. Senator Edmund Muskie (D-Me.), Chairman of the Subcommittee on Health of the Senate's Special Committee on Aging, first introduced a bill to establish such a commission in December 1971. A version of this bill was passed by Congress in December 1974 but was vetoed by President Ford.

WHY STUDY OLDER PEOPLE?

It is quite possible to engage the interest of students by making evident the value of studying older people. Only the old can inform us of the possible final courses of human life, providing us with the vital natural histories of mental and emotional disorders, offering us the outcomes of various personalities, and teaching us the elements of survival as they have accomplished it. Older people can acquaint us with the personal meanings of loss—of status, loved ones, and bodily health—and with the impact of grief (23–25). Much of what we learn from older people can also be helpful in our work with younger patients.

Studies of the nature of late life are necessary for the understanding of the life cycle. Old age has become increasingly visible since the seventeenth century. Longer life spans have "unfolded" the life cycle, making its stages or phases prominent. Aristotle, Cicero, Shakespeare, Rousseau, and other philosophers and writers have considered the total life cycle as a concept and have proposed various methods of dividing and describing it. In the United States social psychologists, sociologists, and psychologists have shown some interest in studies of the life cycle. The first major American book on the psychology of old age was written by G. Stanley Hall in 1922 (26). William James, George Mead, Charlotte Buhler, Robert Havighurst, Theresa Benedek, Erik Erikson, Sidney Pressey, Raymond Kuhlen, Bernice Neugarten, and Marjorie Fiske Lowenthal are among recent writers who have given attention to this subject, with some particular emphasis on old age and the transitional middle-age period.

In the 1950s, lay child psychoanalyst and teacher Erik Erikson awakened psychoanalysts, psychiatrists, and other mental health workers to the fact of adulthood and the idea that humankind is not irrevocably molded in the first 5 years of life. Erikson's concepts of the life cycle and his notions of crucial stages in antipodal form are arguable and difficult to test experimentally. However, his influence has been deserved and considerable and it is dismaying that in spite of his work the life cycle—especially its later stages—has not received significant attention from psychiatry. Rothschild, Gitelson, Grotjahn, Goldfarb, Weinberg, Linden, Busse, Simon, Greenleigh, Thompson, Berezen, Eisdorfer, and Pfeiffer are among the several American psychiatrists whose work has begun to stimulate some research into the psychodynamics of aging as well as the development of treatment approaches (27). However, psychiatry as a whole has not yet developed its own theories of late life, nor has it absorbed fully the studies of human development made by other professions, a problem I have discussed in detail elsewhere (28).

NIMH STUDIES OF HUMAN AGING

Studies of human aging were begun by NIMH in 1955, to take a new look at some of the prevailing ideas and previously reported findings concerning the processes of human aging and the nature of aging persons (23, 25). Medically healthy elderly individuals living in the community were selected for study so that we might maximize the opportunity of assessing the effects of time and chronological aging and minimize the effects of sickness, institutionalization, and social adversity.

Some of the specific questions we had in mind were as follows:

1. Are the changes in cerebral blood flow and metabolic rate described in the literature a result of aging of the nervous system, or are they the result of disease?
2. To what extent is the postulated slowing in speed of reaction time with age the result of a general process of change in the central nervous system?
3. What personality factors contribute to the adaptation and maladaptation of the healthy community resident to the crises of late life?
4. How do the environmental factors of cultural background and immediate circumstances contribute to adaptation and maladaptation of the aged?

To our surprise, we found that psychological flexibility, resourcefulness, and optimism, rather than the stereotype of rigidity, characterized the group we studied. Many of the manifestations heretofore attributed to aging per se clearly reflected medical illness, personality factors, and sociocultural effects. The belief that cerebral (brain) blood flow and oxygen consumption necessarily decreased as a result of chronological aging was not confirmed. It was found, rather, that when such changes occurred, they probably resulted from vascular disease. The men in our sample who were over 65 (N=47, mean age=71) were found to have cerebral physiological and intellectual functions that compared favorably with a young control group. Intellectual abilities declined not as a consequence of the mysterious process of aging but rather as the result of specific diseases. Therefore, senility is not an inevitable outcome of aging. Studies at Duke University and elsewhere point in the same direction. All the usual psychiatric disorders found among the elderly seemed to be similar in their genesis and structure to those affecting the young.

There was evidence of slowing of speed of response as a function of aging. However, such slowing—which on the surface appears so characteristic of old age—was also found to be statistically related to environmental deprivation and depression as well as to declining health.

We repeatedly observed the importance of the immediate environment for adaptation. For example, education, occupation, and other lifelong social factors were not as critical to adaptation as was the degree of current environmental deprivation.

The original NIMH sample was followed from 1955 to 1966. The group was readmitted and reevaluated at the end of 5 years. Much of the report of the 5-year follow-up centered on aspects of survival and adaptation. Nonsurvivors compared with the survivors showed statistically significantly greater incidences of arteriosclerosis and chronic cigarette smoking. Nonsurvivors also tended toward other statistically significant differences: they had not adapted as well psychologically, were more likely to have lost their spouses, and had been more dissatisfied with their living situations. They also had less clearly defined goals. Thus survival was associated with the individual's self-view and a sense of continued usefulness in addition to good physical health. At the end of 11 years, as at the 5-year follow up, good physical status and absence of cigarette smoking were related to survival. Structured and varied new contacts and self-initiated activities and involvement (referred to as "organization of behavior") were also strongly associated with survival, an observation counter to the disengagement theory (29).

SEX AFTER 60

One example of the value of basic investigations to the life cycle perspective in psychiatry is understanding the changes in sexuality in the course of life. The data of Kinsey, Masters and Johnson, Newman and Nichols, Busse, Pfeiffer, and others show the continuation of sexual activity into advanced old age.

There is also a developmental potential in sexuality (30). Sex in young people tends to be urgent and explosive, involved largely with physical pleasure and/or the conception of children. This "first language of sex" is biological and instinctive. It often becomes a way of asserting independence, strength, prowess, and power in the process of discovering one's abilities to be sexually desirable and sexually effective. The first language of sex has been much discussed and written about because it lends itself to study—one can measure physical response, frequency of contact, forms of outlet, sexual positions, and physical skills in lovemaking. There is, however, a second language of sex, which is largely learned rather than instinctive and is often vastly underdeveloped because it depends upon the ability to recognize and share feelings in words and actions and to achieve a mutual tenderness and thoughtfulness. In its richest form, the second language becomes highly creative and imaginative, with bountiful possibilities for enough new emotional experiences to last a lifetime. Yet it is an art that must be developed slowly and painstakingly through years of experience in giving and receiving. This second language expresses the developmental potential of sexuality and needs further study from the life cycle perspective.

COMMENT

I propose that psychiatrists undertake the soul searching necessary in order to resolve the countertransference issues that have interfered with their treatment of the aged. Further, I feel that psychiatrists who have worked through these personal obstacles could contribute directly to altering negative cultural attitudes toward the elderly.

I urge that psychiatrists reexamine their efforts in the care of the older population, their performance under Medicare, and their diagnostic and treatment work in offices, CMHCs, and hospitals. Psychiatrists could seek special courses in their continuing education and expand their reading in gerontology and geriatrics. I also propose that academic departments reassess their teaching and research programs from the perspective of the life cycle as a whole.

I do not mean to imply that psychiatrists should suddenly become geriatricians, but they will be amply rewarded for at least the proportionate representation of the elderly in their services, training, and research. There will be satisfaction both in therapeutic results and in further understanding of the complex life of humankind.

REFERENCES

1. Butler RN, Lewis MI: Aging and Mental Health. St Louis, CV Mosby, 1973
2. World Health Organization: WHO Expert Committee on Mental Health: Sixth Report. Mental Health Problems of the Aging and the Aged. WHO Tech Rep Series 171. New York, American Public Health Association, 1959
3. US Senate Special Committee on Aging: Mental Health Care and the Elderly: Shortcomings in Public Policy (RN Butler, consultant). Washington, DC, US Government Printing Office, 1971
4. Butler RN: Age-ism: another form of bigotry. Gerontologist 9:243-246, 1969
5. Group for the Advancement of Psychiatry: The Aged and Community Mental Health. Report 80. New York, GAP, 1971
6. Perlin S, Butler RN: Psychiatric aspects of adaptation to the aging experience, in Human Aging: A Biological and Behavioral Study, Public Health Service Publication 986. Washington, DC, US Government Printing Office, 1963
7. Libow LS: Pseudosenility: acute and reversible organic brain syndromes. J Am Geriatr Soc 21:112-120, 1973
8. Simon A, Cahan RB: The acute brain syndrome in geriatric patients, in Acute Psychotic Reaction, Psychiatric Research Report 16. Edited by Mendel WM, Epstein LJ. Washington, DC, American Psychiatric Association, 1963, pp 8-21
9. US Senate Special Committee on Aging, Subcommittee on Long-Term Care: Long-Term Institutional Care for the Aged. Washington, DC, US Government Printing Office, 1963
10. US Senate Special Committee on Aging, Subcommittee on Long-Term Care: Nursing Homes and Related Long-Term Care Services. Washington, DC, US Government Printing Office, 1964
11. US Senate Special Committee on Aging, Subcommittee on Long-Term Care: Conditions and Problems in the Nation's Nursing Homes. Washington, DC, US Government Printing Office, 1965
12. US Senate Special Committee on Aging, Subcommittee on Long-Term Care: Trends in Long-Term Care. Washington, DC, US Government Printing Office, 1971
13. US Senate Special Committee on Aging, Subcommittee on Long-Term Care: Nursing Home Care in the United States: Failure in Public Policy. Washington, DC, US Government Printing Office, 1974
14. Gibson RW: Medicare and the psychiatric patient. Psychiatric Opinion 7:17-22, 1970
15. Lewis MI, Butler RN: Life review therapy. Geriatrics 29:165-173, 1974
16. Dubos R: Beast or Angel. New York, Scribner, 1974
17. Gaitz CM, Baer PE: Placement of elderly psychiatric patients. J Am Geriatr Soc 19:601-613, 1971
18. Stotsky BA: The Elderly Patient. New York, Grune & Stratton, 1968
19. Goldfarb AI: Prevalence of psychiatric disorders in metropolitan old age and nursing homes. J Am Geriatr Soc 10:77-84, 1962
20. Henry WE, Simms JH, Spray SL: The Fifth Profession. San Francisco, Jossey-Bass, 1971
21. Kubie LS: Need for a new subdiscipline in the medical profession. Arch Neurol Psychiatry 78:283-293, 1957
22. Joint Commission on Mental Illness and Health: Action for Mental Health. New York, Science Editors, 1961
23. Birren JE, Butler RN, Greenhouse SW, et al: Human Aging: A Biological and Behavioral Study, Public Health Service Publication 986. Washington, DC, US Government Printing Office, 1963
24. Butler RN: The life review: an interpretation of reminiscence in the aged. Psychiatry 26:65-76, 1963
25. Granick S, Patterson RD: Human Aging II: An Eleven-Year Biomedical and Behavioral Study, Public Health Service Monograph 71-9037. Washington, DC, US Government Printing Office, 1971
26. Hall GS: Senescence: The Last Half of Life. Norwood, Pa, Norwood Editions, 1922
27. Busse EW, Pfeiffer E: Mental Illness in Later Life. Washington, DC, American Psychiatric Association, 1973
28. Butler RN: Why Survive? Being Old in America. New York, Harper & Row, 1975
29. Henry WE, Cummings E: Growing Old. New York, Basic Books, 1954
30. Butler RN, Lewis MI: Sex After 60. New York, Harper & Row (in press)

Appendix 3

FEBRUARY 1975 PUBLICATION BY THE AMERICAN FEDERATION OF STATE, COUNTY, AND MUNICIPAL EMPLOYEES, WASHINGTON, D.C.

Deinstitutionalization:
Out of their beds and into the streets

By Henry Santiestevan

Published by the American Federation of State, County and Municipal Employees,
1625 L Street, N.W., Washington, D.C. 20036, (202) 452-4800

February 1975

For many years our union has represented men and women who work in public institutions – hospitals, mental health facilities, geriatrics centers, correctional institutions and others. We have long been sensitive to the minimal level of care that government frequently offers its citizenry. Understaffed, underfunded and ill-equipped, these facilities nevertheless have sought to solve some of the most complex problems facing our society, and to serve individuals whose choices are severely limited.

A few years ago, experts in the social sciences began emphasizing the need to make institutional care less remote, less impersonal, more community-oriented. They spoke of evolving away from big, out-of-the-way "warehouse" centers, toward facilities that were close to population centers, that stressed individual treatment. They suggested that institutions should rehabilitate and reintegrate its clients into society. We supported this philosophy, assuming that the process would be gradually and skillfully advanced.

But a very humane purpose, the idea of "de-institutionalizing" certain social services, has become a dangerous and destructive tool for public officials and administrators who view public programs from fiscal, rather than human, perspectives. Today's newspapers tell us of abuses stemming from private homes for the aging, providing under profitable government contracts services that once were offered in public facilities. Equally brutal has been the relentless march to close mental hospitals, children's homes, alcohol treatment centers and other government care programs – turning men, women and children over to private enterprise alternatives, or to no alternative survival programs.

It seems to us that "de-institutionalization," a lofty idea, has become something very ugly – a cold methodology by which government washes its hands of direct responsibility for the well-being of its most dependent citizens. To examine this possibility, we asked a journalist and social activist from outside our organization, Henry Santiestevan, to spend a few weeks as an observer and to prepare this report. "De-institutionalization: Out of their Beds and into the Streets," reflects his conclusions and his point of view. It concentrates on health, child and geriatrics care, skirting the complex questions that surround penal and correctional programs. It is a layman's report, but I believe his alarm is not exaggerated.

Those who say we must shut down hospitals, end juvenile care and wipe out public facilities for the aged, say the disruption cannot be avoided. They refuse to consider simpler achievable reforms within the existing facilities – more doctors, therapists, counselors, specialists: more comfortable physical plants; a commitment to guarantee decent institutional care through full funding of existing programs.

Institutional reform need not be disruptive, discomforting or deadly to the thousands who look to the state to guarantee their survival. After reading this report, we hope you'll share our concern. It's time we came together, to build a constituency that supports the right of every American to proper institutional care, and takes the responsibility for that care out of the hands of private profiteers.

– Jerry Wurf, President
American Federation of State,
County and Municipal Employees

CONTENTS

A National Scandal

5

How to explain a national non-policy on mental health that releases mental patients into community facilities that don't exist and protects their right to treatment by denying them publicly provided health services?

Passing the Buck

13

Deinstitutionalization saves money for state governments and makes money for the nursing "home" and "halfway house" industry.

Deinstitutionalization: Who's involved

18

Jerome Miller, the nation's leading advocate of deinstitutionalization, is typical of a generation of health service administrators.

Phasing Out Deinstitutionalization

23

A wave of crime, nursing home scandals, and community protests have compelled some state governments to phase out deinstitutionalization.

Building a Coalition

30

Labor, health workers, medical societies and private citizens convinced community leaders that deinstitutionalization is not working.

Health Workers' Concerns

34

Health care workers have had too many negative experiences with deinstitutionalization as a shell-game for budget cuts, layoffs and profiteering.

Towards A National Policy

40

Deinstitutionalization will continue to sweep the land like a prairie fire until the nation adopts a program of decent health care for all.

A National Scandal

Max Krause wasn't murdered.

Shortly after his 77th birthday, on a rainy day in mid-October, Krause was discharged from a mental hospital in a major northeastern city.

It was warm for autumn, so you can't say Max was just thrown out into the cold world. The mental hospital prepared for his departure . . . It held an "auction."

Weeks before Max Krause and other elderly patients were discharged, representatives of for-profit nursing and boarding homes visited the hospital to "bid" for the right to care for the old people. They made a careful study of the patients' conditions, paying particular attention to their Medicare eligibility, their Social Security benefits, pension rights, and welfare entitlements. These funds would pay for their private care, and the profit-making homes wanted to be sure the patients would bring them enough money.

A new boarding home "bid" successfully for Max. He was a good patient — he got Medicare, Social Security, and an ILGWU pension check. It was a good nursing home — a few months earlier, it had been a very nice motel.

Max had no family, so the nursing home people drove him to his new lodgings. That was the last time he went out.

That night, Max behaved as he usually did in the hospital. His days were fine, but some nights he started talking to friends, dead friends, the famous dead, and, finally, God. He cursed his conditions, but there was nobody to hear him because attendants don't come around at night.

Usually, Max didn't have anyone to talk to. There was no recreation program at the nursing home, no social hour for the residents. There was only a TV.

Soon Max just stayed in bed all day. If there were psychiatric professionals at the "home," as there were at the hospital, they'd have said he went into a deep depression.

Then, Max got a bad cold or the flu. A doctor came around to the "home" for his monthly visit and gave Max some pills to take. An untrained attendant visited Max during the daytimes to make sure he was getting his pills. His temperature kept hovering around 101 degrees, but no one noticed.

A month later, Max died. His death certificate listed pneumonia as the cause.

But that was not the real cause. It was a budgetary cutback that closed down his mental hospital ward, leaving Max without medical care.

"Max," is a composite of hundreds of tragic stories of America's new "lost generation," elderly citizens lost to health care professionals. He is not one old person. He is many old people.

This man is not alone.

The population of the nation's mental hospitals has dropped from a high of 550,000 during the mid-1950's to 430,000 in 1969, and 300,000 today.

The trend has been particularly marked among the elderly – in 1969, there were 133,264 aged in asylums, but only 89,912 remained at the end of 1973.

Programs to move patients out of mental hospitals are underway in each of the 50 states, but the largest states have led the way in emptying the institutions.

In New York, there were 84,000 mental patients in 1964. There are 38,000 today. California's mental hospitals handled 55,000 mental patients in 1955; 22,000 in 1967; and 7,000 by the end of 1973. Massachusetts discharged 17,000 mental patients during the 1960s and 1970s.

But this does not mean that anyone has been cured.

Charles Richard Soper checked out of Camarillo State Mental Hospital in California in May, 1973. He was certified by the court as no longer "presenting a danger to himself or others." Two weeks later, Soper took a .22 caliber rifle and killed his wife, their three children, and himself.

Months after the mass murder trial of another released mental patient, jury foreman Kenneth Springer told the California State Senate Committee on the Proposed Phase-out of Hospital Services:

"I'm here today to conjecture that the la\ regarding mental health in the state of California that prohibit the retention and forced treatment of mentally dangerous people are as frightening as releasing known killers from our prisons, aiming them, and turning them loose on society. I might add, that in my opinion, there is very little difference between what I've just described and what is happening routinely in our state's mental health programs."

If Springer sounds insensitive, or alarmist, listen to John Philip Bunyard. Released in 1967 from mental hospitals to which he had been committed periodically since the age of five, the 21-year-old Bunyard told a court officer:

"I don't want to go out there. I feel like a puppy you're putting on the freeway. I don't think I can make it."

Six years later, Bunyard committed two murders, two rapes, and several kidnappings in a wild 500-mile chase through California.

Violent crimes make vivid headlines, but thousands of non-violent patients live desperate and confused lives that impinge on no one else's. And, when as is far more often the case, the mentally ill are victimized, the injustice often goes unnoticed.

The *Washington Post* found a published poet walking the streets of the nation's capital during the holiday season last year. Eithne Tabor, a critically acclaimed author and for 20 years a patient at St. Elizabeth's Hospital, had been thrown out of a private care home following her discharge from the public institution during a wave of patient transfers.

She had been rejected by the foster home because she was too ill and discharged by the hospital because, they maintained, she no longer needed treatment. She had spent a month shuttling back and forth among the hospital, the foster home, the welfare office, and hospital emergency wards. Twice, this homeless woman was arrested by district police.

For Eithne Tabor, life was imitating art. Years before, she had written:

"When I was free,
I walked the streets alone.
Faces and feet flowed past.
Going where?
Being who?
And Nobody knew at all,
Nobody cared."

The victims of social neglect are the released mental patients . . . and entire communities.

In Boston, Massachusetts, an investigation revealed that the proprietors of homes where the patients were transferred often supplemented their incomes by charging residents excessively – and, occasionally, stealing their belongings. At one foster care home in Washington, D.C., residents are exploited as slave labor for household chores, receiving $5 a week for 42 hours of kitchen work.

For the communities without existing facilities, forced to accept the released mental patients, the closing of state hospitals has brought the worst institutional conditions right to their own doorsteps. Long Beach, N.Y. – a faded seaside resort – became the new home for some 1,000 ex-inmates, crowded into decaying rooming houses and hotels. Today, residents complain of "former patients wandering aimlessly, urinating, exposing themselves, frightening children, and occasionally exhibiting violent behavior," according to one eyewitness account.

New ghettoes of released mental patients scar our major cities. In districts like Chicago's Uptown and Manhattan's Times Square, former inmates are abandoned among addicts, alcoholics, and prostitutes on America's new skid rows.

These stories are part of a growing national scandal – the abandonment of the nation's commitment to care for the mentally ill and the growth of an exploitative underworld. Senator Edmund Muskie warns of "a growing and alarming trend in the states to discharge patients from state hospitals into nursing homes, boarding homes, or other smaller community-based facilities . . . dumping or wholesale transfer of individuals, particularly the aged, into facilities that are cheaper but poorly equipped to meet their needs . . . "

In his essay, "Politics and the English Language," George Orwell wrote that men of power try to make indefensible policies acceptable by describing them in incomprehensible terms. "Deinstitutionalization" has emerged as the high-sounding name for a program that purports to transfer patients from dehumanizing institutions into community-based care centers. But, more often, this fad involves budget-cutting by state administrations and profiteering by unscrupulous private interests.

The deinstitutionalizers have acted in the name of two psychiatric reform movements – the drive for community health care and the effort for mental patients' rights.

Historically, there had been other reform movements. The major historian of the history of institutions, David Rothman, notes that in the Jacksonian period, institutions became places of first resort – the preferred solution to the problems of poverty, crime, delinquency and insanity.

The penitentiary was devised and became the dominant institution in the punishment of criminals. Large and imposing insane asylums were constructed, and orphan asylums were built for children.

The Age of Institutions had begun.

Institutions were viewed as mechanisms of reform, rehabilitation and cure, showing how discipline could reform corrupt individuals in the penitentiaries and medical care cure insanity in the asylums. These experiences, carried on in isolation from society, would create moral examples and new respect for social stability in the communities.

These basic assumptions of reform and rehabilitation, born in an era of great expectations, were in a grave decline in 1870, and by the turn of the century were virtually gone.

Rather than humanitarian instruments of moral treatment, medical cure, rehabilitation, and reform, institutions had become vast warehouses of custodial care.

This shift in the uses of penitentiaries, mental hospitals, reformatories and almshouses from agencies for social reform to places of custody marked another fundamental change in social practice.

This change, however, was not characterized by exuberant experimentation with new ideas or optimistic excitement over a mission to reform society. The institutions went through the profoundly significant shift from reformatory asylums to custodial containers of unfortunate human beings with little public awareness or concern. The change did not cost the institutions any public or political support. Legislators continued to funnel public funds into them and they enlarged and grew in numbers. Social historians have suggested that this happened because the institutions were doing what the general public really wanted them to do.

Throughout the 19th Century, most doctors and medical superintendents believed that the only acceptable form of treatment for the mentally ill was institutionalization – hospitalization which could provide a controlled environment and an orderly existence far removed from the patient's own community. The states erected large hospitals in rural settings remote from the communities they served. By the latter part of the 19th Century, these hospitals were sorely over-crowded; most of the patients suffered chronic illnesses and remained hospitalized for long years, usually until death.

Alternatives to such hospitalization began in the United States in the early part of the 20th Century, but were not greatly used until after World War II. (The British and the Dutch already were treating mentally ill persons on an outpatient basis and sharply reducing the number of resident-patients in their hospitals.)

In 1955, the United States Congress set up a commission to study mental health programs and facilities in the nation. The commission issued a report six years later recommending rapid development of outpatient clinics and services and reduced emphasis on hospitalization.

The stage was set for deinstitutionalization.

President John F. Kennedy envisioned an alternative system to state mental hospitals that would apply new advances in psychiatry, drug therapy, and social work. Located in residential communities, community mental health centers would treat people before it became necessary to confine them in large institutions; Kennedy, it must be noted, never advocated emptying the populations of existing institutions into facilities that had yet to be built. Under the Mental Retardation Facilities and Community Health Centers Construction Act of 1963, the federal government would provide a share of construction and staffing money for these facilities.

Civil liberties attorneys won landmark decisions establishing that persons cannot be confined for treatment of mental illness, without, in fact, receiving adequate care. Courts began to set strict standards for treatment in state mental hospitals.

But twelve years after the initiation of community mental health centers, only 500 of a planned 2,000 had been built. In 1972, there were only 20,000 beds in Community Mental Health Centers – compared with 360,578 in state and county psychiatric hospitals. Moreover, instead of serving the lower and middle-income persons who crowd the mental hospitals, the CMHC's attract the more affluent clientele that psychologist William Schofield identifies as the typical beneficiaries of psychotherapy. This group he names the "YAVIS" – young, attractive, verbal, intelligent, and successful.

And last year, in the final mockery of President Kennedy's vision, the Nixon-Ford Administration cut the budget for community mental health care, declaring that the program would be turned over to the states under the "New Federalism."

The libertarian court decisions pushed state mental health costs upward, from $6 per patient-day during the mid-1950's to $20 today. The courts were handing down complex court orders that called for major improvements in institutional care. For financially pressed state governments, the easy way out of the cost squeeze was to cut hospital budgets and send the patients to private nursing homes eligible for federal Medicare, Medicaid, and social security payments.

Today, Sen. Muskie warns,

> ***"Perhaps 2½ million who require mental health services are going without the care they need."***.

This persists although we spend more than $2 billion a year on the present patchwork of mental health care programs. The mentally ill continue to occupy half the nation's available hospital beds. And an estimated 20 percent of all Americans will at some time require professional treatment for mental or emotional ailments.

In the era of deinstitutionalization, these mentally troubled citizens face a "revolving door" policy that shunts them from outpatient ward, to state hospital, to private facility, and back to the outpatient ward when they find themselves unable to function in society. In New York City, fully one half of the patients released from long-term care facilities return to hospital receiving centers.

In Nebraska, where deinstitutionalization is official state policy, the 200-bed Norfolk Regional Center is being reduced to a 25-bed facility. But the patients keep coming back. One patient has been readmitted 25 times. Twelve others have been released and readmitted a total of 127 times within the last two years.

How to explain a national non-policy on mental health that releases mental patients into community facilities that don't exist and protects their right to treatment by denying them publicly provided health services?

The grim answer is that the priorities of the private sector have imposed themselves on public policy. America's health system appears irrational only if one assumes that its goal is to fight disease. In fact, from the small businessman — the physician — to the big businessman — the drug and insurance companies — health care is organized with total rationality to make money. This is an industry where the money is in specialization; clinical pathologists earn $200,000 a year. Working families are treated only at costs that can drive people into poverty, and American medicine has traditionally refused to treat the poor, except in charity wards that for lack of resources, sometimes defy the standards of human dignity and modern practice.

The American Medical Association spent the early 1960s fighting Medicare and Medicaid, but these programs faithfully reflected the priorities of the health industry by bribing it to treat the poor. Medicare and Medicaid let the health industry write the bills for basic care for the poor and elderly, while the government, functioning as a sort of public Blue Cross, picks up the tab. The result is a virtual cost-plus contract for health care, and the industry has grown from a $27 billion business in 1960 to $79 billion in 1972. Sen. Abraham Ribicoff observed that health care shares with its cost-plus twin, the defense industry, "an apparently insatiable appetite for money and an enormously well developed talent for avoiding public accountability."

The mental hospitals have been the charity wards of mental health care. Theirs are the standard defects of public-sector medicine in America. As President Kennedy declared in 1963, the state hospitals "have been shamefully understaffed, overcrowded, unpleasant institutions from which death is the only hope for release." Psychiatric treatment of the wealthy, lavish retreats and drying-out resorts — that's where the money is in mental health care.

For all their faults, however, the state hospitals have represented the major, often the only, public mental health care service. By phasing out these facilities, states save money in their own budgets and provide profit opportunities for owners of private facilities eligible for federal health funds to care for the discharged patients. Released mental patients, with their promise of attracting federal dollars to a private boarding home, have become a gruesome new form of patronage.

Last year, I followed the trail of locked up and shut down mental institutions around the nation in search of the real story of "deinstitutionalization."

I learned that there is a marriage of convenience between state officials who want to cut their budgets and private operators who want to make a quick buck.

I followed the checkered career of Dr. Jerome Miller, who is recognized as the nation's leading proponent of "deinstitutionalization." I visited Massachusetts, where Dr. Miller had recently resigned as commissioner of the Department of Youth Services. A state legislative committee was reporting what it called the "administrative chaos" Miller had left behind. Then I went on to Illinois, where Dr. Miller had become director of Children and Family Services and began closing down public facilities. Shortly after I left Illinois, Miller left office again, amidst growing public concern over the plight of the released patients.

In New York and California, I learned that the two states which pioneered in "deinstitutionalization" of mental patients are hastily reversing the policy after a wave of nursing home scandals, violent crimes, and protests from communities forced to accept ex-inmates.

And in Wisconsin, cradle of the progressive movement and still something of an example for the nation, hospital closings were successfully resisted from the beginning by a coalition of consumers, community groups, and trade unionists.

In these days of full disclosure, let me note that I prepared this study with the cooperation of the nation's largest public employee union, the American Federation of State, County and Municipal Employees, AFL-CIO. AFSCME's membership includes 200,000 health workers, among them many whose jobs are threatened by deinstitutionalization. As a longtime staff member of the United Auto Workers and friend of Cesar Chavez, I might reasonably be expected to sympathize with the union position.

But, whatever I learned during my years in the labor movement, it wasn't to oppose social reform out of a narrow self-interest.

Two years ago, AFSCME endorsed community-based care, knowing that this would change the nation's health service delivery system. Today health workers have reluctantly concluded that deinstitutionalization means "closures, speed-ups, unemployment, and patient neglect," in the words of AFSCME President Jerry Wurf.

I remember vividly a ward in a Minnesota state hospital, hard hit by budget cuts. Housekeeping had been phased out, and one attendant remained to take care of 40 severely retarded youngsters. In addition to caring for the children, the attendant voluntarily did all the cleaning and maintenance work for the ward.

There are concerned workers, consumers, journalists, and public officials. And, for this reason, there is hope that Americans will create a humane system out of the chaos that is mental health care today.

Passing The Buck

Deinstitutionalization saves money for state governments and makes money for the politically influential nursing "home" and "halfway house" industry. The losers are the released patients and the nation's taxpayers who underwrite a hidden federal health policy that provides incentives for local governments to give private entrepreneurs virtual cost-plus contracts for care for the elderly and disabled. This hidden health policy consists of the ambitious social programs of the 1960's which were designed to make health care available to millions of former charity patients but have been systematically abused by the burgeoning health care industry.

In the case of mental health, Federal legislation sharply limits Medicare and Medicaid coverage for treatment received in public facilities. Therefore, while Medicare pays private health care expenses for the elderly and adult disabled and under Medicaid, the federal government provides matching funds to states that provide additional services for welfare recipients. Neither fund can be used for public psychiatric care except that states have the option of covering persons under 21 or over 65. Medicare treatment cost a total of $9.5 billion during 1973, and Medicaid cost $8.7 billion. Yet for all the federal funds injected into the health industry, the government has had no impact on improvement of the health care system except to swell its receipts. This has particularly been true in the area of mental health. Medicare's Section 1801, inserted into the act as a compromise with the American Medical Association, prohibits Federal involvement in system improvements:

> "Nothing in this title shall be construed to authorize any federal officer or employee to exercise any federal supervision or control over the practice of medicine or the manner in which medical services are provided . . . or to exercise any supervision or control over the administration or operation of any such institution, agency or person."

Medicare was a milestone in American social legislation, but its often excessive costs are regular payments of what Sen. Abraham Ribicoff calls the "political price" of the legislation.

A second bonanza for the health care industry is the federal Supplementary Security Income program which offers full support payments for elderly persons who are not living with relatives or in public institutions. SSI pays 100 per cent of the cost of elderly persons living in private homes — and none of the costs for public hospitals.

Welfare payments, 50 per cent federally supported, are also available for residents of private homes although not for mental hospital patients who are already wards of the state.

These federal programs expanded at a time when the states, already facing budget squeezes because of the increasing costs of other programs, were asked to provide additional mental health services. When the courts ordered improvements in Alabama mental hospitals, Gov. George Wallace warned that the changes would cost a sum equal to 60 per cent of the state's budget. The states responded with cuts in their mental health programs and efforts to shift responsibility for the services to private or federal agencies. In Indiana, the 1973-75 biennial budget called for a cut of $2.4 million in institutional budgets to provide community care with no phase-in period. The effort to substitute federal for state dollars has had by far the most significant impact in the transfer of the aged from public institutions into smaller, community-based facilities.

Federal funds fueled the growth of the nursing home business from a cottage industry into a major investment opportunity. Formerly, a family might build a new addition to its house and call it a nursing home. Today, the proprietary boarding home is more likely to be an old hotel, a converted apartment building, or a newly constructed mid-rise building, with several hundred beds. Companies listed on the stock exchange have entered the nursing home business, including Four Seasons Nursing Centers of America, Holiday Inn's Medicenters Division, and American Automated Vending Corp.

The emergence of nursing homes as big businesses was underscored last year when the nation's largest for-profit nursing home chain — Extendicare — was acquired by National Health Enterprises, operators of 90 for-profit hospitals. NHE's huge investment in the acquisition of Extendicare reveals that the health conglomerate anticipated an extraordinary profits future for its nursing home empire. NHE was able to buy Extendicare's 41 nursing homes only after shelling out $12 million in cash, executing $2.3 million in notes for other assets, and taking out mortgages on other facilities.

Explaining his hopes for the nursing home business, NHE chief Donald Mills told a reporter for *Modern Healthcare* that long-term health care is promising because the number of customers, including "government-sponsored patients," can only increase. Today there are 1.2 million long-term care beds, Mills said, but 800,000 more are needed. Nursing homes' income will grow as the elderly move out of hospitals. Mills predicted, and, "In a few years, the federal government will take away states' liberty to underpay for these necessary services." With a virtually guaranteed demand, the typical nursing home represents an investment of some $750,000 and generates approximately as much in revenues each year.

Bigness is no guarantee of responsibility in the nursing home industry; only 7 per cent of those beds are approved by the Joint Commission on Accreditation of Hospitals. The influx of federal funds hasn't changed industry standards from their sorry state in 1966, when Sen. Frank E. Moss declared:

> "In practice, almost any facility in which aged and infirm people live and derive some personal service is called a nursing home. The home with no health service facilities, no trained personnel, no records, and which no doctor enters from one week to the next is called a 'nursing home'."

15

Of the nation's 23,000 nursing homes, more than half are the scene of deliberate physical injury or personal abuse of patients, the Senate Special Committee on Aging reported Dec. 17, 1974. Even among the 7,318 certified skilled nursing homes, more than half fail to meet fire safety requirements, according to the Department of Health, Education, and Welfare.

Every old person is potentially a customer of these nursing homes and a recipient of federal benefits, but cutbacks in state institutions have provided the industry with a captive market supported by public funds. New York State paid $560 million in Medicaid funds, half originating from the federal government, to 600 nursing homes in 1973. Costs range from $22 to $70 a day for each patient, and the average annual cost for each resident is $10,000. The attorney for the Metropolitan New York Nursing Home Association, Stanley Lowell, estimates that 90 per cent of the members' income comes from Medicaid.

The bucks are passed to the nursing home operators, often without the individual elderly recipients having a chance to see them. Upon entering a home, the patient is required to use up all savings above $1,750 before becoming eligible for Medicaid. Then, the nursing home is entitled to receive social security, welfare, and pension payments and deduct these from the patient's monthly bill which is charged to Medicaid. The state authorizes the Medicaid funds as compensation for the nursing homes' operating expenses, debt interest, taxes, and depreciation.

New York nursing homes are guaranteed a 10 per cent profit, yet most industry sources estimate that their actual profits average 20 per cent and often are as high as 40 per cent. Profiteering schemes include complex systems of leases and subleases to obtain higher rents and depreciation, kickbacks from contractors, and nepotism and payroll padding. The most common rip-offs are overcharging, inadequate service, and stealing from patients.

State audits have disclosed that 58 nursing homes — 10 per cent of the state's total — overcharged Medicaid $4,623,288 in 1969 and 1970. Meanwhile, $475,646 was paid to nine homes after they closed. Overcharges are relatively easy since the homes contract for drugs, medical services, food and bookkeeping and their expense claims are not investigated by Medicaid. In 1973, state Welfare Inspector General George Berlinger estimated that Medicaid had paid $1 billion to nursing home operators for unverified expenses.

The same state investigation reported that two-thirds of the homes had serious inadequacies in the services they provided. Nursing home food is notoriously poor throughout the nation — in Chicago, a nursing home operator told Senate investigators he made profit of $185,000 a year, while spending only 54 cents a day per patient on food. Few homes provide activities for patients other than television, and the restless are kept quiet with tranquilizers. The homes' staff often do not include qualified nurses, and doctors rarely visit the facilities.

For the nursing home operator, an additional profit opportunity comes in the mail that brings the patients' social security, pension, and welfare check. An audit of 13 homes in New York City revealed that the facilities had kept a total of $290,000 in checks for patients who had died or moved. Many operators neglect to give patients the $28.50 a month that they are entitled to

Chicken coop converted into nursing home.

deduct from their social security checks as an allowance for personal expenses.

Yet, in rural areas, released mental patients are dumped into facilities much seedier than the urban nursing home. The Senate Committee on the Aged found that the elderly and disabled have been moved into shabby hotels, flophouses, and tenements. And, in New Mexico, the investigators visited elderly people, huddled together in a chicken coop that had been converted into a nursing home.

Despite this record of abuse, there have been only seven referrals to the Justice Department for fraudulent practices in nursing home charges to Medicaid, according to the Social Security Administration. Moreover, in five of the seven cases, the U.S. Government refused to prosecute. One case ended in a conviction and $5,000 fine, with a suspended sentence. Another case is pending.

In this post-Watergate era, Americans' wildest suspicions about the nursing home scandal were given plausibility when Senator Charles Percy announced that he will hold hearings on alleged use of these facilities to launder underworld money. The investigation will also focus on political favoritism to nursing homes and possible cover-ups of fraudulent practices in the industry. New York Congressman Edward I. Koch declares, "Whether accurate or not, a feeling persists that there is too cozy a relationship among the nursing home proprietors, the directors, public officeholders, and the law enforcement agencies."

In New York State, the investigators are probing the State Assembly Speaker and the Brooklyn Democratic boss, both officers of an insurance firm with clients in the nursing home industry. In California, five members of the board of directors of the Beverly Enterprises nursing home empire were big contributors to the election campaigns of Gov. Ronald Reagan, who provided the facilities with thousands of customers by closing state hospitals. In Milwaukee, Wisconsin, a nursing home with 136 violations is owned by the state's largest donor to Richard Nixon's 1972 campaign.

The nursing home industry is close to the real estate, insurance, and legal businesses – the provinces of moonlighting public officials and their friends. Yet this industry depends on the government for a captive market which supplies much of its revenues. Were this industry without blemish in its private conduct, the risks of scandal would still be great. As an industry that has yet to establish a standard of decency, the nursing home business all too often depends on political favoritism.

It's a risky business for all consumers – and far too risky to be entrusted with the care of our mentally ill and mentally retarded.

Deinstitutionalization: Who's Involved

"One of the great challenges to our society in the remainder of the 20th Century is to dismantle state government agency by agency, and distribute the responsibility and financial resources to new mechanisms for the organization and delivery of human services.

"The first segments of state government which should be the focus of this long-range dismantling operation are children's and youth services and any institutions which incarcerate as treatment and to protect society."

Jerome Miller, "A Strategy for Youth in Trouble"

Jerome Miller hasn't had the opportunity to dismantle an entire state government yet, but, as commissioner of youth service agencies in two states during a turbulent five years, he has proven a man of his word. Even his harshest critics in Massachusetts and Illinois agree that children's institutions – or what remains of them – will never be the same after Miller's brief terms of office.

A complex mixture of the naive idealist and the manipulative bureaucrat, Miller headed first an agency for delinquent youth in Massachusetts, then a department for all neglected youth in Illinois. He set about dismantling both with equal vigor until circumstances forced his resignations.

But Miller remains undiscouraged in adversity. After all, there are still 48 other states. Wherever he shows up next, he'll begin again the difficult work of closing down homes for juveniles and moving residents into private facilities in the communities.

When the great deinstitutionalizer shows up next, he or she may not be named Jerome Miller. Miller, the nation's leading advocate of deinstitutionalization, is typical of a generation of health service administrators, budget analysts, and social critics. In every community, the Jerome Millers fill the offices of public agencies, arguing for deinstitutionalization and awaiting the moment when a governor or legislature agrees to cut the health budget and begin relocating patients.

Jerome Miller is a true believer. Regrettably, this former seminarian and career Air Force officer has not taken the time to formulate his philosophy in a book or essay. But a coherent view emerges from his outspoken public utterances – large institutions violate human freedom and must be destroyed.

"We hope to build a system where the client – the child – can walk out the door if he is not happy. He will have the option of other kinds of help."

How to destroy the large institutions? The deinstitutionalizers often ask this question, and Miller has formulated a tentative strategy. In Miller's view, the current system is supported by an establishment of bureaucratic and special interest groups, such as health worker unions and child care lobbies. The real enemy, to Miller, isn't even these entrenched interests as much as the entire concept of "professionalism" in health care, whether in public service or in the traditional charitable agencies.

Quoting social critic Paul Goodman, Miller once declared, "People should have the option to choose a quack." Miller, the theorist, also insists on avoiding trained personnel and on "taking the control of child-care services out of the hands of the professionals, the vendors, and putting in a lot of client input."

Miller, the administrator, would show little sympathy for those who wanted to choose a professional or who maintained that the clients or institutional services include a society that wants protection from juvenile delinquency and effective treatment for its troubled young.

To Jerome Miller, his only clients are the delinquent teenagers or the retarded preschoolers, and these children are the only critics to whom he'll answer. As Miller quotes Aristotle, "The judge of the meal should be the not the chef but the guest."

But Miller the trusting idealist becomes Miller the Machiavellian strategist when it's time to translate theory into practice.

Recognizing the widespread opposition to his goals, Miller declares that "you've got to move fast" in deinstitutionalization in order to get the jump on political adversaries. To do the job of deinstitutionalizing, he relies on for-profit firms which can move without mechanisms of accountability and whose altruism he trusts more than the traditional service agencies. And, once the shutdowns begin and resistance follows, Miller believes that society still benefits because "There'll never be real progress without turmoil." Even if the blitzkrieg against institutions is halted and its architect removed, the turmoil has been "creative chaos," in Miller's view, possible because the disruption of traditional procedures may already be irreversible.

As Miller has said, he didn't intend government service to be a "career job" – at least not in any one state. So far he has marched through two – Massachusetts and Illinois – cutting a Shermanesque path through the states' social service systems.

Jerome Miller came to Massachusetts with every possible advantage. Following a decade of scandals in the state's corrections system, the Legislature in 1969 established a new Department of Youth Services to initiate changes. Gov. Francis Sargent, declaring that "Simply caging children is not the way of an enlightened society," placed the new agency under the direction of the out-of-state reformer.

But Miller took his game plan with him and proceeded as if he were facing hostile opposition. A "Management Audit of the Department of Youth Services," completed after Miller left by the Legislature's Joint Committee on Post Audit, analyzed Miller's method of operation.

Instead of restructuring his own department as the Legislature had urged, Miller used federal funds from the Law Enforcement Assistance Administration to hire people at high salaries to fill new positions. The investigators found this practice "inconsistent with the state classification plan and in conflict with state personnel and civil service regulations."

Policymaking in DYS was shifted to a new "Planning Capability Unit," headed by a $22,000 consultant and staffed with 22 outside employees hired on a contractual basis using federal funds. This unit made the decisions to close institutions and shift patients to private facilities.

Miller then used the Planning Capability Unit and seven regional offices "not for the purpose of developing alternatives but for the actual implementation of a deinstitutionalization program," according to the audit.

By deinstitutionalization standards, the program was an unqualified success. In less than four years, Miller closed down the state's reform schools, paroled vast numbers of incarcerated youths and shifted others to private custodial facilities – without once receiving the approval of the Legislature.

Critics, however, charged that, in his haste to dismantle the system, the DYS boss came up with an unacceptable method of "deinstitutionalization" – letting juvenile delinquents run away.

According to the legislative audit, when the Industrial School for Boys in Shirley was closed down in 1971, 321 inmates were paroled, 230 were transferred to other facilities, and 318 escaped.

In closing the Lyman School for Boys, Miller paroled home 105 of 169 patients who were removed. Another 11 escaped. An additional 100 residents, were "removed" by sending them to a month-long conference at the University of Massachusetts, where the youngsters were supervised by untrained college students. A tenth of the participants ran away during the $40,000 project.

Next, attention was turned to what the legislators considered a model facility for youths of elementary school age, the John Augustus Hall School in Oakdale. A three-building complex, with no barred windows or wired glass, the facility contains children's furniture and has no security features. Under Miller's instructions, DYS emptied the institution and experimented with converting it into a detention facility for older youth. During two months in 1972, 28 teenagers escaped.

In its conclusion, the legislative audit noted that Miller "has also bequeathed insufficient maximum security settings for that number of juvenile offenders which the great majority of those dealing with the problem agrees are necessary, a demoralized department, and an ill-supervised private placement program resulting in increased runaways, deaths, and other attendant consequences."

When Miller was hired away by Illinois in April, 1973, one wag called him "the highest paid runaway in history." But, in Illinois Gov. Daniel Walker, Miller had a new boss who seemed to share the cost-cutting views that had made Miller anathema to Massachusetts legislators.

As director of the Illinois State Department of Children and Family Services, Miller became responsible for some 26,000 homeless, neglected, emotionally disturbed, or abused youngsters – 14,500 of them in foster homes or treatment centers. As the cost of living increased 10 per cent from 1973 to 1974, Miller refused to increase the department's appropriations request. Against Miller's wishes, the Legislature added an extra $5 million to the unit's budget and itemized how it wanted $40.6 million in the appropriation to be spent.

Miller was outraged.

Pursuing his deinstitutionalization strategy, Miller ordered his staff to cut by a third the number of children in treatment centers and other institutions. Slashing the department's college-trained professional staff from 820 to 700, he began an assault on state institutions. He froze the budget for Angel Guardian, a children's home, paying the center $10.80 a day for each child although the actual cost was $22, forcing the facility to close and leaving 200 younsters without a home. The population of state small group treatment homes was cut from 3,000 to 2,000. Edwards Center, the state's temporary home for dependent youth, was converted into a center for delinquents.

Turning to traditional charitable agencies, Miller reduced the reimbursement rate for caring for dependent children from 100 per cent to 80 or even 50 per cent. At the same time, a new for-profit corporation, Browndale, was reimbursed in full at $53 a day to care for emotionally disturbed youngsters – in contrast to the $15 to $40 rate set for established agencies such as Lutheran Child and Family Services, Lawrence Hall, and Children's Home of Peoria.

Browndale, a Canadian multi-million-dollar corporation, became a conglomerate in Illinois when it merged with Kaleidoscope, Inc., another for-profit firm which received contracts from Miller to open all-inclusive group homes in Peoria, Champaign, and Bloomington. Browndale president John

Brown today visits the far-flung outposts of his child-care empire in the company's $1 million twin-jet Mitsubishi plane.

The most controversial of Miller's programs found youngsters entrusted not to multi-national corporations but to flea-bag hotels and, ultimately, even sex deviates and prostitution rings.

The agency paid teen-agers who had been state wards up to $291 a month to take their own apartments and live on their own. Some 900 youths participated in the program which left many in cheap rooms, vulnerable to unsavory elements in the community.

Under a modified version of the program, "transitional living," children as young as 14 were housed in four Chicago YMCA's, where they received some counseling and tutoring. Some youngsters ran away, and others were held by police on charges ranging from truancy to prostitution.

The Chicago newspapers discovered one of these children — a 14-year-old boy named Richie.

Richie had been moved into a YMCA as part of the "transitional living" program. Before long, Richie gained a reputation in the neighborhood as the last of the big spenders. Social workers started asking how he could afford to buy gifts for all his friends.

Richie let them in on his secret. He'd been making new friends at the "Y" including several older men who were paying him $33 a day to pose for pornographic pictures.

As Richie's short, remunerative career ended, Jerome Miller's career also took a turn for the worse. Criticism mounted, and Miller acknowledged that "we had a lot of problems with the 'Y' placements" and that "independent living" was "a lousy program, from top to bottom," with "kids living in flophouses and staying in bed all day."

Miller had become an embarrassment to the Walker administration. The governor waited until several state agency appointments were being announced one August weekend to accept Miller's resignation as head of the Department of Children and Family Services.

"There were indications that Miller didn't know he had resigned until the governor told him," the *Metro East Journal* of East St. Louis reported. He was kept on for a while as a "consultant" to the state, while looking elsewhere for work.

With Illinois and Massachusetts behind him, Miller was reportedly heading for California.

But, to many health planners and public officials across the land, Miller's concepts of deinstitutionalization spelled success, not failure. Even as his Illinois policies became more controversial, Miller addressed symposia on how to make deinstitutionalization work. He propounded his theories, recited his record, and told his followers how to achieve similar records.

Phasing Out Deinstitutionalization

California and New York, the two states that led the way in releasing mental patients for community care, are hastily reversing their policies. A wave of violent crimes, nursing home scandals, and community protests has compelled state governments to phase out deinstitutionalization.

The California story is a tale of liberal reforms in mental health care exploited by a conservative governor, Ronald Reagan, in a cynical effort to slash the state's budget. Reagan had announced a proposal to remove the state entirely from the business of providing mental health care when a legislative investigation revealed the failure of the governor's program and called a halt to closings of mental hospitals.

By March, 1973, the patient population in state hospitals for the mentally ill was 7,264 – down from 34,955 a decade earlier.

State hospitals for the mentally retarded cared for 9,956, compared to 12,686 in 1963.

During Ronald Reagan's administration, beginning in 1966, three of 14 mental hospitals had already closed, and a fourth had ceased accepting new patients. In January, 1973 – before an angry state legislature passed a halt to hospital closings over Reagan's vote – the governor dropped a political bombshell. He planned to close all state hospitals for the mentally ill by 1977, except for two that would be used for criminal offenders alone. Hospitals for the retarded would be eliminated by 1981.

Reagan's total deinstitutionalization plan was the culmination of California's community mental health care plan – a progressive reform that had been distorted beyond recognition.

Under the Short-Doyle Act of 1957, the state provided fiscal incentives for local communities to care for their own mentally ill and retarded. California paid 90 per cent of the cost of local mental health care services for its 58 counties. But, when patients from the counties are confined in state mental institutions, each county must pay 10 per cent of the hospital care costs for its local residents.

This system of state matching funds was distorted in ensuing years into an out-and-out bribe for local communities not to send patients to mental hospitals, no matter how serious their conditions. The Department of Mental health set estimates of the number of patient days each county would need in state hospitals each year, based on previous experience. Then, if the county used fewer patient-days than expected, it received a $15 bonus for each unused patient-day. Irreverently dubbed the "county-bounty," this allowance became an irresistible incentive for county officials to avoid committing local residents to state hospitals.

In 1969, California passed the Lanterman-Petris-Short Act, called "The Magna Carta for the Mentally Ill," requiring that all patients be screened thoroughly at local facilities before being admitted to state institutions. Patients could only be detained for 72 hours, unless they voluntarily chose to be hospitalized or were shown in court to be dangerous to themselves or others.

Following passage of the Lanterman Act, at least 72 murders and suicides were committed by former patients and persons released from local centers. The Los Angeles Police Department reported that, 200 times a month, officers were arresting former patients for bizarre behavior and public nuisances, such as trespassing, exhibitionism, loitering – or wandering along the freeways.

Reacting to reports of violent crime and other anti-social activity by released mental patients, state mental hygiene director Andy Robertson acknowledged: "It has exposed us as a society to some dangerous people; no need to argue about that. People whom we have released have gone out and killed other people, maimed other people, destroyed property; they have done many things of an evil nature without their ability to stop and many of them have immediately thereafter killed themselves."

But Robertson, a determined deinstitutionalizer, had words of reassurance for Californians: "That sounds bad, but let's qualify it . . . the odds are still in society's favor, even if it doesn't make patients innocent nor the guy who is hurt or killed feel any better."

Other mental health professionals were less confident that the act provided adequate protections for the public or the mentally disturbed citizen. Agnews State Hospital Director Dr. John Waters noted: "It isn't enough to tell a judge a patient is depressed and might kill himself. He has to prove it." Said Dr. Allen Hendy, president of the California State Physicians Association: "We're letting patients out who aren't well at all. If they've been violent in the past, we don't keep them . . . We have a patient here who threatened to burn her house. She went right home and set fire to it."

Meanwhile, California became the scene of the same exploitative underworld that has sprung up wherever there are released mental patients and profits to be made housing or caring for them. A chain of for-profit, convalescent hospitals, Beverly Enterprises, Inc., built 38 board-and-care homes in California to accommodate the discharged mental patients. Although none of the facilities had qualifications as providers of psychiatric care, California channelled Medicare funds to the facilities for accepting mental patients. In 1972, Beverly Enterprises netted $79.5 million in revenue – up from $12 million the year before.

Beverly Enterprises had a highly placed friend – Governor Reagan. Five members of the company's board of directors were big contributors to Reagan's 1966 and 1970 campaigns. Beverly's chairman, Roy E. Christensen, was vice-chairman of "The Dinner with Governor Reagan," a major fund-raiser held April 8, 1970, in Los Angeles.

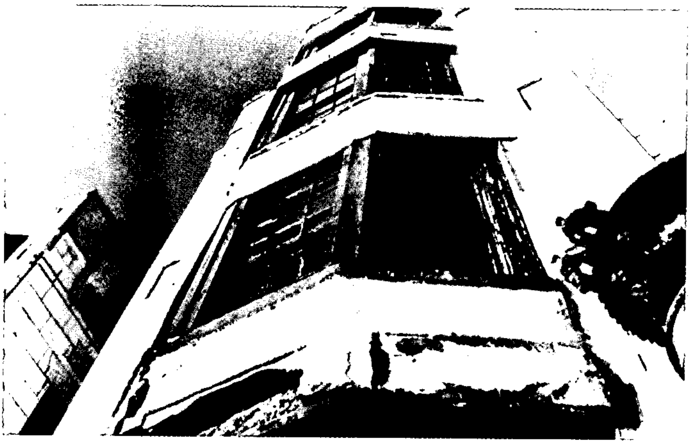
Care for discharged patients became a service anyone could offer. Motels, hotels, tenements, and private houses were converted into board-and-care homes. Among these were rundown facilities, in violation of fire and building codes and without professional medical personnel, which needed and received no licenses. In 1971, all that was required to enter the mental health care business was a $10 state fee. That year, the State Assembly passed a bill requiring licensing of any facility caring for the mentally ill or retarded. In April, 1973, California enacted "emergency" regulations for the care of mental patients outside state facilities. Already dilapidated, high crime ghettos of released mental patients had sprung up in the major citites.

The odor of scandal was in the air. California's state legislature breathed deeply and, in late 1972, appointed a select senate committee to probe the treatment of the mentally ill and retarded under the phase-out of state institutions.

The unit, chaired by Sen. Alfred E. Alquist, was to deliberate and investigate for a full year; but its most trenchant observation came during a tour of wards for the profoundly retarded.

In one ward, some 20 patients – some wearing only diapers, others naked – lay on mattresses on the floor. The patients, some as old as 54, were severely deformed, rent with seizures, and unable to walk or to feed themselves. In another ward, the legislators visited patients with severe behavioral problems, young woman who had to be closely supervised to make sure they did not beat each other up. One patient saw the legislators and began to tear her dress apart until she stook naked and grinning in front of the visitors.

Sen. Alquist asked simply, "Does Andy Robertson really think these people can be put into the community?" The Senators might also have asked, "Can't California provide a better program than this for people who cannot enter the community?"



On March 15, 1974, the committee released its report – a blistering indictment of the policy of dumping mental patients into communities that were unprepared for their arrival.

The committee found that mental hospitals are "an indispensable component of the mental health system in California." The Community Mental Health Programs were "clearly not meeting the needs of discharged hospital patients and others in residential settings."

The counties were failing to provide the necessary out-patient, hospitalization, diagnostic, and emergency services, according to the report. Because health care treatment had become entirely voluntary, some released patients and others who had visited local centers were vanishing from sight – a "slippage factor." Meanwhile, there was little follow-up for those persons who remained in touch with local authorities.

"Ghettos have been created in urban communities, where a large number of chronically ill patients are living in substandard housing," the legislators declared. Because facilities for the released patients could operate with the approval of any of a host of state agencies – including the Department of Mental Hygiene, the Department of Social Welfare, and the Alternate Care Services Unit – some private operators were going from office to office until they received certification.

Turning to the problem of violent crime by patients, the legislators noted: "Patients who were capable of functioning within the confines of a state hospital are being released without provision for their supervision in the community." Consequently, "dangerous patients" were on their own, posing a danger to themselves and others.

The legislature soon passed a bill prohibiting hospital closures without its express approval. The bill was vetoed by Gov. Reagan, then passed again – the first time the state legislature had over-ridden a Reagan veto. Today, with a new governor in office, California has the opportunity to develop a balanced program for mental health care, one which relies on state institutions along with community facilities.

A continent away, the California experience was being repeated in New York. But in the Empire State, patients were dumped into unready communities not out of ideology, either libertarian or anti-government – only out of sheer neglect.

New York State had 85,000 mental patients in 1964 but cares for only 38,000 today. The remainder were discharged without even a rhetorical commitment to creating a network of community mental health care centers.

The discharges began with a 1968 release policy issued by the state Department of Mental Hygiene which maintained simply that patients would be better off in their own communities than in large institutions. In March, 1972, the state agency unilaterally abolished "convalescent leave" as a release status for recuperating mental patients. From now, all patients released from institutions were categorically discharged and pronounced cured. The state no longer was responsible for any follow-up treatment.

It was a mental health adaptation of George Aiken's famous Vietnam peace plan – simply declare the United States the victor and run like hell.

The state announced that, in theory, it favored the development of halfway houses

No follow-up treatment in New York

for released mental patients. But, although 15,000 patients went to New York City alone, the state operated only twelve small halfway houses there.

Dr. June J. Chrismas, Commissioner of the New York City Department of Mental Health and Mental Retardation Services, believes that there is a definite need for alternative services in the community, but that the state policy was adopted "without enough planning ahead."

But at the same time nobody out in the community, either city or state, voluntary or public, was caring about the chronically mentally ill.

Private "halfway houses" were set up, many by state Mental Hygiene Department personnel who became entrepreneurs. They built in the middle class neighborhoods of the city's "outer boroughs." Queens Borough President Donald Manes declared, "The snake pits are being transferred from the institutions to the neighborhoods." And Brooklyn Borough President Sebastian Leone observed: "This is worse than the welfare hotels. With the welfare hotels, they had to use buildings already in existence. Here we're seeing a boom in buildings for discharged mental patients who get very little treatment." In Queens, fraudulent halfway houses jammed released patients into single-family houses, even cellars, while taking the residents' welfare and social security checks.

Other released patients went to facilities that made no claim of providing mental health care. Twenty-five per cent of welfare hotel residents and 5,000 nursing home patients were found to be released mental hospital inmates, according to one survey.

New York's street crime scene found a grim addition in the senseless violence of many released mental patients.

Last year, Richard S. Caputo, 25, walked out of Manhattan State Hospital on Wards Island and did not return. Five days later, he was charged by police with the bludgeon slaying of Judith Becker, 26, a psychologist who had treated him in an upstate New York hospital for the criminally insane. Caputo had been confined there after his indictment for the murder of his 20-year-old girl friend.

Caputo had been transferred the year before from that hospital to Manhattan State, where he was allowed to leave. "He just took off," a spokesman for the psychiatric center said.

For the juvenile offender, the state policy was equally loose and, ultimately, cruel. State Children's Centers stopped admitting new cases, with the result that juvenile offenders were incorrectly sent to facilities for less severely disturbed youngsters. One such unit, the Children's Center in Manhattan, became the target of a probe by the State Assembly Select Committee on Child Abuse after it was revealed that children were terrorized by a gang of delinquent girls released from large state institutions.

New York City suffered from a Kafkaesque mental health policy — one that sent the released patients on a careening course from outpatient center, to state hospital, to the streets, to sleasy hotels and nursing homes, and back to the outpatient centers.

The two major receiving centers for mental patients, Bellevue and Kings County Hospitals, were each getting from 250 to 300 patients a day, many of them previously released from state institutions. Bellevue's psychiatric director Dr. Alexander Thomas, declared: "Our patients keep coming back over and over again. Many patients have been here as many as ten and twenty times. They need treatment for up to six months, which we cannot give them. We know they cannot make it in a community."

Public outcry forced the state to reverse its policy in April, 1974. The Department of Mental Hygiene issued a memo ordering local units not to take the initiative in releasing patients from institutions. But the damage had already been done – the hospitals had been largely emptied, with no alternative care system created.

Assuming office, newly elected Gov. Hugh Carey announced a responsible policy for mental health care. No more patients would be released until a place had been selected in an accredited community care program. Personnel in the state hospitals, their jobs in jeopardy as patients were discharged, would be retained for community mental health work.

If Carey's announcement was not front-page news at the time, it was because the headlines were dominated by state probes of the nursing home scandal that had emerged as part of the failure of deinstitutionalization in New York.

Building A Coalition

Wisconsin residents are justly proud of their state's tradition of good government. When cutbacks began two years ago in the state's mental health care system, widely regarded as one of the best and most progressive in the nation, Wisconsin residents formed a coalition to ensure that change was orderly and responsible.

Deinstitutionalization came to Wisconsin just as New York and California were beginning to reverse the policy of shutting down mental institutions and sending patients out into the communities. The deinstitutionalizers were of the Jerry Miller – not the Ronald Reagan school, self-styled reformers who had influence with Democratic Governor Patrick J. Lucey and liberal members of the state legislature.

The budget cuts were opposed by a coalition that carried weight with Lucey and his legislative allies. Milwaukee residents, fearful of the impact of deinstitutionalization, alerted their city and county officials. Health workers won the backing of the state AFL-CIO. And medical societies convinced respected community leaders, including the major newspapers, that deinstitutionalization without alternative facilities was irresponsible.

A preliminary skirmish was won by the mental health care coalition when the Legislature's Joint Finance Committee rejected Gov. Lucey's 1974 plan to eliminate 112 employees at the Winnebago and Mendota State Mental Health Institutes. The committee allowed Winnebago and Dane Counties to contract indefinitely with the two institutes for primary mental health care, restoring $800,000 to the state budget for this purpose.

The vote came after Winnebago Institute Director Dr. Darold Treffert declared his vehement opposition to eliminating the facility without creating a new system of local care centers. Treffert noted that some 50 per cent of the persons treated at the institute are children and adolescents who would have to be released into communities that are completely unprepared to care for them.

Powerful support for the institutions came from the Wisconsin AFL-CIO, which unanimously endorsed a motion by AFSCME affiliates in the state urging that the threatened facilities be retained because no alternate care was available. The vote came in spite of an appeal by Gov. Lucey for the labor federation to back what he called his "tough and unpopular" budget decision.

But the major battle has been waged over the timetable for deinstitutionalization in Milwaukee, where two old, condemned complexes – North and South Divisions – provide the only care available in the metropolitan area for the mentally ill and retarded.

The facilities are threatened by a program passed in 1971 by the Wisconsin State Legislature transferring the primary responsbility for providing mental health and developmental disabilities programs from the state to the counties. County Mental Health Boards were given the responsibility to replace the state's large, old mental hospitals with community-based facilities. The counties received the responsibility — with no planning time and not enough funds – and today all mental health care is in jeopardy.

The mental health care coalition blocked plans in 1973 to transfer 400 patients from South Division into community facilities that did not exist. Milwaukee Health Commissioner Dr. Constantine Panagis warned the County Welfare Board that private nursing homes were not prepared to accept the 400 patients. The Wisconsin State Nursing Home Inspectors reported major deficiencies in nursing homes which were under consideration as new locations for mental patients. AFSCME District Council 43 organized a citizens campaign to postpone the patient relocations.

And they won. The *Milwaukee Journal* made the simple observation that the patients "must be moved elsewhere" but "there is no elsewhere." The county medical society rapped the relocation plan as "a despicable, dehumanizing, and insufferable act" which would leave 400 patients without any care. County and city officials appealed to the state for funds to keep the patients in South Division, and the state acceded to the demand of a united community.

Despite this victory, budgetary problems have forced a steady exodus of patients from South Division into an unready city. The facility's patient population dwindled from 600 at the beginning of 1974, to 550 at mid-year and an estimated 500 by January 1975. This gradual deinstitutionalization created a "funnel" system shifting responsibility for the patients from the state, to the county, and ultimately, to private, for-profit nursing homes.

Milwaukee, a quiet Midwestern city whose residents are proud of its reputation for clean government and quality services, began to spawn an exploitative atmosphere that could have been transplanted from Manhattan's West Side or Chicago's Uptown.

But health workers, journalists, and dedicated public officials refused to accept the growth of the patient-care rip-off as "business as usual."

When local nursing homes started bidding for the 400 patients expected to be transferred from the South Division, city Welfare Department inspectors found that only one facility was adequate. This nursing home could accommodate only an additional six patients – although gradual deinstitutionalization during 1974 alone placed 100 released patients in the market for private care.

More typical of Milwaukee nursing homes was the Mt. Carmel Home, a major recipient of patients released from the Mendota State Hospital. Mt. Carmel was cited by the State Justice Department for 136 violations of the state nursing home code and faces a possible $136,000 fine. Ody J. Fish, the chairman of Mt. Carmel's parent company, is a Republican National Committeeman.

Following newspaper exposes of nursing home conditions, Lt. Gov. Martin J. Schreiber, in 1970, established an ombudsman's office to handle complaints about the private facilities. In December 1974, Schreiber issued a preliminary report blasting state nursing home officials for inadequately enforcing code standards and allowing operators to postpone repairs indefinitely.

Schreiber revealed that the officials had virtually eliminated the requirement that nursing homes be shut down if they contained violations that threaten the health, safety, and welfare of residents. Instead, Schreiber found, these serious violations were classified as less urgent violations and were allowed to go uncorrected indefinitely.

Meanwhile, mental patients have been subject to the same "revolving door" run-around that has victimized released patients in New York. In Milwaukee, the run-around takes place in adjacent mental hospital complexes.

As South Division, for chronic longterm patients, is phased out, more fortunate residents are transferred to community mental health centers. But the CMHC's are not in the "community" – they're next door, in the North Division, for acute patients.

Half the patients entering North, excluding those in the CMHC's, were discharged by South as chronic longterm patients. Now they're classified, for administrative purposes, as "acute" patients.

Staff cuts at South, while proportional to patient cuts, are hurting the center's capacity to provide services. The patients who are discharged first are the least disabled; those who remain need more care and, hence, more staffing. They probably can never be discharged.

Among the first to realize that the new set-up is creating its own array of problems are the men and women with day-to-day experience in providing mental health care – social workers, nurses, and employees of mental institutions, members of AFSCME. Al Hahn, a social worker with the Milwaukee County Welfare Department, reported:

"At a nursing home that I was assigned to last year, a mentally ill elderly man was allowed to wander repeatedly onto nearby highways and roads until one night he wandered out into a blizzard and froze to death. His body was found, I think, nine days later."

Hahn told me that a survey of one nursing home revealed "approximately forty pages of violations, yet this home is still certified to receive the mentally retarded. Recently, at this home, someone cut initials into the buttocks of a patient who is 80 years old and senile. And they still continue to operate and receive funds."

Jim Dalland, another social worker in Milwaukee, said, "There's a terrific pressure to try to reduce the population (of mental institutions), so they release patients too soon. We've sent patients to nursing homes who shouldn't go . . . They should be in mental institutions . . .

"There's been a real problem in terms of actual care received in these nursing homes which are acting as mental institutions. They generally have very poorly trained people, they are understaffed, they frequently violate the state standards . . . "

Dalland reached into his personal experience as a social worker to tell of a young woman, 18, who had been prematurely released from a county mental institution and placed in a nursing home.

"This girl had spent maybe ten years in that county institution, and had made a lot of progress," Dalland said. "She had had almost hourly outbursts which were quite damaging to herself and others . . . (but) had come to the point where she was able to function well in the institution . . .

"Well, due to the pressure (on county facilities) to place kids, they looked around for TS-3 (maximum level of care) certified nursing homes. There weren't any vacancies, so instead of holding her, they changed her rating down about four steps . . . She was put in a residential facility intended for people who function well."

A few days later, the young woman was falsely accused "in an extremely hostile way" of having taken some money that was missed by another patient.

"She ripped her face apart," Dalland said. "It was just horrible. We had to send a county ambulance over to get her. She had mutilated herself because the nursing home couldn't follow simple instructions not to confront her, never scold her, never threaten her.

"Now as far as I know she is still institutionalized at a county facility . . . Now she's disfigured."

Dalland also charged that inspections of nursing homes by social workers was halted because of political pressure.

"We were constantly inspecting nursing homes," he said, "but the private institutions enlisted the aid of some politicians, would you believe, to relieve the pressure, because we were calling the state and pointing out serious defects. The politicians were supporting these private owners."

Don Miner, a full-time union representative at Milwaukee institutions, charged that the county practice of contracting out to private facilities had caused some conflict-of-interest cases.

"We found that a lot of the good patients, the ones that really didn't require much care, were being shipped out from the county facilities. We found them over at the St. Mary on the Hill Nursing Home. We also found out that the doctor in charge of all the psychiatric services for Milwaukee County was involved with St. Mary's."

Nursing homes "handpick" the patients they want from mental institutions with reference to medical records, charged Ruth Brown, a longterm mental health worker in Milwaukee institutions.

"They come in and look at the patient," she said, "and, if they are too fat and look like they're not easy to care for, they'll reject them . . . We feel that, if they're going to take patients and try to rehabilitate them, as they claim, they should take a look at the medical record to see if they have the facilities or personnel in their nursing home to deal with them . . . "

These are among the stories that AFSCME representatives in Milwaukee are bringing to the governor's special commission on the future of deinstitutionalization.

The governor's commission and Lt. Gov. Schreiber's nursing home ombudsman office are both scheduled to release reports early this year. And the future of Wisconsin's mental health care system rests on decisions that the State legislature will make after receiving these reports.

Health Workers' Concerns

Most American health workers were originally inclined to give the community care movement the benefit of their doubts and a chance to succeed. But many institutional employees were afraid they knew what was happening to the patients when they found themselves being phased out along with the facilities they served.

The health workers union – the American Federation of State, County and Municipal Employees – continues to support community-based health care, provided:

- Current patients are guaranteed proper care.
- The burden is on management to demonstrate that the change will improve health care.
- Employees have the right to be involved in decision-making.
- All workers' job rights are protected.

But health workers have had too many negative experiences with deinstitutionalization as a shell-game for budget cuts, layoffs, and profiteering not to be skeptical of the most impressive sounding plans.

Today AFSCME demands that the current institutional system be improved and continued while funds are allocated to develop community-based alternative care. As part of a national commitment to providing mental health care for all in need, regardless of income, AFSCME urges a system of career ladders for non-professional institutional employees to develop a skilled labor force for community facilities and large institutions.

And, in order to halt the scapegoating of health workers for the failures of the care syste, AFSCME proposed a mental health employees' "Bill of Rights:"

In order to *provide humane treatment to the mentally ill or retarded, all employe must be guaranteed these rights:*

- The right to expect respect and decency in the workplace without discrimination of any type.
- The right to bargain collectively on terms and conditions of work.
- The right to participate jointly in decision-making for the development of responsible policies and procedures.
- The right to negotiate on rules and regulations which are applied at all levels.
- The right to demand adequate staff to protect patients and employees from harm.
- The right to be trained to give care based on the most recent treatment principles.

35

- The right to expect management to correct unsafe conditions immediately.
- The right to refuse to work under conditions which are unsafe for employees or patients.
- The right to expect that patients or residents who are dangerous to others, will be separated from less hostile patients or residents and reside in an area with sufficient specially trained staff.

Rights for mental health care employees are the one reform that has escaped the attention of the deinstitutionalizers. To the Jerome Millers of the land, health workers are incompetent and heartless, concerned only with their job security and with protection from charges. Yet they have been victimized by poor institutional conditions as much as the patients – dumped into a system that has been the neglected charity ward of American mental health care business and which today is imperiled by drastic budget cuts.

The mental health worker deals every day with people American society has rejected, in institutions that have often been neglected, performing tasks that many of us would regard as unpleasant, and at salaries that frequently remain substandard. Mental health workers do these jobs because they care about the patients whom they serve. The non-professional employees are often the staff members closest to the patients, the only workers with a day-to-day familiarity with the conditions of American mental health care. Yet who has listened to their stories?

For several months last year, I spoke with mental health care workers and heard an oral history of the changes in mental health care and the institutions that provide it. A health care worker with 20 years service has seen the cure-alls come and go, and each morning she has returned to the back wards to serve the patients who were supposed to benefit from the latest miracles. It is no wonder that the career health care worker expresses a weariness with the system they have given so many years. These men and women, like all of us, age as they have been used. But I also heard a genuine concern for the patient and even a hope that some day America will develop a health care system worthy of its genius.

Listen to Ruth Brown, president of the AFSCME local at Milwaukee's North and South Divisions. She has worked for 22 years as an attendant on a mental health ward. She has known the fright and dependency of the mental patient, and she is skeptical of the view that the institutional resident can simply be "let out" into the community:

> "These are people who have behavior patterns that make them completely dependent on someone else doing it for them. So that these are people that society is today claiming, 'Oh, well, they can go back into the community.' Time and again, they go out of the nursing home, and time and again they are coming back."

From her own experience, Mrs. Brown distrusts nursing homes and disapproves of for-profit facilities bidding for patients who represent opportunities to pocket public funds. Ultimately, Mrs. Brown believes, caring for the mentally ill is a social responsibility and should be delegated to public or non-profit agencies:

> "I feel that mental patients should have a place to go that cares for them, instead of exploiting them. The private nursing homes just want to make a fast buck. One week, a 'home' is owned by one company; the next week, somebody else is taking over. In a publicly operated facility, or one run by a non-profit agency, the employees are there to serve, not to make money."

And, in order to provide this service, Mrs. Brown urges that health workers be trained out of dead-end jobs into professional careers.

> "We have long-term employees that have been shut into dead-end jobs such as hospital attendant, room service, custodial people, and they call us the non-skilled – the untrained. AFSCME brought a $200,000 grant from the federal government into Milwaukee to train the psychiatric aides. We will not only be able to do the custodial type of care for these patients, but we shall also be able to deal with their mental ability, and this will enable us to provide care without the money interest."

The health workers' views are echoed by the only other people in day-to-day contact with the conditions of mental health care – the patients. The patients are not all deadened or inarticulate. Some can speak eloquently of their experience and some have. Listen to one former patient, Patricia Allen, testifying before California's Senate Select Committee on Proposed Phasing Out of Hospital Services. For Patricia Allen, talk of "community care" is mere rhetoric:

> "Many ex-patients living in board and care homes cannot rightly be said to be 'living in the community.' Actually, they are living in no community . . . For example, their daily existence consists in going to the corner grocery store and back."

> Hospital life was actually better, Mrs. Allen recalls:

> "In a state hospital setting – which is, technically speaking, out of the normal community – patients are able to participate in a scaled down, less threatening semi-community . . . I don't see how future community hospitals can duplicate the facilities that exist in a state hospital."

And Patricia Allen's proposals for improvements are the same as Ruth Brown's – inve in training health care personnel:

> "The remedy? In my opinion, we need many more trained people, 'on the spot,' who can be available both to board and care home operators and to boarding home residents. The answer, as I see it, is people . . . the right people and more of them."

Health workers' concerns come from their on-the-job experience, and often their proposals have been upheld by higher authorities than state agencies.

Health Institutes sponsored by AFSCME

Health workers, aware of conditions in large institutions and in private facilities, are deeply concerned about practices of indiscriminately mixing patients without regard to age, degree or type of disability – or the danger these patients may pose to themselves and others.

In a recent court case in Illinois, AFSCME obtained a court injunction ordering the state mental health director to identify and separate "violence-prone" retarded children into a special facility with sufficient trained staff to develop programs for lessening violent behavior.

As health workers, AFSCME members are outraged when mental patients are exploited by public or private facilities as a source of slave labor. The union participated as a friend of the court in a class action in behalf of patient workers at state hospitals for the mentally ill, asking the Labor Department to apply minimum wage and overtime compensation standards to patients forced to perform tasks that have no relation to work therapy or vocational training.

The lawsuit affected some 200,000 patient workers in 27,000 facilities, according to Department of Labor statistics.

A federal court issued a preliminary injunction against the practice, commenting: "Economic reality is the test of employment, and the reality is that many of the patient-workers perform work for which they are in no way handicapped and from which the institution derives full economic benefit."

Concerned with institutional conditions, the union also filed as a friend of the court before the U.S. Supreme Court in support of a former patient in the Florida State Hospital, who has maintained that treatment was unjustifiably denied him following his involuntary commitment. The ex-patient was awarded $38,500 in damages against two doctors at the state hospital in a Court of Appeals decision which upheld the right to treatment of an involuntarily, civilly committed person.

Health workers' concerns have emerged at a series of 10 regional health institutes sponsored by the union for employees in 30 states. AFSCME Program Development Director Linda Tarr-Whelan told a U.S. Senate hearing: "What they tell us is a constant story – a lack of coordination of manpower and facilities, and a lack of recognition that effective community mental health care involves particular planning for the chronically mentally ill who have been long-term institutional residents and they are discharged from state institutions."

Mental health care workers have been at the center of drastic changes planned by politicians and administrators yet few have thought of talking with the state employees and hearing this "constant story" of failure.

Their union, AFSCME, believes that the health workers' concerns are as legitimate as those of any other party to the care delivery system, and is working to bring these concerns into the planning process.

Towards A National Policy

The trail of deinstitutionalization took me to Massachusetts, Illinois, New York, California, and Wisconsin. But, even as each of these states has come to realize the failure of simply shutting down mental health institutions, other states have begun to adopt the same discredited policies. Deinstitutionalization will continue to sweep the land like a prairie fire until the nation adopts a program of decent health care for all.

Future historians may view deinstitutionalization as a phase in a series of mental health nostrums that failed, well-packaged patent medicine that did not deliver a cure. Already, in Britain which pioneered the theory that patients should be released from large institutions, a report by a committee of representatives of the British Medical Association, concluded that "only when it (deinstitutionalization) is a proven success will it be prudent to plan for curtailing or abolishing existing facilities."

But deinstitutionalization took a particularly menacing course in America, where health care is provided for profit by a largely unregulated industry and a vicious system of second-class service for the poor still prevails.

Under this dual system, treatment for the affluent attracts much of the talent and resources of the mental health care establishment. The wealthy can pay for extensive psychiatric care, but workers and the poor cannot afford mental health services even on an emergency basis. Deprived of the fees of the wealthy and the services of the most skilled psychiatric professionals, the large mental institutions have become a giant charity ward.

The philosophy of deinstitutionalization has provided an excuse to cut back on even these meager services in order to save money for local governments and make money for private entrepreneurs. The incentives have come in the form of federal money available only to private facilities and crude inducements — such as California's notorious "county-bounty" — to dump patients out of mental hospitals into the streets.

America has come to view mental patients as bodies with money attached — not human beings to be cared for and loved. Veiled in the rhetoric of personal freedom, a new barbarism has emerged. Dr. Robert Reich, director of psychiatry for New York City's Department of Social Services, writes:

> "Freedom to be sick, helpless, and isolated is not freedom. It is a return to the Middle Ages, when the mentally ill roamed the streets, and little boys threw rocks at them."

Years before the advent of the deinstitutionalizers, another generation of social reformers turned their attention to slum clearance. In their haste to end the evils of the slums, they forgot to build new housing for the poor. Families were left homeless, while private developers made fortunes out of "urban renewal." The scandal halted only when the federal government insisted that the cities develop a "workable program," for relocation housing before receiving urban renewal funds.

Today, America needs a "workable program" requirement for alternate systems before the deinstitutionalizers are allowed the satisfaction of removing even one more patient from a state hospital when he or she has nowhere else to go.

Here are three steps towards a workable program for decent mental health care:

1. Stop bankrolling irresponsibility.

Public funds should only be used for non-profit and public facilities — the scarce tax dollars must be used for badly needed care — not profits. Government should cut off the federal funds — taxpayers' dollars — that have financed the transfer of patients from state hospitals to substandard nursing homes.

Federal, state, and local governments can and should all deny Medicare and Medicaid funds to nursing homes and board-and-care facilities that violate standards of health and safety and quality care. The Social Security Act, Medicare, Medicaid, and Welfare should be amended to permit funding for inpatient costs at public psychiatric facilities that meet appropriate standards.

Federal mental health assistance to state and local governments that use funds to close down public institutions without preparing a workable program to care for discharged patients in adequate community facilities should be ended.

2. Plan publicly and democratically.

There should be a moratorium on administrative discharges of mental patients from state institutions until there has been planning through a public process for a network of community services.

The planning process should include consumers, professionals, employees, and community groups. Current patients must be guaranteed the right to continue care. Current employees must be guaranteed their jobs. The patients who have been dumped out of their beds and into the streets should have priority in the few community mental health centers which exists.

Planning should emphasize a balanced system approach, including improvement of present facilities during the transitional period. Recent court decisions supporting a "right to treatment" for patients admitted involuntarily and the "right to protection from harm" for institutionalized patients carry with them the requirements that conditions of under-staffing, under-funding, and legislative neglect be corrected. State governments must assume the fiscal responsibility for implementing the court decisions.

Human rights committees should be developed within any facilities receiving federal or state funds. These committees should include professionals, consumers, community, and employee representatives and should serve in an advocacy role in improving all services provided.

Facilities receiving public funds should be regularly audited by the dispensing agencies.

3. Build a balanced system.

State mental institutions, with their proven ability to provide longterm intensive care, must continue to play an important role in any system of the future. They need more funding and staffing — not less.

But the nation should also build the 2,500 Community Mental Health Care Centers called for in the 1963 legislation.

These should be governed by boards representing community residents, reversing the present trend of their domination by professional interests and the CMHC's concentration on the affluent clients of private psychiatry.

CMHC's should bring their services to poverty areas, as well as others, and include rehabilitation services and psychiatric social work.

They require continued federal funding in view of the findings of a recent General Accounting Office study which determined that CMHC's cannot survive on aid from state and local governments and fees from individual patients.

A balanced system demands a public investment in a skilled mental health care labor force. The nation cannot lose the services of the men and women who work in our health care institutions. Let's build on their skills to provide the quality of mental health services that the system has not yet been able to deliver.

The mentally ill are a constituency without a voice. They are society's outcasts, but they could some day be our friends, our neighbors, our loved ones — or ourselves. They have little political or economic power. Until the advent of deinstitutionalization they were virtually invisible. The politician can shortchange them without fearing retribution at the polls. The entrepreneur can cheat them without fac[illegible] losses in the marketplace.

But there is also a coalition of conscience, concerned with the plight of the mentally ill. This coalition consists in part of the traditional advocates of better treatment, the mental health societies and the charitable agencies. A new concern has been expressed by the civil libertarians and the public interest lawyers. And this coalition includes mental health care employees who are proud of their work and vitally interested in the quality of the service they provide.

These Americans know that a society is judged by how it treats the most helpless.

Appendix

BOOKS

Chambers, David L., *Alternatives to Civil Commitment of the Mentally Ill: Practical Guides and Constitutional Imperatives.* (Page proof copy)

Chu, Franklin D. and Trotter, Sharland, *The Madness Establishment,* Ralph Nader Study Group Report on the National Institute of Mental Health, Grossman Publishers, New York, 1974.

Ennis, Bruce, *Prisoners of Psychiatry – Mental Patients, Psychiatry, and the Law,* Harcourt Brace Jovanovich, Inc., New York, 1972.

Rutherford, Andrew, *The Dissolution of the Training Schools in Massachusetts,* The Academy of Contemporary Problems, Columbus, Ohio, 1974.

ARTICLES

Cawley, Robert and McLachlan, Gordon (Editors), *Policy for Action,* A Symposium on the Planning of a Comprehensive District Psychiatric Service, Oxford University Press, London-New York-Toronto, 1973.

Chase, Janet, *Where Have All the Patients Gone?,* Human Behavior, October, 1973.

Christmas, Dr. June J., *Obligation to High Priority Target Groups: Philosophical Implications,* Paper presented at Regional Conference of National Institute of Mental Health on Developing Effective Community Health Center Programs, April 30, 1968.

Goodman, Walter, *The Constitution V. the Snakepit,* The New York Times Magazine, March 17, 1974.

Offir, Carole Wade, *Field Report – Civil Rights and the Mentally Ill: Revolution in Bedlam,* Psychology Today, October, 1974.

Torrey, Dr. E. Fuller, *The Irrelevancy of Traditional Mental Health Services for Urban Mexican-Americans,* Paper prepared for presentation to American Orthopsychiatry Association, San Francisco, 1970.

DOCUMENTS

California Legislature, Senate Select Committee on Proposed Phase-out of State Hospital Services, Final Report, March, 1974.

Health Services Legislation, 1974, Hearings before the Subcommittee on Health of the Committee on Labor and Public Welfare, U.S. Senate, 93rd Congress, Second Session, on S. 3280, May 1 and 2, 1974.

Kennedy, Pres. John F., Message from the President of the United States Relative to Mental Health and Mental Retardation, H.R. Document No. 58, 88th Congress, 1st Session, 1963.

Massachusetts Management Audit.

Muelver, Emil, Statement issued for AFSCME Milwaukee District Council 48, October 26, 1973.

Tarr-Whelan, Linda, Testimony on Health Services Act of 1974 before Subcommittee on Health, Committee on Labor and Public Welfare, U.S. Senate, May 1974.

Wurf, Jerry, *The State of the Union,* Keynote Address by AFSCME President to 20th International Convention, June 10, 1974.

Congressional Quarterly Almanac

1. Congress Enacts New Mental Health Programs, 1963, pp. 222-228.
2. President Asks New Tools to Fight Mental Illness, Test of Pres. Kennedy's Special Message on Mental Illness and Mental Retardation, 1963, pp. 1001-1005.
3. Mental Health Centers, 1967, pp. 227-228.
4. Congress Passes Community Mental Health Legislation, 1970, pp. 180-189.
5. Twelve Health Programs extended through Fiscal 1974; 1973, pp. 489-493.
6. Expiring Health Programs, 1974, pp. 1231-1232.

Appendix 4

STATEMENTS FROM INDIVIDUALS AND ORGANIZATIONS

ITEM 1. LETTER AND STATEMENT FROM CAESAR A. GIOLITO, DIRECTOR, GOVERNMENT RELATIONS, AMERICAN PSYCHIATRIC ASSOCIATION; TO WILLIAM E. ORIOL, STAFF DIRECTOR, SPECIAL COMMITTEE ON AGING, DATED JANUARY 13, 1976

DEAR MR. ORIOL: Enclosed is the statement by the American Psychiatric Association proposing the establishment of a Presidential Commission on Mental Health and Illness of the Elderly. We understand from Dr. Robert Butler that Senator Moss has requested this statement.

We hope that you will include it in the hearing record and the Congressional Record, and use it in any other way you see fit.

With very best personal regards.

Sincerely,

CAESAR A. GIOLITO,
Director, Government Relations.

[Enclosure.]

PRESIDENTIAL COMMISSION ON MENTAL HEALTH AND ILLNESS OF THE ELDERLY

STATEMENT OF THE AMERICAN PSYCHIATRIC ASSOCIATION

The American Psychiatric Association, which represents 23,000 psychiatrists in the United States, advocates that a Presidential Commission on Mental Health and Illness of the Elderly be established.

The mental health and illness of aged in America is an area that presents not only severe problems, but also a potential for exciting rewards to the elderly and to society in general.

High visibility in our highest councils of government is paramount if we are sincere about making a serious commitment.

The association feels strongly that we should make such a commitment. The Congress stated in a report by the Special Committee on Aging of the U.S. Senate in November, 1971, "Mental Health Care and the Elderly: Shortcomings in Public Policy," that "Public Policy in mental health care of the elderly is confused, riddled with contradictions and shortsighted limitations, and in need of intensive scrutiny geared to immediate and long-term action."

Yet, at the present time we have only a time limited 1-year committee in the Department of Health, Education, and Welfare which has half a year of its life remaining, and has not yet gotten off the ground.

Persons over 65 years of age constitute more than 10 percent of the population, yet they receive less than 2.3 percent of outpatient psychiatric services, but occupy 28 percent of all public mental hospital beds. About 5 percent of the aged population are in institutions of all kinds. Approximately four-fifths of the institutionalized aged are in nursing homes, homes for the aged, and personal care homes. Fifty-six percent of all nursing home residents are considered to be "senile."

Robert N. Butler, M.D., noted psychiatrist, gerontologist, and author on the aging, stated in a recent hearing before the House Select Committee on Aging that, "I find people are usually dumbfounded to learn that one out of every four suicides in the United States are committed by people over 65 years of age—twenty-five percent of all suicides. The highest suicide rate in the United States occurs in white men in their eighties."

He states that the conditions of poverty under which 7 million elderly live are known to contribute to mental breakdown, among them malnutrition, stress, and victimization through crime.

The fact that quite frequently the elderly are separated from the mainstream of society and relegated to inferior or nonexistent roles contributes significantly to the personal deprivation that places them at high risk of incurring mental illness.

Deprivation of personal contact and everyday necessities of life create physical and emotional problems that are often life threatening.

Yet, meaningful intervention through medical and psychiatric services frequently produces dramatic improvement and often total reversibility in the elderly person's physical or mental condition.

The elderly receive only a very small percentage of total mental health services. The contributing reasons can be ascribed to varying sources, from the limitations of the elderly, both physical and psychological, in availing themselves of existing services; the prejudices of our youth oriented society toward the elderly, too few and inaccessible services, economic inability to pay for appropriate services, and the therapist's reluctance to treat elderly people.

The Group for the Advancement of Psychiatry cited as two of the numerous reasons for the therapist's reluctance to treat as, (1) the therapist thinks he has nothing to offer old people because he believes that they cannot change their behavior or that their problems are all due to untreatable organic brain disease, and (2) the therapist believes that his psychodynamic skills will be wasted with the aged because they are near death and not really deserving of attention.

Yet, those who have been treating the aged mentally ill have said that it gives them exceedingly high personal reward; that the aged tend to respond in a very human and appreciative manner. This perspective must be imparted to medical schools and other educational institutions in order to dispel erroneous myths that inhibit the therapist from treating the aged.

Basics, too often ignored and not made available, such as transportation to treatment sites, or delivery of services in the location of housing, provision of meals (although meals on wheels has already made a remarkable contribution and needs extension), and other daily necessities and amenities of life must not be overlooked.

Lately, we have seen the discharging of thousands of aged from State mental hospitals, as part of the trend toward deinstitutionalization, only to be "dumped" into the community where they live in dilapidated rooming houses, hotels, or inferior nursing or foster homes, and are victims of gross neglect.

The Group for the Advancement of Psychiatry in its report of 1970 on this subject viewed the aged mentally ill as pawns for funding availability. They illustrated this by stating, "The trend toward 'moving bodies' from State hospitals to extended care facilities in order to attract larger Federal payments increases the alarming prevalance of relocation and its accompanying disorders."

As Dr. Butler points out in his book *Why Survive? Being old in America*, "When signs of emotional problems and mental disorders emerge in old age, immediate diagnosis and treatment are crucial, particularly in the case of the reversible brain disorder. Otherwise these conditions can become chronic and irreversible although still subject to palliation. Prompt care can be preventive in avoiding full-blown functional disorders if, for example, depression or anxiety can be alleviated. Older persons ordinarily face more stresses than the young and, given their declining reserves of strength, they may require swift attention in order to avoid being overwhelmed emotionally."

A National Institute of Mental Health study illustrated the following incidence of new cases of mental illness of every category:

	Cases per 100,000
Over 65	236.1
35–54	93.0
25–34	76.3
Under 15	2.3

Nevertheless, as stated before, those over 65 received only 2.3 percent of outpatient psychiatric services, unfortunately severely limited in medicare benefits for mental illness despite very low costs to the program.

This association issued a position statement on aging in March, 1973. The position stated that a comprehensive system of health care should be established for the aged that provides for the proper evaluation of the individual's health needs; psychiatric medical, social, and supporative measures not only to maintain health but also to rehabilitate the sick and infirm; continuity and long-term care when and where necessary; and preventive health measures together with a continuing education program encouraging the preservation of health in all ages.

The American Psychiatric Association therefore strongly endorses a Presidential Commission on Mental Health and Illness of the Elderly to catalyze public and professional awareness so that a national strategy may soon be developed and implemented to correct this national disgrace.

ITEM 2. STATEMENT OF PHILIP H. VAUGHN, MILWAUKEE, WIS.

I have a profoundly retarded daughter, with several physical defects, 32 years of age, residing at Southern Wisconsin Colony and Training School. The State Department of Health and Social Services are now in the process of discharging Colony residents to community residential facilities.

The Department of Health and Social Services gives the Colony superintendents a schedule of discharges to be met each month and on a yearly basis. Then, for example, Superintendent Garstecki, Southern Colony, passes it on. His memo No. 208, July 1974, to his staff ordered that: 184 are to be discharged by March 18, 1975; 66 are to be discharged by March 18, 1976; 40 are to be discharged by March 18, 1977. Then the staff begins the shuffle on who to discharge to comply with the numbers game. The criteria for discharge is not based on the individuals' needs, but rather to comply with the order to "dump" them out of the Colonies into communities without regard for proper facilities, programs or minimum levels of care.

I work quite diligently to establish facilities for any mentally retarded person who can benefit by community living and such persons can do very well in group homes. Certainly, nursing homes are not the place for these retardates, yet there are hundreds of them placed there.

I have a large file of newspaper clippings on nursing home problems in Milwaukee County. When there is such a prolonged flurry of bad reports, it is very likely something is seriously wrong. And, if the rumors of kickbacks, drug abuse, over-charging, and confiscation of personal funds are true, it would be shocking.

Some nursing homes here are owned by out-of-State operators who may own two or three homes operating under different names. These operators may have up to 100 or even 200 mentally retarded residents in each home. They frequently pay only minimum wages and, therefore, they have a large turnover of help. They are in business to make a profit for the owners and they will cut corners to do it. Can we consider this a "normalization" program placing hundreds of defenseless persons, who can't even make a protest, in the same arena with these sharp operators?

The church affiliated nonprofit nursing homes, whose motive is compassionate care, refuse to accept mentally retarded residents because they say nursing homes are designed to take care of the sick, the terminally ill, and are not a place to spend a lifetime of living.

Finally, nursing home inspectors should not report to the Department of Health and Social Services who also make the placements and license the homes. It is like permitting a builder to make his own building inspection. Violations of codes and quality of care go on for years in some homes without correction. Inspectors should report to some enforcement department who in no way is connected with placements or the operation of the facility. And they need "clout"—and lots of it.

I hope your good work will help to improve conditions for the mentally retarded and all disabled persons.

○